

A GUIDE FOR COMMUNITIES



Fetal and Infant Mortality Review Manual 2nd Edition



N A T I O N A L
NFIMR
FETAL-INFANT MORTALITY REVIEW PROGRAM



Fetal and Infant Mortality Review Manual
2nd Edition



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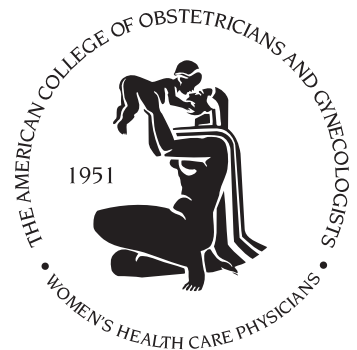
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National Fetal and Infant Mortality Review Program
The American College of Obstetricians and Gynecologists
PO Box 96920
Washington, DC 20090-6920
202.863.2587

nfimr@acog.com

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- *A Manual for Fetal and Infant Mortality Review* (1992) by Paul M. Wise, MD, MPH and Louise M. Wulff, ScD (eds)
- *Fetal and Infant Mortality Review: A Guide for Communities* (1998) by Kathleen Buckley, MSN, CNM, Ann M. Koontz, DrPH, CNM and Sean Casey, MSW, MPH
- *Sustaining the FIMR Program: A Toolkit* (1999) by Darlene Kerr, MEd and Ellen Hutchins, ScD
- *Fetal and Infant Mortality Review: A Decade of Lessons Learned* (2000)
- *Fetal and Infant Mortality Review: A Guide for Home Interviewers* (2002) by Jodi Shaefer, RN, PhD, Danielle Noell, ARNP, MSN and Mary McClain, RN, MS
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Foreword

This second edition of the FIMR *Manual* is designed to provide communities interested in developing a new FIMR program or continuing an existing FIMR program with a step by step guide for implementing FIMR and making systems change happen for women, infants and families through FIMR. It is intended to be a practical guide, based on the cumulative best practices of the many FIMR programs that have survived and thrived over the past two decades.

This *Manual* is also written with the understanding that many of the decisions that go into developing projects like FIMR are local in nature.

There are many aspects to FIMR for which there are no right or wrong approaches, only the way that works best in a particular situation. On the other hand, in the experience of FIMR programs and the evidence from the national evaluation of FIMR, certain components of FIMR are better done one way than any other. This book points out the things that have worked best in most programs.

FIMR is a dynamic process. As more communities implement FIMR and as the number of FIMR experts continue to expand, there will be more information to share. Please continue to respond to NFIMR with your insights, new information and assessments about the FIMR process.

Kathleen Buckley, MSN, CNM
NFIMR Director

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CHAPTER 1

The Fetal and Infant Mortality Review Process



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The Fetal and Infant Mortality Review Process



Introduction

Infant mortality is viewed as a sentinel event that serves as a measure of a community's general health status as well as its social and economic well-being. Excess rates of infant deaths persist, and infant deaths still constitute more than half of all deaths occurring to children ages 0–19 years in the United States. (1) During the past decade, communities have witnessed ongoing changes in the financing and delivery of health care services, greater attention being given to core public health functions and increased emphasis directed to improving quality and accountability. Faced with these trends and mandates, maternal and child health (MCH) experts and advocates have sought to be responsive while assuring that the needs of women, infants and families continue to be met.

Fetal and Infant Mortality Review (FIMR) is a community process that can address these challenges. Nationwide evidence demonstrates that FIMR is an effective perinatal systems intervention. A national evaluation of FIMR has systematically documented that (2-4):

- The presence of FIMR appears to significantly improve a community's performance of public health functions as well as enhance the existing perinatal care system's goals, components and communication mechanisms.
- The focus of FIMR on systems of care and identifying gaps in care results in action being taken in a way that interpretation of vital statistics data alone does not necessarily promote.

FIMR is used at the local level for assessing, planning, improving and monitoring the service systems and broad community resources that support and promote the health

and well-being of women, infants and families. Information from reviews is being used to guide program and policy development and define and maintain quality services and resources. FIMR provides an opportunity to:

- *Monitor the effects of a changeable health care system.* FIMR provides invaluable information that helps communities understand how changing conditions impact services and resources and affect families throughout the community trying to access or utilize services.
- *Obtain unique information not typically available from vital statistics.* FIMR information complements local population-based fetal and infant mortality data. Multiple sources of data are utilized in the process. In many cases, case review team members are the only individuals ever to see all of the pieces aggregated together and thus are privy to the most comprehensive information about provision of services, community resources and institutional policies. In addition, few local MCH initiatives actively seek out such an extensive family voice as FIMR. The family or maternal interview offers the rare situation to hear from the consumers. These comments usually provide significant information about health equity and disparities among diverse populations in the community, the problems families face and their knowledge, attitudes and beliefs about health. In addition, the information present reveals whether or not quality services and community resources are available, accessible, culturally appropriate and responsive to the community. (5) It also offers insights into why services and resources may not be effective.
- *Enhance the performance of core public health functions.* In particular, national evalua-



tion findings reveal that communities with a FIMR as compared to those without are significantly more likely to be engaged in activities related to these core public health functions (2, 3):

- Data assessment and analysis (e.g., analyze data about pregnant women and infants)
- Client services and access (e.g., promote access to appropriate pregnancy care through use of a common risk assessment instrument)
- Quality assurance and improvement (e.g., develop population-based standards of care for pregnant women and infants; initiate changes in local or state regulations)
- Community partnerships and mobilization (e.g., collaborate with or provide expertise to community initiatives about pregnant women and infants)
- Policy development (e.g., produce a plan about health needs of pregnant women)
- Enhancing workforce capacity (e.g., educate providers; convene meetings about high-risk pregnant women and infants)
- *Implement a continuous quality improvement (CQI) technique.* CQI developed as a means in industry to achieve a better product by identifying best production practices and implementing them. National organizations and programs concerned about quality health care (e.g., Institute of Medicine, Joint Commission on Accreditation of Healthcare Organizations, Agency for Healthcare Research and Quality, federal Maternal and Child Health Bureau [MCHB]) now emphasize adoption of quality improvement strategies and use of performance measures. CQI methods are being used increasingly

in health care to identify problems, analyze underlying factors contributing to the problem, re-design system approaches or resource allocation to resolve the problems, and subsequently determine if change in the process is successful. (6-9) FIMR employs these essential steps in its process to develop creative and innovative service systems practices and solutions for communities.

“...there is no infant death rate which can be viewed with complacency... The interest shown by the citizens of every town studied, the hearty good will of the mothers whose interviews are the indispensable basis of the work, encourage the bureau’s hope that the [infant mortality] inquiry will prove increasingly valuable as a stimulus to more active protections of the youngest and tenderest lives throughout the Nation.”

Julia C. Lathrop, Children’s Bureau, 1915

Fetal and Infant Mortality Review Process—A Cycle of Improvement

The overall goal of fetal and infant mortality review is to enhance the health and well-being of women, infants and families by improving the community resources and service delivery systems available to them. 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 factors associated with those deaths, establish if they represent system problems that require change, develop recommendations for change, assist in the implementation of change and determine community effects.

The primary objectives of all FIMR programs include:

- Examine and identify the significant health, social, economic, cultural, safety and educa-



tion systems' factors that are associated with fetal and infant mortality through review of individual cases

- Plan a series of interventions and policies that address these factors to improve the service systems and community resources
- Participate in the implementation of community-based interventions and policies
- Assess the progress of the community-based interventions

Carrying out the program objectives in a continuing fashion creates a cycle of improvement for the community.

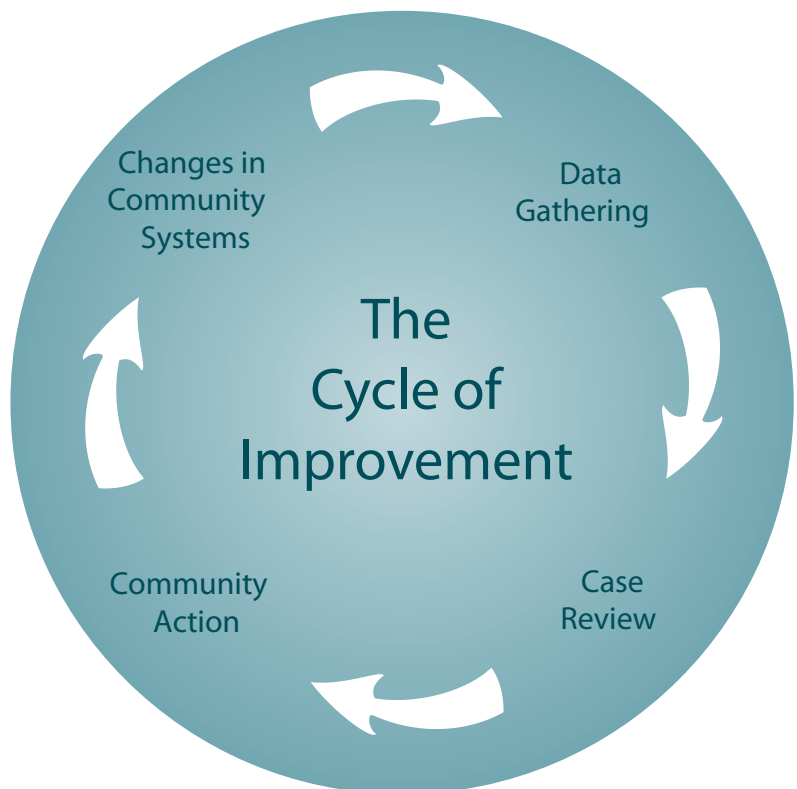
Concepts fundamental to the FIMR process are listed on p. 9 and will be elaborated upon throughout the manual. These program characteristics reflect the experiences from many states and locales. From the outset, the FIMR process was designed as a two-tiered process to call attention to the distinct but equal analytic function and action function. The process calls for separate community teams to carry out these two functions, and in fact, the national FIMR evaluation indicates that employing a two-tiered structure for FIMR appears to enhance the program's effectiveness. (10) A brief description of the teams and their functions and the overall process follows; detailed information appears in other manual chapters.

For each case of fetal or infant death to be reviewed, information is collected from a variety of sources, which may include physician and hospital records along with those from home visits and relevant community program records. Information is obtained in an interview with the family, usually the mother. All identifying information (i.e., names of families, providers, institutions) is removed and an anonymous summary of the case is presented to the case review team (CRT).

Members of the CRT represent a broad range of providers, institutions, advocates, professional organizations and public and private agencies that provide services and resources for women, infants and families. The CRT will ask questions as it examines each case, such as:

- Did the family receive the services or community resources they needed?
- Were the service systems and resources culturally and linguistically appropriate?
- Are there gaps in the system that need to be addressed?
- What does this case tell us about how families are able to access existing local services and resources?

As a result, the CRT identifies barriers to care and trends in service delivery and suggests ideas to improve policies and services that affect families.





Typically, recommendations from the CRT are presented to a team of individuals referred to as the community action team (CAT). The CAT is composed of two types of members: those with the political will and fiscal resources to create large-scale system change and members who can define community perspective on how best to create the desired change in the community. The CAT translates the case review team recommendations into strategies for action and participates in implementing interventions designed to address the identified problem.

Critical to the FIMR process is the notion of a feedback mechanism to assess whether recommendations and actions are implemented and problems are resolved. The continuous nature of the process provides an opportunity to make these appraisals. Examination of new cases over the long term can shed light on whether a system or resource problem has been resolved, and reveal that new actions have indeed been incorporated into systems of care. In addition, other assessment tools may be developed to further inform the CRT and CAT about the progress of interventions.

“...the FIMR structure and process...creates a setting and a set of concrete activities wherein everyone has a contribution to make and everyone learns from the process. The case study findings indicate that because the FIMR process extends beyond problem identification to promote problem solutions, observable changes in practice and programs occur; ‘things get fixed’ and participants are inspired to take further action.”

Holly Grason and Mira Liao, FIMR National Evaluators (2)

What FIMR Is Not

Many new FIMR programs experience a phase in which community members or local health professionals expect FIMR outcomes or results that FIMR was never designed to accomplish. Knowing some of the more common misconceptions may help future programs avoid them. Based on many years of experience, communities implementing FIMR have come to accept that (11):

- The FIMR process is not about fault-finding or assigning blame for the death. Blame cannot be determined with the subsets of medical information that FIMR abstracts, nor should it be attempted. Comprehensive local and state professional peer review and public health and institutional quality assurance programs are already in place and respond to this issue.
- The FIMR process is not about conducting original research on the causes of infant death. Population-based literature exists on that subject. In addition, the information collected about individual cases may not fulfill requirements necessary to contribute to this scientific knowledge base.

Why Do FIMR?

Communities may decide to develop a FIMR process for any number of reasons and at any time. Here are just a few reasons communities give for starting FIMR programs:

- The community needs better information about the operation of family services and their impact in order to plan for the future
- The community needs information about the effects of changes in the health care system on mothers and infants
- Existing needs assessment does not seem to adequately reflect the concerns and problems of the community



- The county health department needs a way to strengthen the core public health functions or to institute a continuous quality improvement system
- Local coalitions want to begin working together on better policies for families in their community
- Indicators of maternal and infant health status are changing for the worse (e.g., rates of fetal, infant or postneonatal mortality, or rates of preterm births are increasing)
- Differentials in infant mortality across communities or racial/ethnic groups are too great

Some communities have raised the question of whether the FIMR process can directly and independently reduce rates of infant mortality or low birth weight. Recognizing that infant mortality and its major causes and contributors (e.g., preterm birth, congenital anomalies, etc.) are complex and not subject to simple solutions, it is not reasonable to expect that FIMR alone can affect health status in the short term. However, the FIMR process is an effective perinatal systems approach that can serve as a valuable part of the ongoing assessment, planning and monitoring functions communities undertake to improve the health of women, infants and families. As an ongoing cycle of improvement for service systems and resources is sustained through FIMR, it is expected that outcomes will improve over time.

“The process that brings together diverse people to learn from the story of a family that experienced a fetal or infant loss helps awaken both commitment and creativity. The stories illustrate community needs that are clearly concrete, local and significant, while the interaction among diverse community participants generates ideas for action that

might lie beyond the imagination and power of an individual provider or agency.”

Seth Foldy, MD, Milwaukee, WI

FIMR Benefits

FIMR is an action-oriented, community process that leads to improvement in health and other family services and resources. The national FIMR evaluation findings described earlier reinforce its benefits. Through FIMR, it can be said that many, disparate community members join together and become the experts about the entire local service delivery system and community resources for women, infants and their families. As FIMR teams work together over time they generate a spirit of teamwork and understanding that crosses gender, cultural, racial and social divides. Experts tell us that successful community groups, such as FIMR, can (12):

- Identify gaps in current services, a key part of needs assessment, and cooperate to fill those gaps
- Expand available services by cooperative programming and joint funding
- Plan for better coordinated services through interagency networking and communication
- Develop a greater understanding of maternal and child health community needs by seeing the whole picture, not just a part
- Identify similar concerns and, at the same time, learn from diverse perspectives that members from varied backgrounds bring to the process
- Reduce interagency conflicts by putting aside issues of competition and turf, to focus on common local problems affecting health care delivery systems and reduced resources



- Mobilize community action to effect needed changes through the strength of collective advocacy as well as through actions of individual organization leaders
- Foster personal and professional satisfaction and growth among their participating members
- Give families a voice in the process of service and resource improvement
- Achieve enhanced visibility and credibility for family issues with policy makers, funders, the media and the broader community
- Decrease costs by avoiding duplication of services
- Conserve resources by identifying resource-saving opportunities

FIMR programs also provide important benefits to bereaved families. The home interview itself can facilitate the grieving process. The home visit has led to provision of other assistance to the mother and family members to help with resumption of family life.

“FIMR is the most fulfilling, interesting, satisfying, frustrating and important work that I have engaged in. Beyond selfish self growth, I firmly believe and have seen the changes in health care delivery that have been directly influenced by our team.”

*John E. Wright, MD, Pediatrician and
FIMR Case Review Team Leader, Broward
County, FL*

Who Should Lead FIMR?

Within the community, it is necessary to decide which agency, organization or institution (or a combination of them) will take the lead for implementing FIMR. Many different kinds of agencies, such as local or state health

departments, local maternal and child health coalitions and local hospitals or regional perinatal centers have all been successful as FIMR leaders. Each has its advantages and disadvantages.

Health departments often are an ideal site for FIMR. Today, about 2/3 of FIMR programs across the country are sponsored by local health departments. The support of a local health officer sponsoring FIMR can open doors, attract the attention of other agencies and gain the endorsement of elected officials. Access to records useful in the FIMR process, especially vital records, can be facilitated within the health agency. On the other hand, members of the community initially may be wary of local government intrusion into their personal issues.

Many FIMRs are implemented by local coalitions such as those associated with the federally sponsored Healthy Start projects, Healthy Mothers/Healthy Babies or regional perinatal consortia that represent a number of perinatal and maternal and child health advocates and service delivery agencies. Such coalitions may have the advantages of diversity, enthusiasm, community backing and knowledge of community values. On the other hand, they may have trouble gaining access to institutional records and have to spend time building alliances with large public agencies or medical centers.

A few local hospitals or regional perinatal medical centers have implemented FIMR. They bring expertise and access to some in-patient records and the relevant medical personnel. However, a FIMR program implemented by a hospital or medical center has the potential of being too medically focused or focused on issues only of importance to that institution. In addition, a FIMR pro-



Key FIMR Concepts

- *Analytic and action process* that highlights and gives equal weight to the identification of community problems and to the implementation of community-based remedies
- *Systematic evaluation of individual cases* (case reviews)
- *Identification of a broad range of factors* (e.g., socioeconomic, administrative, and environmental systems) contributing to adverse outcomes, not just medical factors
- *Inclusion of information not available through routine quantitative methods* (e.g., family interview). Uses population-based data (e.g., vital statistics) as a complement to the case-specific data
- *Cases viewed as sentinel events* illustrating system and resource issues. Infant and/or fetal deaths are viewed as frequently occurring events that can illuminate community-level system and resource issues throughout the continuum extending from the preconception period through infancy
- *Avoidance of preventable/non-preventable classifications of deaths* due to the ambiguity of these categories and because the intent of the case review is to identify opportunities for change in policies and programs
- *Avoidance of blame* (anonymous cases and confidential process; explicitly not a medical audit; examination of associated factors rather than causes)
- *Population-oriented* with a defined sub-state geographic area as the focus (as opposed to a hospital-based review, in which cases are representative only of the hospital's patient base). Action strategies are to benefit the entire maternal and infant population in the community
- *Two-tiered process* to distinguish and emphasize the analytic function (collect data; review cases; draft preliminary recommendations) and the action function (refine and implement action strategies, such as policies and programs, to address the identified systems and resources issues; disseminate findings to community)
- *Feedback mechanism* to assess whether or not recommendations and actions are implemented and problems are resolved
- *Multidisciplinary involvement* that promotes participation of a broad range of community partners, recognizing the value of diverse community perspectives
- *Adaptability to varying local conditions and resources*
- *Complementary method to other maternal/infant health quality improvement activities*. Coordination and collaboration with related programs boosts program efforts
- *Integral component of an ongoing needs assessment, program planning, implementation and evaluation cycle* (essential functions in public health practice)

Adapted from: Koontz AM, Buckley KA, Ruderman M. The Evolution of Fetal and Infant Mortality Review as a Public Health Strategy. *Matern Child Health J* 2004;8 (4): p.198 (with kind permission of Springer Science and Business Media)



gram located at one hospital might have difficulty gaining access to records at other hospitals, especially if they are seen as competitors. Community members or advocacy groups might view the hospitals, especially large hospitals or hospital groups, as disengaged from the deeper concerns of the community and consequently may distrust the motives of a hospital-based FIMR.

Regardless of which organization implements the FIMR program, coordination and collaboration with all likely local players is crucial for the success of the program. Ultimately this will involve addressing some of the weaknesses described above regarding the type of agency that implements the program. The hospital may have to spend more time forging community collaborations, while the local coalition will need to focus on developing relationships with institutional decision-makers.

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CHAPTER 2

Laying the Groundwork



CHAPTER 2

Laying the Groundwork



Introduction

Community readiness is always an element critical to the initiation of the FIMR process. To be successful, a community that wants to begin FIMR should already have in place and be able to rely on 1) local consensus about the need to address issues related to adverse maternal and infant outcomes as well as the service systems and community resources available to families, 2) support from at least some professional or community coalition groups and 3) the commitment of a few individuals who can work as a planning group to lay the groundwork upon which to build the process and motivate others to rally round it. Members of the planning group usually include staff of the agency or institution implementing FIMR (e.g., city or county health department or local perinatal coalition), but may also include other community or professional leaders who are enthusiastic about the FIMR process and volunteer to play a role in developing the local FIMR program.

This chapter focuses on the steps the planning group should take to develop the programmatic features that support FIMR. Chapter 3 describes important aspects of building community support. It should be noted that while these two functions appear in separate chapters for descriptive purposes, the planning group must work on them concurrently (see Chapter 3).

Laying the groundwork for FIMR usually takes about 6–8 months. Programs will need to:

- Identify the community/geographic area of focus
- Identify community resources/assets
- Determine the type and number of cases to be reviewed

- Determine FIMR's relationship to other types of death review
- Identify and address legal and institutional issues related to the review
- Establish systems to maintain confidentiality and anonymity
- Establish a system to identify cases
- Select data collection and processing methods
- Identify costs and funding sources
- Designate the program director and coordinator
- Formalize policies and procedures
- Build in opportunities for initial and ongoing training

While the planning group needs to accomplish all of the tasks listed above, the order in which they need to be addressed may vary from community to community. Some communities may already have accomplished one or more of these activities before the planning group begins its work.

Identifying the Community/Geographic Area of Focus

Before choosing the area to be addressed by the fetal and infant mortality review program, it is critical to have a clear understanding of the nature of local maternal and infant health problems using vital statistics and indicators of other community characteristics. This information will provide the basis for determining the community/geographic area that will be the focus of FIMR as well as the number and type of cases that will be reviewed.

The local county or city department of health should be the best source for existing vital statistics information. In fact, the public health department may have all the information that a



program might need. If some additional information is needed, the local health department may be able to access it or to identify analytic experts who could assist with obtaining it. Note that data from a linked birth and death file, when available, will yield more comprehensive information. Other sources of vital statistics information may include the state health department (although this information may not be as current as local information), schools of public health, reports from local MCH/perinatal coalitions or task forces and vital statistics analyses carried out by organizations involved with related endeavors, such as Child Death Review (CDR) or Perinatal Periods of Risk (PPOR).

Some suggested questions to ask the health department are:

- How many fetal and infant deaths are there in the community (or city, county, state) each year?
 - How many of these are fetal, neonatal and postneonatal?
 - What are the rates of these deaths?
 - What are the causes and distributions of the fetal, neonatal, postneonatal and infant deaths?
- Are things getting better or worse?
 - How have the rates changed over time?
- Are these rates lower or higher in our community than in others?
 - How do the rates compare with similar communities (or cities, counties or states)?
 - How do the rates compare with the Healthy People 2010 objectives?
- Are there particular areas of the community at greater risk?
 - What are the rates at the smallest geographical area of analysis (e.g., census tract or zip code)?
- What types of people experience fetal/infant loss?
 - What is the distribution of mothers by age, race, ethnicity, parity and education/income?
 - How do these distributions differ from those of all births in the community?
- What other facts shed light on local infant mortality?
 - When are women beginning prenatal care?
 - How many prenatal visits are they attending?
 - What is the distribution of birth weight (and gestational age) among all births and among infant deaths?
 - What is the distribution of birth-weight-specific infant mortality rates?
 - What types of accidents and injuries cause infant deaths?

After viewing vital statistics data, the planning group might also consider whether other broad indicators of community well-being from social services, education, child care, employment, housing, transportation and other areas might help describe the community. These additional indicators could also be broken down to show differences according to age, race, ethnicity, parity or education/income.

It cannot be emphasized enough that analysis of such complex population-based data is likely to be only as good as the skill and experience of the persons doing it. The planning group should candidly assess the skills and resources that are available for carrying out an analysis



Selected Indicators of Community Well-being

The following indicators are examples of types of information that can help a community better understand the status of local families.

- Poverty rate
- Literacy rate
- Immunization rates for infants
- Number of infants without health care coverage
- Reported cases of domestic violence among pregnant and parenting women
- Number of foster care placements
- Number of families on child care waiting lists
- Unemployment figures
- Employment figures for women who are single heads of households with small children
- Incarceration rates for pregnant and parenting women
- Voter participation rates
- Housing mobility rates
- Percentage of substandard housing
- Other indicators: as appropriate to the circumstances of individual communities

Adapted from: Melaville AI, Blank, MJ. Together we can: a guide for crafting a profamily system of education and human service. Washington (DC): U.S. Government Printing Office, 1993:39

of vital statistics information and other community indicators. Are there people involved in FIMR who have experience in such matters? Are they knowledgeable about obtaining access to data, developing mortality rates, asking the right questions, selecting appropriate comparisons and translating data into information that the larger community can understand? Are

there other people who could be called upon to lend their expertise in this area? A logical place to look for additional expertise is with the local maternal and child health director, public health epidemiologist, vital records registrar, university faculty or other individuals who are likely to have some experience working with multiple sources of population-based data.

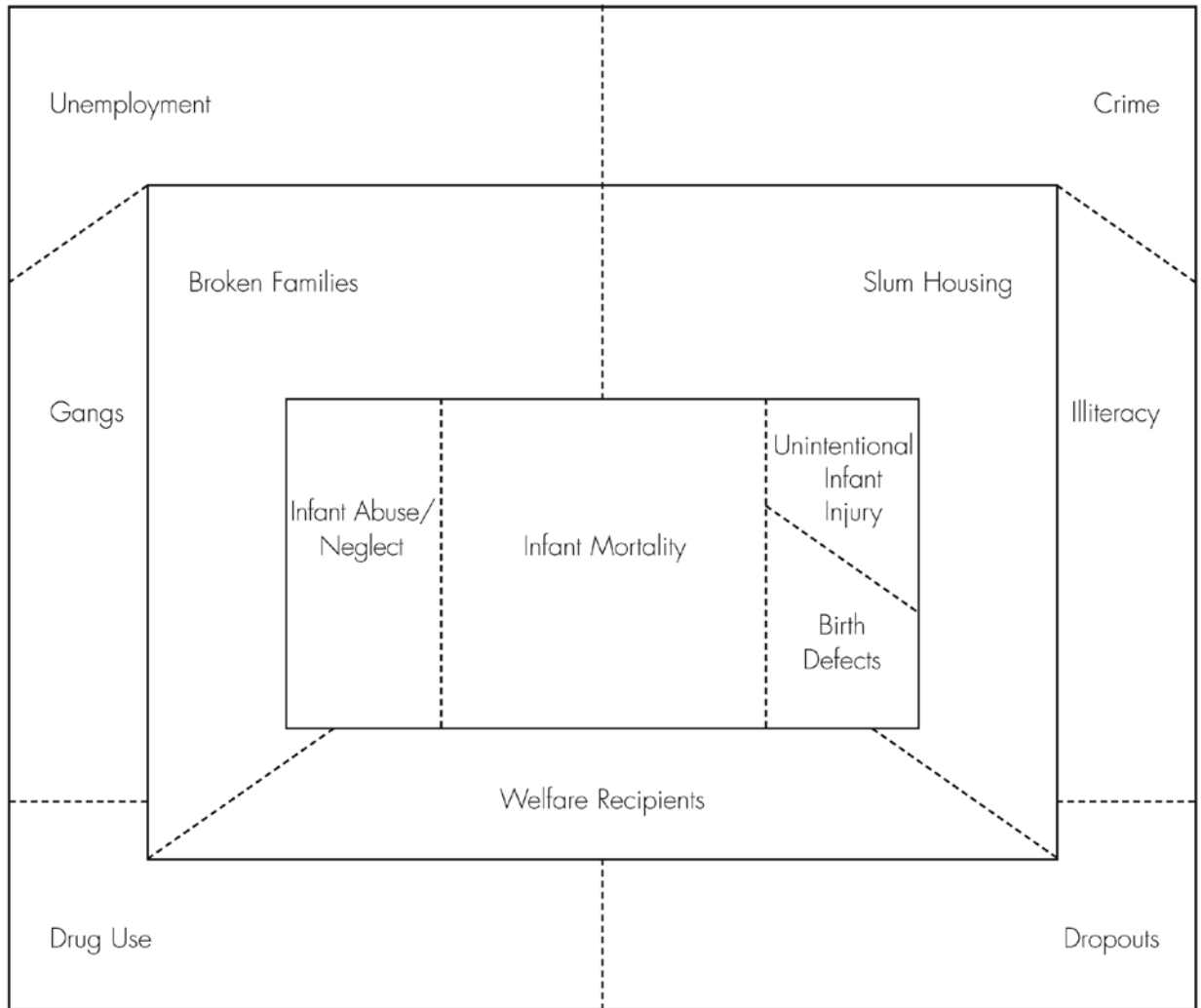
After this initial analysis of overall community indicators, the geographic area and the boundaries of the community for review should be chosen and defined very specifically. It may be a city, a county, a perinatal region or a collection of zip codes or census tracts. The region for examination may also be selected to match that of earlier studies or that of a current initiative which is addressing infant mortality in high-risk areas.

The most logical definition of the geographic area is that it be a true community and not one patched together for FIMR. Local ownership and the will to create change should be evident. Questions to be addressed in defining the community include, but are not necessarily limited to (1):

- How should the geographic area comprising the FIMR community be defined? Will it include an entire city, county or perinatal region, only those zip codes or census tracts with the most adverse outcomes, or will a cross-section of the community be represented?
- Is the community defined in a way that will translate into local ownership, accountability and pride?
- Is the geographic area one that allows calculation and comparison of its own maternal and infant health indicators with other standard vital statistics information already compiled by the larger community, county and state?



Illustration 1: Neighborhood Needs Map



Adapted with permission from: Kretzman JP, McKnight JL. Building Communities from the inside out: a path towards finding and mobilizing a community's assets. Chicago, IL. Institute for Policy Research, Northwestern University, 1993.

- How many fetal and infant deaths are expected per year in the community chosen for FIMR? (see additional discussion in section 3 of this chapter)

Early in this phase, the FIMR planning group should distinguish between the fetal and infant deaths of residents of the geographic area chosen for FIMR, as determined by the address on the infant's death certificate, and the fetal and infant deaths that occur in the area. A decision must be made regarding which group(s) of deaths to review. This decision is

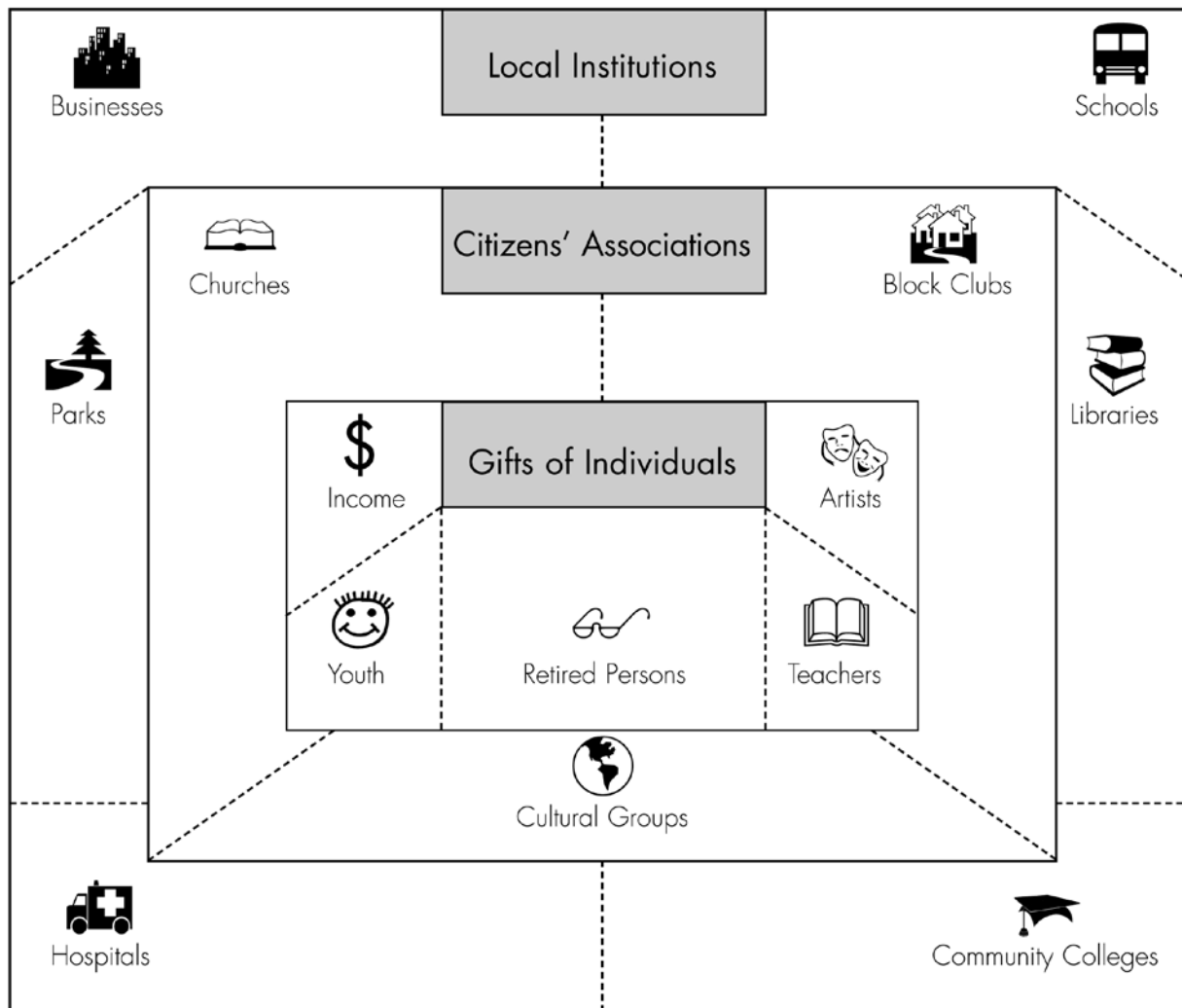
likely to be influenced by such circumstances as extent of non-resident deaths or presence of a subspecialty perinatal center in the community. Almost all FIMR programs choose to review only deaths of actual residents of the community chosen for FIMR because these cases best reflect the functioning of their entire local service system.

Discover Community Resources/Assets

As has been stated in the previous section, all FIMR programs must begin by building a



Illustration 2: Community Assets Map



Adapted with permission from: Kretzman JP, McKnight JL. Building Communities from the inside out: a path towards finding and mobilizing a community's assets. Chicago, IL. Institute for Policy Research, Northwestern University, 1993.

community needs assessment. The assessment must include vital statistics data on fetal and infant mortality, low birth weight, neonatal and postneonatal mortality, the incidence of birth defects, SIDS, etc. as well as other indicators of the community such as the percent of substandard housing, high school drop out rates and so on.

FIMR programs indicate it is also beneficial to identify positive community assets. This is a paradigm switch from *documenting needs* to *discovering* assets. This technique involves looking

carefully at their community to determine the capacities, assets and skills associated with various public and private institutions, community associations, organizations and individuals. (2, 3) Information about community assets will further help the case review and the community action teams understand the strengths of the community upon which future actions can be built, as well as better appreciate how to engage the community to address problems or gaps.

In addition, most FIMR programs compile a directory of current health and social ser-



vices and resources. This is a valuable source of information for the FIMR teams as they begin their reviews and an essential tool for the home interviewer who will use the directory to make referrals for the families who are interviewed. The directory is usually reviewed annually and updated, as necessary. Perinatal networks or coalitions, a community health worker program or the local health department may already have developed such a list.

In the past, some programs have found that community teams get a better idea of available services and resources when they visually display them (e.g., colored pins on a large map) at all team meetings. Today, some programs are using GIS mapping software to develop a picture of available services and find that type of mapping very useful.

Finally, the planning group should be aware that important agencies and community resources available in the community might not overlap or deliver services within the same geographic boundaries. For instance, the public health department will serve a city or county, the WIC program will serve low-income areas, a community health center may serve certain zip codes and transportation or housing departments may be either county-wide or city-specific. In addition, state maternal and child health programs may have defined perinatal regions or other types of service catchment areas that may be relevant. In order to have a complete needs assessment of the community chosen for FIMR, all of these different boundary lines also need to be identified and described.

Determining the Type and Number of Cases to Be Reviewed

It is important to take into account the number of cases that a team can review in a year's time.

A well run case review team (one that has been meeting for six months or so, and is a fully functioning group) will generally review an average of 3-5 cases in a two-hour team meeting. Team meetings are usually held monthly, or as necessary, to review the target number of cases. FIMR teams can review approximately 60 cases a year (5 cases/month x 12 months = 60 cases).

If numbers permit, review of all cases is the preferred option. For example, if there were 60 fetal and infant deaths in the defined area during the year, FIMR would review all 60 deaths in order to describe the fetal and infant mortality problem in detail. Many FIMR programs find that initially reviewing all fetal and infant deaths, when feasible, gives them a better picture overall of the community and its services and resources. One or two years of reviewing all deaths may be followed with more selective reviews of the particular kinds of deaths on which the community wants to focus.

If the number of annual deaths is too large to review or there is interest in limiting the focus, the FIMR program must make decisions about selecting a subset of cases, including number and types of cases. While some programs randomly sample cases, still others review only fetal, only neonatal, or only postneonatal deaths, or they review some combination of the three. Decisions about which type of cases to review should be based on the case review team's annual or biannual examination of vital statistics data and other information about the causes of infant mortality and how these statistics change over time. For example, if postneonatal deaths contribute the most to the overall infant mortality rate or the rate of postneonatal deaths seems high compared to other communities, perhaps reviewing postneonatal deaths would be the first priority. The decision is a local one. FIMR



Lessons Learned

The purpose of FIMR is not to review hundreds of cases per year, but to take the time to review each abstracted case carefully, completely and from the broader perspective of adequacy of community resources and systems of care for women, infants and families.



programs may want to consult an individual with sampling expertise for assistance in determining the most appropriate way to select a subset of cases for review.

Please note that the FIMR model presupposes an ongoing, prospective review rather than a retrospective review of cases. Thus, if a program began in April, the team would review all cases (or the designated sample) that occurred after that date. A program might go back to collect information 3–6 months prior to its start date to establish a backlog of cases to review. However, collecting much older information is not advisable because it will be difficult and time-consuming to locate families for the interview and the information collected may no longer reflect the current systems of care or resources in the community.

With hard work and persistence, it is possible to review more than 60 cases per year. One program with 150 infant deaths per year made a commitment early on to review every infant mortality case in the year the program started. They accomplished their goal over an extended period (18 months). Another program decided to have three review teams (fetal, neonatal and postneonatal) convene monthly and were able to accomplish three times the number of reviews. However, reviews of this volume may strain the case review team's ability to work effectively over the long term.

There also seems to be a minimum number of meetings and cases that must be reviewed yearly. For the FIMR process to be effective, FIMR programs report that the case review team must meet at least four times a year. If the team members review 3–5 cases at a meeting, then the number of cases per year ranges between 12 and 20.

Lessons Learned

While a range of 12–20 cases is appropriate for small cities or counties with few infant deaths, that number would be inadequate for larger communities with many more infant deaths. Review of fewer cases may lead to inaccurate recommendations and actions. If numbers are too few, some communities have expanded their geographic area to other contiguous communities that share the same service delivery system and include review of additional cases occurring in those communities. Other communities with a small number of cases have expanded the type of reviews to include not only deaths, but additional cases of living infants with injuries, low birth weight or physical disabilities.



Deciding FIMR's Relationship to Other Types of Death Reviews

Many communities may already have some type of death reviews in place, such as a Sudden Infant Death Syndrome (SIDS) study group, or Child Death Review (CDR). The FIMR program should make sure to identify all such reviews and decide what its relationship to them should be and whether some functions from other processes can be coordinated. For example, if another program, such as a SIDS program, is currently in place in the community, FIMR programs have joined forces with SIDS staff to ensure ongoing bereavement services to families. Sometimes FIMR programs also collaborate



with the local SIDS program to conduct the standardized FIMR home interview.

Many communities may already have CDR panels in place. Such panels are commonly set up to review deaths not related to natural causes (e.g., coroner or medical examiner cases, homicide). These panels initially were investigatory in nature (i.e., they reviewed the facts of child deaths to ensure that issues relating to abuse, neglect or other culpability for each case were identified and dealt with appropriately) although greater attention now may be focused on prevention.

Typically, CDR panels include representatives of local law enforcement agencies, the coroner or medical examiner, district attorney's office and child protective services, as well as pediatric providers and public health officers. Many CDRs are established and protected by legislation. An important difference from FIMR found in most of these groups is that cases are not reviewed anonymously; in fact, group members may bring to the meeting written information or records from their agencies pertaining to each case. (For more information about CDR and other types of mortality reviews, see Chapter 9.)

Identifying Legal and Institutional Issues Related to the Review

Immunity

The laws and regulations relevant to the process of fetal and infant mortality review are found primarily in state rather than local or federal laws. All states have laws that afford immunity to those participating in certain types of reviews. Because these laws vary enormously from state to state, it is very important to check state laws as part of the FIMR planning process. Seek legal advice from an attorney familiar with these issues in order to structure the review so as to maximize available legal protection. Attorneys affiliated

New York State Public Health Law § 206.1(j) Commissioner; general powers and duties

1. The commissioner shall:

(j) cause to be made such scientific studies and research, which have for their purpose the reduction of morbidity and mortality and the improvement of the quality of medical care through the conduction of medical audits within the state. In conducting such studies and research, the commissioner is authorized to receive reports on forms prepared by him and the furnishing of such information to the commissioner, or his authorized representatives, shall not subject any person, hospital, sanitarium, rest home, nursing home, or other person or agency furnishing such information to any action for damages or other relief. Such information when received by the commissioner, or his authorized representatives, shall be kept confidential and shall be used solely for the purposes of medical or scientific research or the improvement of the quality of medical care through the conduction of medical audits. Such information shall not be admissible as evidence in any action of any kind in any court or before any other tribunal, board, agency or person.

with state or local health organizations should be helpful resources.

Immunity means that the FIMR records relating to a particular case, as well as the minutes of the case review meeting and any other written records of the case review, cannot be subpoenaed or brought to court. The FIMR process may be specifically named in the state laws or more often FIMR may be included under such general terms as "professional review, peer review or public health research". In addition, protection from testifying is usually extended to individuals on the case review team and FIMR staff.

Immunity also usually means that written information about cases is not discoverable through



state laws or the federal Freedom of Information Act (FOIA). These laws basically give any private citizen or organization the right to request from the local, state or federal government all written information that the particular office has in their files on any given topic. It's important to be certain about protection relative to the FOIA because newspapers and other media reporters use this routinely to access government records and a few have mistakenly thought that they could access FIMR information. Simply put, based on programs' experiences, once a person requesting records is told that the FOIA does not apply, that closes the discussion and there are no further problems for FIMRs.

As an added precaution, FIMRs should also consider avoiding cases in which litigation is expected to take place or in which families are being charged in the death of the infant.

While situations requiring such protection are rare, all FIMRs must seek protection as a necessary precaution and as an important reassurance for professionals serving on the case review team. Some states, such as Florida and South Carolina, began reviews under general state statutes and then enacted specific legislation to further safeguard the process.

Access to records

In planning FIMR, it is also important to make sure that all available laws related to accessing medical records and vital statistics certificates are found and interpreted by state or local health department attorneys. Most laws that provide immunity for reviewers and review teams' written material may also allow access to medical records.

In addition, many states have other regulations that permit access to medical and vital statistics records for "investigations for the benefit of the health of the public" or

FIMR Program Medical Records Release Consent Form

Purpose of the Study

The (name of FIMR Program) is conducting a study of miscarriages and infant deaths in our area. The purpose of the study is to learn more about each death and to find ways to help families such as yours in the future. To achieve these goals, each case review will have two parts: a summary of a personal interview with you (or other family member) if you agree, and a review of records related to your infant's care and your pregnancy, delivery and other records that may pertain to the purpose of the study.

Participation in this program may not benefit you or your family directly but may prevent other families from having a loss like yours. If you would like to participate, your signature on this form will allow the Program Team to review the health records related to your loss.

Confidentiality of Records

All information that identifies you, your family or your health providers will be removed before the case is reviewed by the Program Team. All documents and information that identify you as a participant will be kept in a locked file cabinet and all the Fetal and Infant Mortality Review staff have signed a written oath to protect your privacy.

Compensation

Your involvement in this program is voluntary and you will not be paid for participating.

Questions

If you have any questions concerning your rights as a participant, please call (name of individual) who is with the (name of sponsoring agency) at (phone number).

Consent

I have read this form and understand the purpose and conditions for participation in the FIMR Program. I grant the FIMR Program access to health records related to my case during the study. I understand that all information obtained will be strictly confidential, and that neither my name, my infant's name nor the name of anyone else in my family will appear in any reports or be given to anyone else.

Print Name: _____

Signature: _____

Witness to Signature: _____

Date: _____

Adapted from: Western North Carolina FIMR Program, Asheville, NC



HIPAA Section 164.512(b) Public Health Disclosures

Uses and Disclosures for which an authorization or opportunity to agree or object is not required. A covered entity may use or disclose protected health information without the written authorization of the individual, as described in § 164.508, or the opportunity for the individual to agree or object as described in § 164.510, in the situations covered by this section, subject to applicable requirements of this section.

(a) Standard: uses and disclosures required by law.

(1) A covered entity may use or disclose protected health information to the extent that such use or disclosure complies with and is limited to the relevant requirements of such law.

(2) A covered entity must meet the requirements described in paragraph (c), (e), or (f) of this section for uses or disclosures required by law.

(b) Standard: uses and disclosures for public health activities.

(1) Permitted disclosures. A covered entity may disclose protected health information for the public health activities and purposes described in this paragraph to:

A public health authority that is authorized by law to collect or receive such information for the purpose of preventing or controlling disease, injury, or disability, including, but not limited to, the reporting of disease, injury, vital events such as birth or death, and the conduct of public health surveillance, public health investigations, and public health interventions; or, at the direction of a public health authority, to an official of a foreign government agency that is acting in collaboration with a public health authority.

comparable purposes. Vital statistics data are housed in local city and county health departments. Therefore, a FIMR program sponsored by the local health department would probably have an easier time accessing records.

Some FIMR programs access medical records through the federal Health Insurance Portability and Accountability Act (HIPAA)

(4). HIPAA permits a covered entity, such as a hospital, to disclose protected health information to a “public health authority” for certain public health activities. A “public health authority” is “an agency or authority of the United States, a State, a territory, a political subdivision of a State or territory, or an Indian tribe, or a person or entity acting

under a grant of authority from or contract with such public agency, including the employees or agents of such public agency or its contractors or persons or entities to whom it has granted authority, that is responsible for public health matters as part of its official mandate.” (See Appendix C for in-depth Information about HIPAA)

A covered entity may disclose protected health information without authorization from the individual to “[a] public health authority that is authorized by law to collect or receive such information for the purpose of preventing or controlling disease, injury, or disability, including, but not limited to, the reporting of disease, injury, vital events such as birth or death, and the conduct of public health surveillance, public health investigations, and public health interventions.”

A public health authority that is a covered entity may use protected health information for these same purposes. Many of the activities related to FIMR programs fall within the purview of the HIPAA public health disclosures. This permitted disclosure, however, applies only to FIMR programs that have public health agencies as sponsoring agencies or that are acting under a grant of authority from or contract with a public health agency. Disclosures to FIMR programs that are acting under the auspices of a public health agency will be permissible under the federal privacy rule. Further, HIPAA does not preempt state laws that provide for the reporting of disease or injury, child abuse, birth or death, or for the conduct of public health surveillance, investigation or intervention.

If it is not possible to access medical records under the auspices of some state law or the federal HIPAA regulations, records usually can be obtained if the mother signs a consent form



to release her records and that of her infant. If this is the case, the planning committee will need to develop a form that the mother can sign to release records and this form should be reviewed and approved by state or local attorneys. Accessing medical records through informed consent procedures, however, is not the preferred method because signing the consent form is a barrier to participation for some mothers and families and may result in a smaller and skewed set of cases.

Consent for home interview

A legally valid consent form is also essential for the mother (or other family member) who agrees to participate in the home interview. Attention should be given to ensure that all respondents understand, prior to the interview, the purposes for which the information is being collected, the potential risks and benefits and steps being taken to protect their confidentiality. This information is typically included on the consent form given at the beginning of the interview and signed by the respondent.

The FIMR interviewer should witness and co-sign the consent form to document that the mother has been informed of these issues and understands them. In developing a consent form, it is important to seek legal advice about state statutes governing informed consent to be sure that the form that FIMR will use covers all the provisions in the statutes and to have the form reviewed by the appropriate state or local legal authorities.

Dealing with Institutional Review Boards

Some hospitals, universities and other agencies may have Institutional Review Boards (IRB). Their purpose is to review all research proposals that are generated by the institution in order to ensure that: 1) the research question and design to study it are valid; and 2) any “human

subjects” (persons who may participate in the study) are not harmed. Depending on which agency sponsors FIMR, it may be necessary to clear the program through that agency’s IRB. In addition, the program may want to access records from hospitals, and some or all hospitals may require their IRBs to approve the process.

Making application to IRBs may seem like a paradox given the philosophy that FIMR is not a research program; rather, it functions as a continuous quality improvement process for the community. However, FIMR does have data collection forms and will conduct interviews with bereaved families. Early on it may help to have a discussion with the IRB (or provide written information) about the reasons why the FIMR process is not a research project and should not be subject to the review board process. The Centers for Disease Control and Prevention (CDC) has generated guidelines for describing attributes of public health research and non-research. During an NFIMR activity with the CDC regarding an adaptation of FIMR, the FIMR process was examined against the criteria in these guidelines, and was determined to be a non-research project (See p. 24). The information may be helpful to assist IRBs in understanding the true public health focus of the FIMR process.

Nationwide, about one-quarter of all programs have had to go through the IRB process. The process takes time and effort. IRB approval involves both a written response to a somewhat lengthy set of questions about the program and possibly one or two formal meetings with all the members of the board. Many IRBs only meet quarterly so that 6-9 months may pass before IRB approval can be obtained. As a general rule, if the program can avoid this hurdle, it is best to do so. If a program knows that it must pass the IRB approval process, it is important



Fetal and Infant Mortality Review (FIMR) Program: Statement of Non-Research Status

FIMR functions as a continuous quality improvement process in the community and, as such, is a non-research, public health prevention program. The information below is provided to demonstrate how the “non-research” determination might be explained to an Institutional Review Board.

General Attributes of Non-Research:	True for FIMR?
Intent of the project is to identify and control a health problem or improve a public health program or service;	YES. The intent of FIMR is to enhance the health and well being of pregnant women, their infants and families by improving local service systems and resources available to them.
Intended benefits of the project are primarily or exclusively for the participants (or clients) or the participants’ community;	YES. The intended benefits of the program are primarily for local women, infants and families.
Data collected are needed to assess and/or improve the program or service, the health of the participants or the participants’ community;	YES. The data collected are used to identify the significant social, economic, cultural, safety and MCH health systems that are associated each case and use these findings to improve local service systems and resources.
Knowledge that is generated does not extend beyond the scope of the activity;	YES. The knowledge generated is for the benefit of the participants’ local communities.
Project activities are not experimental.	YES. The FIMR methodology has been successfully used in over 200 communities and a national evaluation has determined that FIMR is an effective perinatal systems initiative.

General Attributes of Research:	True for FIMR?
Intent of the project is to generate generalizable knowledge to improve public health practice;	NO. The intent of FIMR is to enhance the health and well being of women, infants and families by improving services and resources available to them within the participants’ communities,
Intended benefits of the project may or may not include study participants, but always extend beyond the study participants, usually to society;	NO. While some of the benefits extend beyond the individual participants, the benefits largely extend to the participants’ community. The tools used are available to other communities, but the data are not, and the information about cases from individual projects has never been nationally collected or generalized.
Data collected exceed requirements for care of the study participants or extend beyond the scope of the activity.	NO. The data collected are used to identify the significant social, economic, cultural, safety, MCH health systems factors that are associated with improving care of women, infants and families in the participants’ communities.

Research theory from *Defining Public Health Research and Public Health Non-Research*, available at: www.cdc.gov/od/science/regs/hrpp/researchDefinition.htm

Side by side FIMR and research components adapted from table developed by Margaret Lampe, RN, MPH, Project Officer, Centers for Disease Control and Prevention, Maternal-Child, Pediatric & Adolescent Studies, Epidemiology Branch, Division of HIV/AIDS Prevention



to get placed on their agenda as soon as possible. Here are some tips in dealing with IRBs once the process is underway:

- Be aware that FIMR probably is unique in the types of proposals the IRB has reviewed
- Be prepared to briefly describe the underlying purpose of FIMR (i.e., continuous quality improvement versus research), but only if requested. Sometimes, more information shared about FIMR during the actual IRB process itself only confuses the Board and makes the approval process longer
- Respond promptly to written and oral questions from the IRB
- Provide answers only to the questions asked, do not volunteer extra information
- Seek advice; try to recruit a colleague who has already gone through the process and knows the IRB members

Child abuse reporting laws

All states have laws that require physicians, nurses, social workers, teachers and other health and human service professionals to report suspected child abuse and neglect. These statutes all confer immunity from civil and criminal prosecution upon those reporting. The FIMR program is bound by these requirements.

The requirements are important for FIMR in two ways: 1) the home interviewer may observe neglect or abuse in the home; or 2) review of the case itself may lead the team to suspect abuse or neglect. The home interviewer who suspects abuse of the deceased infant or observes abuse or neglect of surviving children in the home must report it. If review of a case uncovers suspected abuse or neglect, it is the program director's responsibility to report it to the appropriate agency. Because each geographic area may have a different reporting

system, the method should be locally determined before the case reviews begin.

Experience from FIMR programs indicates however, that it is extremely rare, if ever, that such a report must be made. For example, because of legal and ethical concerns, FIMR programs usually suggest that no home interview be conducted in suspected or known homicide cases. FIMR programs also indicate that it is very unlikely a family will invite an interviewer into their home if there is an ongoing abuse problem involving the surviving children. Timing of the FIMR case review in relation to the time of death generally precludes that the FIMR case review team would be the first to uncover abuse and neglect. All homicides and almost all cases of sudden unexpected infant death in which family members were thought to be abusive or neglectful immediately become coroner or medical examiner cases and have already been investigated before the time the CRT reviews the case (usually 4–6 months after the event).

Establishing Systems to Maintain Confidentiality and Anonymity

A unique confidentiality issue regarding FIMR is the fact that many pieces of information about clients and their care are drawn together to form one anonymous base of knowledge about a particular death. Each piece in itself is confidential in nature. In many cases, FIMR staff and CRT members are the only individuals ever to see all of the pieces together and thus are privy to the most comprehensive information about provision of services, community resources and institutional policies, as well as community members' lifestyles.

Preserving the privacy of all the involved parties is therefore of paramount importance to any FIMR program. Local providers and institu-



FIMR Home Interview Consent Form

Purpose of the Interview

(NAME of sponsoring agency) is conducting a Fetal and Infant Mortality Review (FIMR) Program. The purpose of this program 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 **(NAME of sponsoring agency)** will ask you a series of questions about the death of your baby and about your pregnancy, health, family and use of health care 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 for future families.

Alternate 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 questions concerning the interview or the Fetal and Infant Mortality Review Program, you may call **(Name of contact person)**, collect, at the **(NAME of sponsoring agency)** at **(contact telephone number)**.

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 that 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 else.

Print Name: _____

Signature: _____

Date: _____

Interviewer's Name: _____

Interviewer's Signature: _____

Date: _____

Adapted from: Alameda/Contra Costa Perinatal Network FIMR Program, Oakland, CA



tions will not participate in the FIMR process or provide records for review without assurance that all information will be kept strictly confidential. The planning group should be aware of what information is confidential, such as:

- Names, addresses, telephone numbers and other contact information for participants
- Any document that contains both the name and medical record number for a participant
- Completed interview questionnaires
- Completed medical record abstraction forms
- Tracking forms or cards which link the FIMR case number to a family name
- All other forms and papers with individual case information on them
- Case summaries, even de-identified ones
- Any description of a case containing enough facts by which individuals could be identified, including the actual date of birth and date of death

All of these documents should be clearly marked “Confidential”. Case descriptions or other information should be suitably summarized so that they no longer identify individuals. Keep them separate in a locked file cabinet and destroy them when they are no longer of use.

After the case is reviewed by the community review team, all paper records of the case should be shredded, if the state law permits. Any records that link the FIMR case number to a family’s name should also be destroyed. An investment in a shredder specifically dedicated to the FIMR program is a worthwhile investment.

Computer records should not contain information linking program case numbers to names of individuals, providers or institutions. As a rule, avoid entering any names and addresses into data bases; they have little long-term use

and the potential for harm is great. No computer system, however protected, is really safe from attack. Computerized information, even without specific identifying information such as names and addresses, could be used to identify individual cases and therefore access should be restricted in the same manner that access to paper records is restricted. Computer data bases should be assigned a secure password that only one or two FIMR staff will know.

The FIMR staff’s and the case review team’s knowledge of the facts of cases is also confidential. Discussion of cases should be only behind closed doors, and then only for the purposes of developing better insight into the problems presented in a particular case. A formal pledge of confidentiality form should be developed for CRT members to sign at every meeting before they begin the review process.

The potential for harm to program participants and the program itself is great if confidential information is not contained properly. If staff are unsure of how to treat a certain document, they should always err on the conservative side. Being overly cautious about confidentiality is best. In summary, at every level the local FIMR process must be completely confidential:

- All abstracted medical and related records and the home interview are stored in locked files
- All identifiers (e.g., patient’s name, provider’s name, hospital or clinic sites) are deleted from the abstracted records and the home interview
- The case summary is anonymous
- All CRT members should sign a pledge of confidentiality form that prohibits them from discussing review specifics outside the team meetings (See p. 28, 29)



Fetal and Infant Mortality Review Case Review Team Pledge of Confidentiality and Working Cooperatively

1. All FIMR information (including case summaries) and case review team (CRT) discussions are to be regarded confidential. As a team member, you are expected to:
 - Protect and secure information in your possession
 - Not discuss or share information about individual cases and the proceedings of the CRT outside of the CRT meetings
 - Not photocopy or duplicate case summary information
2. Do not discuss or share information about the FIMR program, the case review process, case review findings or any other aspect of FIMR with the media (print, television or radio).
3. Refrain from naming individuals associated with the case (including family members, providers or institutions) or sharing anecdotal information about them during the CRT meetings, including during the actual case reviews.
4. Your participation in this group is highly valued; it is vital to be a team player with the other CRT members and the FIMR staff.

I, _____,
agree to adhere to the above requests to work
cooperatively with other team members and
the FIMR staff and keep case information and
discussions strictly confidential.

Signed: _____

Date: _____

Adapted from: Eastern Virginia Medical College
FIMR Program, Norfolk, VA

- CRT meetings are closed to the public and minutes of their meetings are confidential and stored in locked files

- The confidentiality of the reviews is protected by relevant state statutes

As the groundwork for FIMR is being laid, programs will need to be prepared to respond to professional or institutional concerns such as: the reviews may result in censure of providers or institutions or that the FIMR home interview may provoke medical liability suits. The planning group should stress the strict confidentiality of the FIMR model and review all the safeguards mentioned above. Providers and institutions need to be reminded that FIMR reviews are de-identified and thus it is impossible to connect providers or institutions to actual cases.

Even if it might seem that some information could reflect on an individual or institution, the information is abstracted from the record, summarized and reported to the team, and thus is synthesized multiple times by the time the team reviews it. Legally, that information is usually categorized as hearsay and would not be admissible in any type of legal action. Finally, after decades of experience and literally thousands of interviews having been conducted in all parts of the country, the home interview has not provoked liability suits.

Establishing a System to Identify Cases

All FIMR programs need to develop a timely system to identify where and when infant deaths occur well before they have begun case reviews and family interviews. Ideally, it should take no longer than two to three weeks from the date of the infant death until notification of the FIMR staff. It is important to identify cases in a timely fashion in order to 1) ensure that the mother can be found and asked to participate in the interview; 2) begin the process of abstraction of medical records; and 3) ensure a timely review of cases by the



Fetal and Infant Mortality Review Case Review Team Confidentiality Pledge

The Fetal and Infant Mortality Review is a confidential process. Surviving family members or care givers, service providers, and service providing agencies are to be protected from disclosure of information outside of the review meetings. Informed consent for maternal interviews and conditions or release of medical records from service providing agencies specifically guarantees this protection.

The nature of the review meeting is designed to encourage free discussion and exploration of issues. Participants may express opinions which do not reflect their agency position, or which may later change. Some factors discussed will be sensitive: many will involve matters of values and beliefs, or may concern cultural variables. In order for there to be a free exchange of ideas, it is important that opinions expressed are not repeated outside of the meeting, or used to express judgments about any individual, agency or profession.

Actual recommendations or findings of the CRT should not be represented outside of the review meetings until reviewed by the Community Action Team and an action plan is developed.

The findings and recommendations of the FIMR CRT will not necessarily become official Carroll County Government policy. On the other hand, the County may choose to formally support some or all of these actions.

As a FIMR CRT team member, I pledge to:

1. Refrain from discussing or sharing information about the case, the case summary and the proceedings of the CRT outside of the CRT meeting
2. Refrain from speculation about the identity of the case (mother, family, providers, and/or agencies) before, during or after the meeting, even when I may recognize an aspect of the case
3. Respect the opinions and positions of fellows members; differing opinions are welcome, but should be expressed in a respectful manner and any disagreements should remain in the confines of the meeting
4. Support the work of the FIMR CRT by discussing publicly the general work of FIMR, but not disclosing any specific findings or recommendations until the Community Action Team has developed an action plan
5. Promote the work of the FIMR action plan by disseminating the FIMR action plan developed by the CAT to my institution, agency, or community members and soliciting ideas and resources that may be useful in the plan, as needed

Signed: _____

Printed name: _____

Date: _____

Adapted from: Carroll County MD FIMR

case review team. Cases will not adequately reflect the current service delivery system or community resources if they are two or three years old by the time they are reviewed.

Finding cases may be very easy. The local vital statistics registrar may agree to forward all death certificates indicating age one year or less to the FIMR program within a week

or two of the death. However, lacking that cooperation, programs find innovative ways to ascertain cases, such as:

- Arranging to review hospital admission and discharge logs in all possible areas (e.g., emergency department, labor and delivery, neonatal and pediatric intensive care units, morgue) and hospital death logs on a regular basis



- Establishing referrals from and maintaining contact with hospital bereavement nurses or counselors, funeral directors, hospital medical records staff, medical examiner or coroner, police officers, emergency medical transport services teams, clergy and community health workers
- Communicating with agencies and programs such as WIC, Medicaid, welfare programs, Department of Social Services and home visiting/case management units
- Coordinating with existing local programs such as SIDS, etc.
- Reviewing the obituary columns in local newspapers

Selecting Data Collection and Processing Methods

Critical to FIMR is identifying what information is needed and a method to collect it. It is important to collect information in a standardized fashion to facilitate review of each abstracted case from the larger perspective of adequacy of community resources and systems of care for families. However, creating standardized medical record and related data collection forms and programming them into a software package for storage and processing can be exorbitant in time and money for any individual FIMR program and derail the whole FIMR process. One or two FIMR programs have spent several years developing original forms, but have not reviewed a single case.

Lessons Learned

A real barrier to success for FIMR programs is failure to implement an effective system to identify cases.



Lessons Learned

As a general rule, new FIMR programs are almost always better off adopting existing data collection forms and software for collecting and processing of information, rather than creating new ones. As a program grows and gains knowledge of the kinds of information that are really useful to its teams, staff can then begin to evaluate and revise the forms to meet the needs of their community.



To facilitate FIMR program implementation, the NFIMR program has revised and updated their data collection forms and accompanying software. The software includes a feature that will generate a summary of each case that can be used during the CRT review. Programs are encouraged to use this system and modify it to fit local needs. To order the free software and forms, go to the NFIMR web site: www.nfimr.org. If the NFIMR system does not fit local needs, programs are encouraged to contact the NFIMR office where staff can link them with other programs that have alternate data or information systems.

For most groups the easiest part of determining what information to collect is to think in terms of sources. Typically, most FIMR information is collected from:

- Family interviews
- Birth and death certificates
- Autopsy reports
- Hospital records: labor and delivery, newborn, neonatal and pediatric care units, emergency room
- Outpatient records: prenatal, pediatric well baby and sick baby visits



- Others: WIC, public health nursing home visits, transport logs, Department of Social Services

However, the harder question is not from where the information will come but what and how much information is needed. Every program in its planning stage should take the time to reflect on what information is needed and how it will be used. The temptation is to collect as much as possible and worry about what is needed later. This may turn out to be a costly and inefficient method of information gathering.

At the same time, a program should not be too restrictive in deciding what kinds of information to collect. If a primary objective for FIMR is to identify systems factors associated with fetal and infant deaths in the community, the process should not attempt to pre-identify all the factors that may be important. FIMR by design casts a wide net for such factors, rather than limiting itself to a narrow range of identified factors. The information collection forms, although they must have some structure and consistency, must also allow for identification of a wide variety of issues that will arise from case to case. This process, in short, must be able to capture the uniqueness of each case.

In the beginning of the case review process, FIMR experts report that the case summary must have enough clinical information to be “medically credible”. This means that the medical professionals on the team must be able to understand the case from their point of view. (5) During the first reviews, the CRT may have to table a case because of lack of some clinical information (e.g., blood gases, types of inpatient medications, etc.) that medical team members feel is crucial. As the team develops greater attention to the community-wide systems issues, the

need for this detailed medical information will decrease substantially. Thus, the type of information that is collected and judged to be most useful by the review team will change over time.

Another deciding factor for information collection is how the information will be used. The main use for FIMR information is to create an expansive narrative summary of what happened in each case. Another is to develop a data base that can be used for an aggregate analysis of cases that complements and supports the qualitative case review analysis. Every FIMR program by definition will engage in the first process, but not every program will engage in the second.

Every program needs to collect information to be able to relate the story of each case from a systems perspective, including but not limited to factors such as access, barriers, patient education, psychosocial assessment, lifestyle choices, coordination of services, discharge planning, etc. However, programs should not feel compelled to conduct an aggregate analysis unless they clearly have a need for it later and can identify community experts who are willing to volunteer to help them complete it.

This distinction between collecting information for case review versus collecting data for aggregate analysis is borne out in the selection and creation of forms. Interview questionnaires and abstraction forms will have to be organized to provide enough basic information on any fetal, neonatal and postneonatal death to describe what happened in each case. If a larger, more detailed data base for aggregate analysis is being developed, then the forms should be more detailed and more rigorously designed and tested.

Also, in choosing which information to abstract, an effort should be made to assess



realistically the ability of the local program to collect it. In general, vital statistics data at the county or city level are easy to obtain with the assistance of the local health department. Hospital-based records are usually more easily obtained than private provider office-based records. A suggested process for assessing the relative importance of individual information elements is to:

- Review the individual items on the NFIMR data abstraction forms or some other forms currently being used by an experienced program to identify which ones are of interest to the planning group
- Assess the match between which items are important and which are likely to be available
- Assess the match between the accuracy of the wanted information and the accuracy of the available information
- Build in some redundancy to make sure important items can be captured for every case (birth weight, age of mother, etc.)
- Assess the level of effort and possible cost associated with data collection from each source
- Assess the professional and institutional support for use of Zeach source
- Choose items that are important, but also easy to collect, and cost-effective

Identifying Costs and Funding Sources

The most frequently needed resources for FIMR relate to the collection, review and reporting of information. These include, in descending order of cost and importance: dedicated staff time (for medical case abstraction, home interviews and overall program coordination), clerical services, space, duplicating, printing and mailing.

One approach to estimate the cost of the FIMR program is to calculate the percent of full time equivalent (FTE) staff salary needed for the mid level FIMR coordinator position. The FIMR coordinator position usually ranges from 0.5 FTE to 1.0 FTE and the salary is generally comparable to a senior local health department nursing position. This cost will vary by state and county salary scales.

Another approach is to project the cost based on the number of cases to be reviewed multiplied by an estimated cost per case. Across the country, experience has shown that the average cost per case appears to range from \$400–\$700, depending on local personnel costs. Thus, the cost of a program reviewing 60 cases would range from \$24,000–\$42,000 (3–5 cases x \$400–\$700 x 12 months). While the cost-per-case is a helpful tool in estimating overall program costs, the program should determine which reimbursement mechanism best serves its purposes (i.e., allocating resources piecemeal by paying for case abstraction or interviews on a case by case basis or supporting a dedicated staff position for this responsibility).

It should be noted that the above program costs are base-line estimates and do not include the in-kind contributions of the agency sponsoring FIMR or the contributions of the service providers, community leaders, advocates and families in the community who volunteer their time to serve on the case review team or the community action team.

These estimates also do not take into account the reality that all interventions proposed by the FIMR community action team will challenge every community to expand its capacity and mobilize additional resources for women, infants and families.



Funding sources for FIMR programs vary. While many programs have benefited from seed money from federal or private sources, these temporary, one-time only funds are intended to help communities get started and to develop long-term local support. Many times state health departments have funded FIMR with Title V Maternal and Child Health (MCH) Services Block Grant dollars. FIMR in this case may become an integral part of the state MCH needs assessment process that is federally mandated. Local public health departments can similarly incorporate the FIMR process into existing efforts, and it can become part of their efforts to implement the core public health functions of assessment, assurance and policy development.

Regardless of the original funding sources, successful local FIMRs are increasingly savvy and resourceful. They are able to build a variety of local partnerships and find creative short-term and long-term funding to sustain their efforts, such as:

Lessons Learned

Costs of FIMR actions/interventions are not usually borne by the FIMR program. Typically, the CAT mobilizes agency, institutional and community policies, programs, resources, capital and/or services to accomplish proposed changes.



- Non-profit organizations (e.g., March of Dimes; Healthy Mothers, Healthy Babies Coalitions) may provide space, equipment and printing costs, as well as staff support
- Businesses may provide direct support as well as space, equipment and printing costs. One FIMR program has its entire

office space donated by the local bank. Another program receives donations of free food from local restaurants for the case review team meeting.

- Private local foundations may be willing to provide start-up funds for staff salaries
- Local community public health and related service agencies may provide staff, space and funding. For example, in one program the local hospice has volunteered to conduct maternal interviews free of charge. In another, the local health department dedicates a portion of a public health nurse line item for home interviews. In a third program, a county birth certificate surcharge supports the entire program.

Designating the Program Director and Coordinator

Almost all agencies who take the lead in implementing FIMR provide a major in-kind contribution. Usually this is the dedicated salary (5–10% FTE) of the person in the sponsoring agency who will assume the role of the FIMR program director. This person may already be involved in the planning group. In order to be most effective, the FIMR program director may be the agency director. If not, the program director should have influence in the sponsoring agency and be able to work directly with the head of the sponsoring agency, as well as be viewed as a leader in the overall community. The FIMR program director assumes overall responsibility for the planning process and for building and maintaining community-wide support for FIMR and good working relationships with other agency leaders. These activities are absolutely critical to the program's success.



The FIMR director will review the case summaries before each CRT meeting to make sure they are complete, and in most cases be the team leader for both the case review team deliberations and the community action team meetings. S/he will hire the FIMR staff and be responsible for their overall supervision as well as assuring adequate training for staff including abstractors and home interviewers. The FIMR director will publish and circulate the annual report which the CRT and CAT will draft, with the assistance of the FIMR coordinator (see p. 35).

The lead agency, with advice, as appropriate, from the planning group will also designate a FIMR coordinator (40–50% FTE). During the planning phase, this mid-level position is usually assigned to an individual already working in the sponsoring agency in a complementary position (SIDS coordinator, Pregnancy Risk Assessment Monitoring System [PRAMS] program coordinator, etc.). This assignment may continue after the program is up and running or, if funding allows, a new position may be created for a program coordinator. The incumbent then assumes the responsibility for the tasks related to planning FIMR as well as the ongoing day to day management of the program, and reports to the program director. The coordinator prepares the case summaries that the CRT reviews, schedules all meetings of the CRT and CAT and drafts minutes of these meetings.

This FIMR coordinator will supervise the FIMR staff who abstract case information, and interview mothers, keeping a close eye to see that these activities are completed in a timely fashion (see p. 36). In smaller FIMR programs, the coordinator may also pitch in to abstract some or all of the records or conduct a portion of the home interviews.

Lessons Learned

It is very important to understand that the mid-level FIMR coordinator functions best when paired with the influence and commitment of a senior program director in the sponsoring agency. The FIMR coordinator should never be expected to fulfill the responsibility of the senior policy role of the FIMR director. It is unlikely that a mid-level FIMR coordinator could rally and maintain the broad-based community support that will be needed to make the program successful.

It is also not the role of the FIMR coordinator to be responsible for implementing the actions recommended by the case review team and the community action team. The teams must look to their membership and community resources to achieve community improvements. Placing all responsibility for change on the mid-level FIMR coordinator is not consistent with the FIMR methodology and could detract from accomplishing the multiple tasks associated with the case review function as well as result in burn-out for staff. So too, when team members become disengaged from the process of improvement, they may lose interest and not stay involved with FIMR, and more importantly, the FIMR process suffers from the lack of their influence to achieve significant change in the community.



Formalizing Policies and Procedures

At some point during the planning process, the planning group will want to begin keeping a written record of the emerging policies and procedures for conducting FIMR in the community. These guidelines will be the program's detailed description and road map. They should be expected to evolve and expand as the program grows and should be revised on an annual basis, adding items to reflect the most current policy. This will be even more important in the rare occasion when two or more agencies plan to



implement FIMR jointly and need to work from the same written agreement on what is to occur. For a program that is just beginning, a sample table of contents of the written policies and procedures may include, but is not limited to:

- Written description of the program mission statement, goals and objectives
- Job descriptions (e.g., director, coordinator, interviewer, abstractor)
- Case review team (CRT) and community action team (CAT) responsibilities
- CRT and CAT rosters
- CRT and CAT meeting format
- Methods for maintaining confidentiality
- Methods for conducting an annual or biannual review of vital statistics data and revision of the focus of reviews, if necessary
- Methods for finding cases
- System for case selection
- Method for finding and contacting mothers
- Methods for conducting home interviews
- Methods for medical records abstraction
- Community resource directory
- FIMR program data abstraction forms (e.g., Medical Record Abstraction, Home Interview Instrument)
- Approaches for reporting to community

Build in Opportunities for Initial and Ongoing Training

The national evaluation of FIMR revealed important results regarding the effects of training of FIMR directors, staff and team members. The researchers asked FIMR directors whether they, their staff and the FIMR team members had received training in perinatal health, ways to use information produced from case reviews and strategies for implementing action agendas. The

Fetal and Infant Mortality Review Program Program Director (Part-Time)

PROGRAM DESCRIPTION

The overall goal of Fetal and Infant Mortality Review is to enhance the health and well-being of women, infants and families by improving the community resources and service delivery systems available to these families. FIMR brings together key members of the community to examine information from individual cases of fetal and infant death to identify the factors that contributed to those deaths, determine if those factors represent system problems that require change, fashion recommendations for change and assist in the implementation of change.

JOB RESPONSIBILITIES

This position is responsible for the management of the ongoing Fetal and Infant Mortality Review Program and supervision of staff as well as assuring adequate training for staff including abstractors and home interviewers. The director will work with key members of the community to determine how best to ensure that together these community leaders are able to develop recommendations and implement FIMR actions. The director serves as the program's liaison to community leaders, physicians, hospitals, related family service providers and agencies, as well as to civic groups, advocates and consumers. The director is responsible for chairing all team meetings, and developing written reports, grant proposals and other documentation pertaining to the program. Position reports directly to the County Commissioner of Health.

QUALIFICATIONS

A master's in Public Health, Public Administration, Nursing, Social Work or related field is required. A doctorate is preferred. The candidate must also demonstrate proven experience/skills in the health care field (pediatrics, obstetrics or related field), background in health program development and administration, complete understanding of the structure and functions of county and community health and related systems and resources, knowledge of the theory and practice of the continuous quality improvement model as it relates to community development, experience with data analysis, organizational and interpersonal skills; and have experience working with diverse populations and chairing complex, multi-organization meetings.

SALARY

Commensurate with skills and experience.

Adapted from: San Diego County Department of Health IMR Program, San Diego, CA



Fetal and Infant Mortality Review Program Coordinator

PROGRAM DESCRIPTION

The overall goal of Fetal and Infant Mortality Review is to enhance the health and well-being of women, infants and families by improving the community resources and service delivery systems available to these families. FIMR brings together key members of the community to examine information from individual cases of fetal and infant death to identify the factors that contributed to those deaths, determine if those factors represent system problems that require change, fashion recommendations for change and assist in the implementation of change.

JOB RESPONSIBILITIES

This position is responsible for implementation of the day to day Fetal and Infant Mortality Review Program. This coordinator will supervise other FIMR staff who abstract case information, and conduct home interviews. Other activities include developing case summaries, scheduling and attending all team meetings and developing written minutes resulting from meetings. Also may include conducting some interviews with bereaved families, also tracking some medical records and serving as program liaison to the other community interviewers and to hospital medical records' departments. Position will report to program director.

QUALIFICATIONS

Bachelor's degree and minimum five years experience in the health care field (pediatric, obstetric, public health or related fields). Understanding of community health care systems and resources, data analysis methods; organizational and interpersonal skills required for scheduling interviews. Background or training in bereavement counseling skills and cultural competency is mandatory.

SALARY

Commensurate with skills and experience.

Adapted from: Healthy Mothers-Healthy Babies Coalition FIMR Program, Broward County, FL

answers lead to notable findings, including the following (6, 7):

- A significant association between receipt of training for FIMR program participants and their adopting a broader scope of attributes and roles related to making improvements in perinatal health systems and status
- Training in developing action agendas was associated with more than a three- fold increased frequency of reported roles related to serving as a forum for community concerns about perinatal health, educating communities about perinatal health issues, assessing perinatal health status and perinatal health care system policy development
- Receipt of training related to how to use case review findings and strategies for implementation of recommendations by the FIMR director and/or staff was significantly related to an increase in the average percentage of actions implemented
- Training in all three areas for the FIMR director was related to carrying out essential maternal and child health services, especially activities associated with community partnerships and mobilization

In summary, the national evaluation of FIMR concludes that training for the FIMR director, staff and team members will help local programs expand their roles and functions and move from recommendations to action. This connection should prompt local planners to pay special attention to the training background of FIMR program participants, and ensure needed start-up training for the director and staff as they come on board as well as for new CRT and CAT team members. Right from the start, attention should be paid to building in ongoing time and resources for continued training on a periodic basis for program staff and team members.



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CHAPTER 3

Building Community Support and Collaboration



CHAPTER 3

Building Community Support and Collaboration



Introduction

The FIMR planning group must specifically recruit a wide variety of members to support the program as well as serve on the case review team (CRT) and the community action team (CAT). Supporters and team members should include policy makers, representatives of organizations and professional groups as well as family representatives and consumer and advocacy groups.

This chapter describes important aspects of building community support and collaboration for FIMR. The previous chapter, Chapter 2, focuses on the steps the planning group should take to develop the programmatic features that lay the groundwork for the program. Please

note that while these two sets of activities appear in separate chapters for descriptive purposes, the planning group must work on them concurrently. Building community support and collaboration for FIMR and at the same time, developing its programmatic features usually takes about 6–8 months. Figure 1 displays these sets of complementary activities.

Selecting the Right People to Get the Job Done

Choosing the right mix of individuals to serve on both the FIMR case review team and community action team is crucial to the success of the process, and requires very careful planning. According to experts in building community

Essential Steps for Initiating a FIMR Program

Assure Community Readiness

Develop Programmatic Features (6–8 months)

- Define the community
- Analyze the problem
- Identify geographic area
- Determine types of cases
- Describe services and resources
- Develop resources directory
- Determine relationship to other review processes
- Identify costs and funding sources
- Identify and address legal and institutional issues
- Setup procedures and policies for:
 - Confidentiality and anonymity systems
 - Case selection
 - Data collection and processing methods
 - Forms
 - Record abstraction
 - Family home interview
- Reporting to community
- Administrative functions

Build Community Support and Collaboration (6–8 months)

- Determine sponsoring agency
- Build support from community sectors
 - Public health
 - Hospitals
 - Health professionals
 - Social services
 - Community advocacy
 - Consumers
- Identify FIMR team participants
- Assure:
 - Diversity
 - Influence
 - Commitment
 - Consumers
- Hold town meeting
- Introduce FIMR concepts
- Develop mission statement

Initiate FIMR Case Reviews



alliances, and echoed by the experiences of many FIMR programs, membership should include individuals who will bring diversity, influence, commitment and consumer participation to the table. (1)

Diversity requires that both the CRT and the CAT memberships represent a wide array of personal and professional knowledge, expertise and experience, the ethnic and cultural diversity in the community and a broad, creative range of organizations including some who may not have been included in traditional maternal and child consortia. Choosing members who, in the totality, exemplify multi-cultural partnership, family/consumer-community service agency partnership, multi-agency partnership and public health-private provider partnership is vital to building FIMR team diversity. Business leaders and unions, including those that represent employees who are women of childbearing age, might also be included in the partnership network.

It can be expected that the different opinions brought to the table by such a diverse membership may make for some lively and at times even divisive team meeting discussions, especially during the first-year CRT and CAT meetings. However, FIMR programs indicate that this type of group interaction is a positive sign because it paves the way for establishing the common ground of understanding that is critical to FIMR review and action and aids team sensitivity to the many cultural values, attitudes and beliefs in the community. Finally, diverse CRT and CAT team membership sets a community standard of cooperation and mutual respect that should be a model for individual team members, their respective organizations and the community as a whole.

Influence refers to those policy makers, institutional and professional leaders, and/

or organizational spokespersons who have the power to make decisions for and mobilize fiscal and programmatic resources on behalf of their constituency, agency or organization. Team members with influence will usually be the leader in charge of a specific agency, organization, an elected official, or a high level staff member clearly entitled to represent them and make decisions.

Commitment concerns a team member's proven track record over time of putting what is good for women, infants and families before what is expected or convenient for his or her own organization or professional interest. Commitment means that the member has already demonstrated the ability to some degree to act as an advocate or champion for improvement in systems to which deeply rooted and long-standing policies or interests oppose such change. However, not all team members come to the table as proven community advocates; mobilizing this spirit of commitment especially among new or younger community members is one of the overall benefits of active participation in the FIMR process.

Consumer participation should be an integral part of the FIMR process from the beginning and throughout the process. In general, consumers are individuals who live in the community chosen for FIMR and use its services and resources. A special component of consumer participation for all FIMR programs is to ensure inclusion of family members who have suffered a fetal or infant loss in the roster of both the CRT and the CAT.

Bringing the consumer perspectives into the FIMR process is essential to broadening the knowledge base and creativity of the teams and greatly enhancing the character of the actions they will develop and implement. Because FIMR team membership requires active participa-



tion in divergent and occasionally heated group meetings, consumers who already have some experience in community advocacy groups seem better able to cope with those dynamics and actively join in the discussions. Members can be recruited from bereavement support groups, hospital or health center community advisory boards, church-based organizations, civic groups, tenant groups, advocacy groups and community development corporations. In order to ensure community representation, the planning group should make a special effort to identify and address any barriers (e.g., transportation, child care, etc.) that may make it difficult for community members to participate.

Choosing Case Review and Community Action Team Members

Some community stakeholders will be more appropriate participants on the CRT. Professionals and agencies on the case review team should be representative of consumers as well as professionals and agencies that provide services or community resources for families in the community chosen for the FIMR program, such as the local health department (including perinatal data expert), both primary and tertiary care institutions, obstetric and pediatric providers, hospital administrators, Medicaid supervisors, WIC program nutritionists, family planning providers, health educators, community health workers and drug treatment centers representatives. Other representatives might include pastoral counselors, minority rights advocates, a member of the Chamber of Commerce health committee and members from the local SIDS community.

For example, one FIMR program has developed a diverse CRT of 15 members which includes the local health department, the university medical school department of OB/GYN, the federally supported Healthy Start program, the medical examiner's office, the

perinatologist from the tertiary care center, the Sudden Infant Death Center coordinator, the African-American health coalition, the Latino health organization and the state Maternal and Child Health Division. Also included are a managed care organization representative, WIC, social service and Medicaid representatives, a family member who has experienced an infant death, a prenatal care coordinator, a family planning provider, the director of the community health worker program and an alcohol and drug abuse service director.

Other individuals and agencies/organizations will collaborate on policy development through the CAT. The CAT is composed of two types of members: those with the political will and fiscal resources to create large-scale system change and members who can define a community perspective on how best to create the desired change in the community. One example of a FIMR CAT has 25 members, including the mayor and members of the city council, presidents of local hospitals, the director of the local medical society, directors of several local government agencies (the Housing and Redevelopment Authority, social services, the schools), the local Commissioner of Health, the CEO of the managed care organization and representatives from the Chamber of Commerce, the state Resource Mothers program, the state Maternal and Child Health

Lessons Learned

It is most important not to form a new and distinct FIMR CAT unless no other comparable group exists in the community or the existing group is working to capacity. Unnecessary replication of teams can lead to overlap in membership, duplication of tasks and increased workloads, and result in less than optimal attention being given to FIMR.





(MCH) program, a perinatal epidemiologist, a military parenting program, the state Child Abuse Prevention Services, a family member who represents the local bereavement support program, the Urban League, the local March of Dimes chapter, the Kiwanis Club, the community health center advisory board and the Hispanic health services coalition.

Many communities already have a functioning group or perinatal initiative that has the characteristics necessary to fulfill the role of the CAT. This includes such entities as a prenatal/perinatal regional consortium, a community advisory board, a mayor's or county executive's blue ribbon panel on infant mortality, a Healthy Mothers, Healthy Babies Coalition, a consortium for a federal Healthy Start project, etc.

Given the close working relationship of the CRT and CAT, some CRT members may also be members of the CAT (e.g., Commissioner of Health, Director of Social Services, etc.). In addition, some members of the CRT may rotate onto the CAT after several years of service and vice versa.

As a starting point, use the Community Participation: A FIMR Member Checklist (see p. 45) to develop a preliminary list of potential FIMR CRT and CAT members and review the following questions as the list is being finalized. (2):

- Does the list include a broad-based, multi-partner array of agencies and individuals who should be involved in the FIMR teams?
- Does the list include families and consumer advocates that represent the diverse ethnic and cultural groups in the community?
- Have specific members of the case review team and the community action team been identified?

- Are there sufficient members with the desired level of influence or administrative responsibility included in both teams?

In choosing a wide range of team members, but still keeping the team's size down to a manageable number, FIMR programs indicate that they sometimes look for a few members who can "wear two hats," i.e., those who represent more than one constituency or point of view. For example, programs have included the local head of the medical society who is also a practicing obstetrician, a commissioner of health who is a pediatrician and provides well-baby care in the health department clinic, a police chief who is a SIDS parent, a director of a community health worker program who lives and works in the community most at risk for adverse outcomes, a family planning advocate who was a teenage mother, etc.

After potential CRT and CAT members have been tentatively identified, the planning group should begin meetings with these individuals and groups with relevant interests to recruit team members as well as gain the commitment of the community. Recruiting key members will take time, patience and planning. As members come on board, they should in turn use their interagency influence and connections to recruit other potential partners. In this stage of building local support, FIMR programs tell us not to overlook the informal power of personal friendships among agency leaders in building support for FIMR.

The planning group should also brainstorm to market FIMR to potential detractors, asking the following questions: "Who is in a position to obstruct our efforts? How can we help them see the advantages of working together and involve them?" (1)

Worksheet 1: Community Participation: A FIMR Member Checklist

PLEASE INDICATE THE NAME OF THE PERSON WHO CAN PARTICIPATE IN THE FIMR PROCESS

Reminder: Some community members will participate on the Case Review Team or on policy development through the Community Action Team. Everyone benefits from improved collaboration.

Key Community Leaders

- ☐ Mayor, County Executive: _____
- ☐ Religious Leaders: _____
- ☐ Business Leaders, Chamber of Commerce: _____
- ☐ Civic and Fraternal Groups, such as Kiwanis, Jaycees, AKA, Junior League, etc.: _____
- ☐ Educators: _____
- ☐ Others: _____

Health Care Providers

- ☐ Obstetrician/Gynecologist: _____
- ☐ Pediatrician/Maternal-Fetal Specialist: _____
- ☐ Obstetric/Pediatric Nurse: _____
- ☐ Social Workers: _____
- ☐ State and/or County Medical Society: _____
- ☐ Hospital Administrator: _____
- ☐ MCO/HMO Representative: _____
- ☐ EMS: _____
- ☐ Others: _____

Public Health Providers

- ☐ City and/or County Health Department(s): _____
- ☐ Medicaid: _____
- ☐ Medical Examiner: _____
- ☐ WIC Supervisor: _____
- ☐ Outreach Workers: _____
- ☐ Family Planning Representatives: _____
- ☐ Others: _____

Human Service Providers

- ☐ Child Welfare Agencies: _____
- ☐ Substance Abuse Services: _____
- ☐ Mental Health Services: _____
- ☐ Department of Corrections: _____
- ☐ Housing Authority: _____
- ☐ Transportation Authority: _____
- ☐ Other: _____

Consumer and Advocacy Groups

- ☐ March of Dimes: _____
- ☐ Healthy Mothers/Healthy Babies: _____
- ☐ MCH Coalitions: _____
- ☐ Perinatal Infant Grief Professionals: _____
- ☐ Bereaved Family and Other Consumer Representatives: _____

Consumer and Advocacy Groups

- ☐ Family Support Groups (SIDS) Alliance, Compassionate Friends, etc.): _____
- ☐ Minority Rights Groups: _____
- ☐ Women's Rights Groups: _____
- ☐ Union and Workers Rights Groups: _____
- ☐ Housing and Tenants Rights Groups: _____
- ☐ Others: _____

Adapted from: Striffler N, Coughlin, PA, Magrab, PR. Communities can workbook series: developing collaborative services for children. Washington, DC: Georgetown University Child Development Center. 1994:4 and Phelps, A. Florida Department of Health



When approaching potential members who represent professions, organizations or other entities, the FIMR planning group must be prepared and should: (3)

- Have an understanding of the organization's purpose or mission and any current issues that the organization is addressing
- Have in mind specific ways the organization being approached might assist FIMR to move recommendations to action and on which team (case review or community action) the member would best serve
- Describe the general purpose and objectives of the FIMR process in simple terms
- Explain the reasons why the community in general would benefit from the FIMR process, and the specific benefits to the potential members' organization, including ways FIMR may help to achieve the organization's purpose or mission
- Reinforce the rigorous confidentiality of the FIMR process and address any issues that may be of concern to that particular organization
- Facilitate a frank discussion of the potential members' view of the FIMR process and respond to any specific concerns

Also be aware that some of the strongest FIMR team members are those who see their individual work on behalf of FIMR not only as a general benefit to women, infants and families in their community, but also as tied to fostering their own professional growth. Whenever it seems appropriate, reinforce this professional benefit to potential team members.

Convening a Community Meeting

After the meetings with the individuals described above have created a broad base of community support and the program ground-

work has been established (see Chapter 2), many FIMR programs convene a community meeting to bring together all the key individuals and agency representatives who are willing to support the program as well as those who have volunteered to serve on the CRT and the CAT. This initial meeting of service providers, community leaders, advocates and families in a community can be a critical component in coalescing community ownership and enthusiasm, and setting the stage for future collaboration. Local FIMRs have always worked hard to make sure this first meeting is a success although each tended to work in isolation. To help facilitate the planning of this meeting, specific strategies from local FIMR programs and some general advice from coalition building experts from Georgetown University are summarized below. (4)

When planning the meeting, the most convenient times should be carefully reviewed beforehand with each invited participant and a time set which accommodates the majority of schedules. In different communities, weekday mornings, noon or early evenings have all been chosen as acceptable meeting times for this first meeting. A weekend meeting is almost never well attended and should be avoided. Serving refreshments or a light meal is beneficial. In addition, sharing a meal seems to promote a more relaxed and friendly atmosphere at FIMR meetings.

Lessons Learned

Caution: The FIMR process should be discussed in person beforehand with everyone who is being invited to attend the meeting. Any individual concerns about the process should be addressed ahead of the meeting. One unenlightened participant can disrupt the whole meeting.





Deciding the location of this first meeting is a key issue and care should be taken to find a neutral site. A neutral site helps assure all of the participants that this initial meeting is not for the benefit of any one agency or individual. These meetings have been held in schools, banks, civic centers and hotel meeting rooms. Needless to say, whatever facility is chosen, the meeting room should be pleasant, bright, quiet and airy.

The person chairing the meeting will set the tone for overall community collaboration and support for FIMR. The chair may be the

director of the FIMR lead agency or another individual. Ideally, a chair should be chosen who is knowledgeable about and skilled in dealing with diverse groups, is non-partisan and is well respected by all as a community leader. The chair must also have belief and confidence in the FIMR process. Both are important to a successful FIMR meeting. The chair should lead the meeting using a relaxed informal low-key approach which will help convey a spirit of collaboration and gain the trust of community members.

Sample FIMR Town Meeting Agenda*

A 1½ hour town meeting including MCH providers, agencies and community members who will participate as team members in the FIMR process.

Purpose To build consensus to implement the FIMR process.

Desired Outcomes

- Introduce FIMR community team members
- Increase participants' understanding of the benefits of FIMR
- Compose an action plan to initiate FIMR

Agenda			
What (content)	How (process)	Who	When (minutes)
<ul style="list-style-type: none"> ■ Welcome/Purpose ■ Ground Rules ■ Review of Agenda 	<ul style="list-style-type: none"> ■ Review ■ Clarify ■ Agree 	Meeting Leader	9:00 – 9:15 (15')
Introductions/Getting Acquainted Exercise	<ul style="list-style-type: none"> ■ List 	The Group/Meeting Leader	9:15 – 9:30 (15')
Benefits of FIMR (Includes brief overview of MCH vital statistics data)	<ul style="list-style-type: none"> ■ Review ■ Clarify 	Meeting Leader	9:30 – 9:50 (20')
Mission statement development (optional)	<ul style="list-style-type: none"> ■ List ■ Clarify ■ Agree 	The Group/Meeting Leader	9:50 – 10:10 (20')
Next steps	<ul style="list-style-type: none"> ■ List ■ Clarify ■ Agree 	The Group/Meeting Leader	10:10 – 10:25 (15')
Adjourn			10:30

* Note: Communities should modify this agenda to best suit their needs.



About 6–8 weeks before the meeting is scheduled to be held, a formal letter of invitation along with a tentative agenda should be sent to invited participants. The invitation should be signed by one or more widely respected community leaders, e.g., the head of the agency sponsoring FIMR, the mayor, the head of the medical society, the Commissioner of Health, etc.

The first item on the agenda should be a brief welcome by the chair and a discussion of the overall purpose of the meeting (five minutes). The next order of business is introducing the meeting participants to each other. Experience has shown that not all individuals at the meeting may know one another. FIMRs say that this occurs even among the multiple organizations that provide services to the same women, infants and families. One idea is to ask each participant to address the items listed in the Getting Acquainted Exercise. This exercise can be distributed to the participants or displayed on an overhead or slide. To keep the meeting moving, introductions should be kept short and to the point, not more than one minute each. However, if the number of meeting attendees is very large, this exercise may need to be tabled due to time constraints (one minute introduction x 35 attendees = 35 minutes).

The next item on the agenda should be an explanation of the potential benefits of FIMR (15–20 minutes) for the community and the facilitative role of the FIMR lead agency in bringing the group together. Be careful to avoid any comments which might inadvertently sound as if the real purpose of convening the community is solely to promote the FIMR lead agency agenda. Such comments can be very divisive, bring up standing turf issues and derail the whole community collaboration process. NFIMR

Getting Acquainted Exercise

During this getting acquainted exercise, please briefly share the information listed below:

1. Your name
2. Your connection (individual, family, agency or program) with women, infants and families and their needs
3. A one-liner on your individual interest or your agency's primary purpose
4. A recent personal, family or professional achievement that you would like to share (optional, but a great ice breaker)

Adapted from: Magrab PR, Elder J, Kazuk E, Pelosi J, Wiegink R. Developing a community team: A companion to the community workbook for collaborative services to preschool handicapped children. Washington (DC): Georgetown University Child Development Center; 1981.

has developed a slide presentation specifically for this part of the meeting that introduces the community to the FIMR process. (See NFIMR Order Form online at www.nfmr.org.) This is also the point in the agenda to review information about local maternal and infant health indicators and overall family status that was collected in the planning phase (see p. 13–17). Another optional item may be to relay to the audience some successful practices from other FIMR sites (5–10 minutes).

Depending on the group's overall enthusiasm and support for FIMR, some programs have allocated time at this meeting to develop a formal mission statement. This statement can also be developed at a later date. The statement reflects what the group hopes to accomplish. Over time as the group deals with multiple complex issues, it will be important



Calhoun County FIMR Mission Statement

We are committed to a long-term community partnership to improve health of our families and their newborn children throughout Calhoun County. We pledge to impact maternal-infant service systems and community resources through cooperative education, prevention and intervention throughout our communities. Together, we will achieve improvement in the service system and ultimately in the health status and well-being of women, infants and families.

for the group to revisit their reason for being in order to keep them on track and guide the group in making the best decisions for the community. (2) The following example of a mission statement is adapted from the Calhoun County, Michigan FIMR program.

Finally, the group should come to a decision about the next steps necessary to activate FIMR (10–20 minutes). The planning group and the sponsoring agency walk a fine line in this first meeting. They do not want to force the community into action, but they do want to move them past the program activities already completed in the planning phase (i.e., developing abstraction forms, staff protocols, etc.). Although these are potentially sensitive discussions, in practice, most FIMR programs do well in their first meeting and motivate the community to move forward with FIMR.

CHAPTER 3 REFERENCES

1. Melaville AI, Blank MJ. Together we can: A guide for crafting a profamily system of education and human services. Washington (DC): U.S. Government Printing Office; 1993
2. Striffler N, Coughlin PA, Magrab PR. Communities can workbook series: Developing collaborative services for children. Washington (DC): Georgetown University Child Development Center; 1994
3. Wise PH, Wulff LM, editors. A manual for fetal and infant mortality review. Washington (DC): American College of Obstetricians and Gynecologists; 1992
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CHAPTER 4

Abstracting Medical Records and Conducting the Home Interview



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Abstracting Medical Records and Conducting the Home Interview



Introduction

Once the program development work is complete and community support is ensured, the sponsoring agency should begin pulling together the agency staff who will be responsible for the FIMR work of abstracting medical and related records and conducting home interviews. Basic descriptions of the roles of the medical abstractor and home interviewer are presented in this chapter.

Additional information about these two essential FIMR responsibilities can be found at www.nfmr.org. Detailed references for each new home interviewer include the *Fetal and Infant Mortality Review: A Guide for Home Interviewers* (2003) and a webcast titled *FIMR Home Interviewing*. Each abstractor should view the streaming video *Collecting Data for Fetal and Infant Mortality Reviews*.

Practical experience suggests that people most likely to thrive in the labor intensive and emotionally challenging roles of FIMR staff include professionals and paraprofessionals, especially community residents, who:

- Are flexible and creative
- Are team players
- Are self-motivated and self-select to work on the FIMR program
- Have experience in the maternal and child public health sector
- Genuinely appreciate the cultural diversity of the community and the assets and strengths of families
- Understand and respect community values

Abstracting Medical Records (1)

Medical records abstraction is a core ingredient of FIMR. Abstractors should have sufficient clinical experience with obstetric and pediatric

Fetal and Infant Mortality Review Program Medical Records Abstractor Part-Time (4–8 hours per week)

PROGRAM DESCRIPTION

The overall goal of Fetal and Infant Mortality Review is to enhance the health and well-being of women, infants and families by improving the community resources and service delivery systems available to these families. FIMR brings together key members of the community to examine information from individual cases of fetal and infant death to identify the factors that contributed to those deaths, determine if those factors represent system problems that require change, fashion recommendations for change and assist in the implementation of change.

JOB RESPONSIBILITIES

The abstractor reviews and abstracts information from the medical records for the Fetal and Infant Mortality Review program. The abstractor regularly receives cases and forms from the program coordinator and completes them within a specified time period.

The abstractor is responsible for contacting hospitals to retrieve medical records for specified cases, reviewing records at each hospital, filling out appropriate abstraction forms and providing additional information on each case based on clinical interpretation of records. Most records are found at area hospitals, while additional records may be sought occasionally at other facilities. The abstractor will prepare medical records information and attend case review team meetings, when possible. Position will report to the FIMR program coordinator.

QUALIFICATIONS

Clinical background in obstetrics and pediatrics, neonatology or perinatology. Medical or nursing degree required. Attention to detail. Flexibility, ability to accomplish tasks in short time frames. Computer skills, including familiarity with Microsoft Word. Must have own automobile with valid insurance.

SALARY

Commensurate with skills and experience.

Adapted from: the Perinatal Network of Alameda/Contra Costa FIMR Program, Oakland CA



care so as to be able to understand the information as they abstract it. Generally, perinatal nurses are the best equipped to conduct FIMR abstractions though physicians, social workers and others have been used by various programs. A mechanism for accuracy checks should be built into the abstraction system. Reliability can be checked by periodically comparing the results of two abstractors on the same case. This checking is particularly important in the beginning, when abstractors will have more questions about which information is needed to answer an item in the abstraction forms.

The abstracting process takes time. Abstraction of one record may uncover another source of information for the mother or infant not previously identified. Initial abstraction involves the death and birth certificates, hospital records for delivery, newborn assessment or newborn intensive care, prenatal records (if a copy is on delivery chart) and any additional hospitalizations in those institutions. For complete prenatal and pediatric information, additional data may need to be obtained from private providers, as well as public health clinics, community case management providers and other sources.

Obtaining access to records

Prior to the actual medical record abstraction efforts, the FIMR planning committee will have had to establish the method for obtaining access to medical records. This process may have entailed making sure that there are state statutes to allow for access to records, complying with HIPAA regulations, going through an individual hospital's IRB, if necessary, or establishing some other type of agreement between the agency sponsoring FIMR and the hospital to allow record abstraction. Even so, the medical records staff themselves can be expected to want to know what the program is doing, who will be examin-

ing the records, how many records are expected to be involved and how often the abstractor will be coming to the hospital.

An important responsibility for the abstractor is to establish good working relationships with the medical records staff of each hospital where records will be abstracted. Medical records staff may also want to examine the abstraction forms the FIMR program intends to use. Follow-up meetings with administrators and medical records directors may also be necessary. Taking time to lay the groundwork with the medical records staff will pay off in long-term cooperation. The abstractor should also make the program's year-end written report available to hospital staff. Some FIMR programs say that arriving at the hospital medical record room with an official letter from the head of the agency sponsoring FIMR that explains the program facilitates the abstraction process (see sample letter).

Access to the records of private providers may be more difficult to obtain. Release of information from private providers is voluntary and usually not covered in the state laws that allow for release of hospital records. Fears of legal action may prevent some providers from choosing to participate in the review. A letter about the program should be sent along with an example of the abstracting form that will be utilized; this may help to dispel fears and encourage participation. It may also help to ask the provider to abstract the patient's record; this allows the provider the opportunity to omit any items that are felt to be not pertinent. To see the type of information that is being collected may reassure providers about the process.

In private offices, it is important to identify whom the abstractor will be contacting to follow-up a request for medical information—



for example, the office manager or nurse. Because physicians' schedules are so hectic, it is difficult to establish direct communication with them and the office manager often becomes the gatekeeper of the records. In general, the least number of office staff involved in requests to

access records, the better. Keeping a confidential communication sheet with the record to note the names and titles of the persons in each private office with whom the abstractor talks is one way to keep an accurate record of all case contacts and communication.

A Sample Authorization Memorandum from the County Health Officer

To: Whom It May Concern

From: Jane Smith, MD, MPH
Commissioner of Health Services
Kerry County
25 Main Street
Sunny City, CA 12345

Date: April 14, 2008

Subject: Authority to Conduct Fetal and Infant Mortality Review (FIMR)

The Department of Health Services in Kerry County has been charged by the State of California with conducting the FIMR Project for Kerry County. The purpose is to study fetal, neonatal and postneonatal deaths in order to identify systems factors associated with them. A primary objective is to pinpoint possible gaps in services, which may be amenable to community or governmental action. Information is gathered from birth and death certificates, medical records, autopsy reports and family interviews.

Standard medical record abstraction forms, developed by the National Fetal and Infant Mortality Review Program—a partnership between the American College of Obstetricians and Gynecologists and the federal Maternal and Child Health Bureau, are used to collect a small subset of information from these records. In turn, FIMR staff summarizes this information. Names of providers, institutions and families are carefully removed from the summary in order to de-identify the information. Anonymity and confidentiality are key to FIMR.

The anonymous, de-identified summaries are presented to the interdisciplinary Case Review Team for interpretation, conclusions and recommendations. The FIMR Community Action Team provides a mechanism by which the Department moves recommendations to community-wide action to improve services and resources for women, infants and families. Under provisions of California Health and Safety Code §100325 (General Powers of the Department of Health Services), the local health officer may obtain access to medical records for the purpose of public health investigation of fetal and infant deaths.

I have assigned this authority to implement the FIMR Project to my staff in the County Department of Health Services/Family Health Programs/Maternal and Child Health Section. This letter provides authorization for the FIMR Project staff to review relevant health and medical records from your institution for this purpose. I certify that the records, which we request, pertain to an infant who has died.

This authority shall be valid until April 13, 2009 and will be re-authorized on a yearly basis.

I urge you, as a key partner in this process, to facilitate access to information for review of this case. For more information about the FIMR Project, you may contact me at the address above or at (include phone number). I appreciate your cooperation in this public health endeavor to further promote and protect the health and well being of women, infants and families in Kerry County.

Adapted from: the Florida Department of Health Pregnancy Associated Mortality Review, and Kern County, CA and Los Angeles County, CA Programs' Authorization Memoranda.



Procedures and tips for abstracting records

1. Call hospital(s) to arrange to review records. Be sure to agree upon a time to examine the records. The record room will usually be able to pull the requested record within 24–72 hours.
2. Assemble packets for each case containing case identification information (mother's name(s) and date of birth; infant's name(s) and date(s) of birth and death) and appropriate forms. For example, fetal losses would include prenatal and delivery forms; infant losses would include additional forms, such as the newborn intensive care or out-patient pediatric record abstraction forms.
3. Identifying information should be stored in a locked file and carried in the locked trunk of the car to the hospital. Each form should have only the case number on it. No identifying information should be written on abstracting forms.
4. Review records only in designated areas of the hospital. Do not photocopy any portion of the record.
5. Determine if additional records should be requested from physicians' private offices or other facilities.
6. Contact physicians to arrange to review records. In some offices, information can be obtained over the phone.
7. Document laboratory results pertinent to the diagnosis. For example, if cause of death is anemia, the case review team will want to know the laboratory values. Or if infection is noted, check to see if cultures were done and, if positive, record any treatment provided.
8. Circle discrepancies in information to help keep track of differences.
9. Record dates and times for important events, such as presentation at hospital admission, estimated date of confinement, rupture of membranes, delivery, transfer and discharge.
10. Record any supportive information that will help with writing the case summary.
11. Keep a record of barriers that were encountered during abstracting, such as access difficulties, discrepancies in documentation, illegibility and records that are lost.
12. Pace yourself; these records can be emotionally exhausting.

How long does abstracting take?

It is difficult to calculate the exact time for abstracting a case. Some cases are much more involved than others. Some records may be far away and require extra transportation time. In general, abstraction of a typical case takes about 1–2 hours depending on the type of death and the intensity of care provided. Beginning abstractors will take a longer time because they need to get comfortable with the abstracting forms. Abstractors may also find themselves waiting at hospitals for records to be found. Depending on the number of deaths to be reviewed each year, abstracting may be a part-time job. Generally, less program time is invested in abstracting records than in conducting home interviews.

Obtaining additional information on a case

Additional information, other than from the interview and medical records, can be important in developing a case summary. Most common additional information comes from the coroner or medical examiner. Other



sources include police, fire and EMS records in cases of SIDS, automobile injury or other non-hospital deaths case management records, and social services agencies, including those that administer Medicaid, WIC and other benefits.

Coroner and Medical Examiner Information. In most communities, deaths are referred to the coroner or medical examiner if the death occurred in a suspicious, unnatural or otherwise questionable circumstance. In most states, coroner or medical examiner referral is mandated in cases in which SIDS is suspected. Coroners and medical examiners may be located in a variety of agencies. In some states, they are part of the local law enforcement agency; in others they are part of the public health structure. The location of the coroner or medical examiner will affect the ease of access to records. FIMR programs may need to put more effort in working with law enforcement agencies than with those in public health. Coroner and medical examiner records typically yield a variety of information, including:

- Investigation reports, including results of interviews with family members, first responders, physicians and others
- Autopsy reports
- Toxicology reports on the infant
- Copies or abstracts of police and EMS reports
- Contact information for additional family members

FIMR programs should review the reports on all FIMR cases referred to the coroner or medical examiner, even if the coroner or medical examiner record is not expected to yield anything new on the case. Sometimes, the coroner's record is remarkable for what is

not included as well as what is found there. Over time, many programs, as well as the Centers for Disease Control and Prevention, have developed recommendations for improved investigation of certain types of infant deaths (see Chapter 9).

Law Enforcement Records. Police, fire and emergency response records are useful in cases involving SIDS, intentional injury, unintentional injury and any other case where law enforcement played a role. Access to such records may be limited in some communities, depending on where FIMR is situated. Programs have used such information to develop recommendations for improved emergency response, improvement of local domestic violence services and improvement of product safety standards.

Social Services Agencies and Other Public Health Programs. Agencies that administer programs such as Medicaid, WIC and food stamps are important to FIMR in determining whether the people who should be receiving such services are in fact getting them. Records from such programs can point out the barriers that families face while trying to establish eligibility and receive assistance. These records also point out duplication of services or efforts, or cases where providers are over-burdened with paperwork or other tasks. Access to social services records may vary depending on the particular program's regulations. Some programs have limited their scope to finding out only whether or not the family was enrolled in a particular program; others have tried to get more detailed information on individual clients. Programs must proceed carefully on such information to ensure that proper safeguards for preserving privacy and confidentiality are observed.



Other public health agencies, such as family planning, public health nursing and infectious diseases should be approached for information when necessary. Information from these agencies can be used to determine whether services are reaching those in need, and for identifying barriers to receiving services. Privacy and confidentiality must be observed with these agency records, as well.

Conducting Family Interviews

The importance and purpose of the FIMR home interview (2)

“Maternal interviews give a voice to the disenfranchised in my community, those without clout or power. FIMR provides a rare opportunity for the ‘providers’ in a community to hear from the ‘consumers.’”

Patt Young, FIMR Interviewer, Alameda/Contra Costa Counties, CA

A cornerstone of FIMR is the conduct of a home interview with the bereaved family, most often the mother. Throughout this document, including most forms, “mother” is used to refer to the primary infant caretaker who is interviewed. The maternal interview provides the mother’s perspective of her baby’s death and allows her to describe her experiences in her own words. This yields information not usually captured in routinely collected health records. FIMR team members report that the home interview provides some of the most valuable information in the review.

The home interviewer conveys the mother’s story through the case summary presented to the FIMR review team. Thus, the voice of each bereaved parent reaches the community at large. Team members are better able to gauge the extent to which services and

community resources are available, accessible and culturally appropriate. They can more readily identify areas of deficiency or inequality in service delivery systems and can begin to address these problems more effectively.

The FIMR interview process can provide solace to the grieving mother. It affords an opportunity to offer emotional support as well as referring mothers to needed health or social services. However, the FIMR home interviewer does not assume the role of a professional grief counselor. FIMR interviewers are encouraged to access or compile a comprehensive list of culturally appropriate community resources, support groups and educational materials. The FIMR interviewers refer mothers to professional counselors, trained bereavement counselors, local SIDS professionals or peer support programs. In this way, the FIMR home interviewer works with the family to develop an ongoing support program as needed.

In summary, the purposes of the FIMR maternal interview are:

- To learn about the mother’s experiences before and during pregnancy
- To learn about events during the infant’s life and around the time of death
- To identify community assets and deficits that affected the mother’s life during the pregnancy, birth and death of her infant
- To accurately summarize and convey the mother’s story of her encounters with local service systems and her loss to the community through the FIMR case review
- To assess the family’s needs and provide culturally appropriate health and human referrals as needed



- To facilitate the bereavement process and provide appropriate referrals

The FIMR interviewer

The FIMR interview provides a great deal of information about the fetal or infant death and also challenges the interviewer's ability to provide emotional support to a mother experiencing grief and bereavement. In general, a mother may not always be looking for all of the answers about why her baby died but appreciates the opportunity to talk about the life and death of her baby.

Training in the FIMR process, which includes interviewing and active listening techniques, cultural competence and general bereavement support, is necessary before the first interview is scheduled. It is also essential to have knowledge of community resources and the ability to make a wide variety of referrals. The interviewer must be familiar with the cultural and ethnic groups in the community and be comfortable with home visiting. On a personal level, a commitment and recognition of the importance of the FIMR mission enables the interviewer to continue this challenging work with bereaved mothers.

The FIMR interviewer must also be committed to maintaining the strictest confidentiality. Case information must be kept anonymous. Information about the mother, her caregivers or institutions that provided services to her or her baby cannot be discussed with colleagues. Locating mothers without divulging the purpose of the visit to others can be challenging, but it is important to establish trust with the mother and protect her privacy.

NFIMR has developed a standardized home interview form to collect information about preconception care, prenatal care, maternal nutrition and other health habits, past

pregnancy history, labor and delivery, other background information about the mother and father, and stress and grief reaction to the loss.

Who should be interviewed?

Typically, the mother is interviewed because she is most likely the primary caretaker of the infant and can relate her unique experiences associated with pregnancy, labor and delivery and care of the infant, as well as the degree of satisfaction with the care that she and her baby received during that time. Because the highly personal and sensitive questions contained in the home interview concern information that the mother may not wish to divulge to anyone else, most FIMR programs interview the mother privately and separately from other members of the family.

Occasionally, the mother and father may request that they be interviewed together. Fathers can contribute information to the interview as well and certainly can reap the same cathartic benefit of talking about their loss that mothers do. On the other hand, on a rare occasion, an abusive spouse may not want his wife to talk to the interviewer alone and insist he be present. The interviewer must make a judgment call and distinguish among supporting the bereaved families, safeguarding the mother's privacy and obtaining information.

One way to compromise in this situation and to give both parents the opportunity to discuss the loss of their infant is to start a general discussion with the mother and father together using the following open-ended questions from the NFIMR interview:

- Tell me what happened to (refer to baby by name, if given).
- How was the baby's death explained?



- Thinking back on the entire experience, what would make things better for you?
- What do you think needs to be done to help other families who experience the death of an infant?

The remainder of the interview then can be conducted with the mother alone. Another option is to separately interview the father as follows:

“I am delighted that you want to participate in the interview. While part of the information pertains to feelings and concerns your wife had during pregnancy, there are special sections that you can answer. We will interview you after we record the special information from your wife.”

The interviewer will then have to decide which questions in the NFIMR home interview the father will be able to answer (e.g., Part H—Information On Father, questions 1–6; Part I—Living Situation, questions 1–8; Part J—Life Changes, questions 9–10, etc.).

If the mother is deceased or, for some other reason, is not the primary caretaker of the infant then whoever has assumed that role may be interviewed, such as: the infant’s father, grandmother, aunt or other family member or the adopted or foster mother. This caretaker may not be able to fill in certain parts of the interview (i.e., prenatal care, labor and delivery) but the insights into the health and well-being of the infant are key.

Qualifications of the interviewer

Home interviewers are paid staff, but should be chosen from a pool of qualified candidates who volunteer to take on the challenge of working with bereaved families. Most FIMR interviewers are appropriately trained public health nurses or social workers who have extensive experience in maternal and child

health and bereavement counseling. Other programs have successfully used community health workers. At a minimum, the interviewer must have sufficient bereavement training to ensure that s/he will do no harm. An individual having only basic skills should receive regular supervision from someone with more advanced-level training in counseling the bereaved. Regardless of the training background of the interviewer, the right personal qualities are vital. Families relate well to an interviewer who is empathetic, mature, warm, sincere, non-judgmental and interested.

Ava Ledford, a SIDS Coordinator with the South Carolina Department of Health and Environmental Control and one of the first successful FIMR home interviewers in the early 1990s, observed that a successful FIMR home interviewer is one who:

- Understands his or her own feelings regarding death
- Is comfortable with mothers who have experienced an infant loss
- Recognizes that infant death can be an important and overwhelming event in the mother’s life
- Reassures the mother that she or he is there to provide a service and not to criticize her actions or behaviors
- Believes the mother will benefit from each visit
- Feels the visit is not an intrusion but an opportunity to provide support and reassurance, as well as gather information
- Realizes that most mothers want to talk about their babies and their losses
- Takes direction from the mother on the length, scope and other components of the visit



“One of the most important things to remember in doing an interview with parents whose children have died is that the parents long for an opportunity to talk about the child that they have loved and lost. Parents want to find meaning and value in that child. They want to help someone else (by giving information for the FIMR home interview). The general population tends to believe that early losses are not important and quickly forgotten. A FIMR interview with the parents who have lost a baby gives validity to that grief...If you care and are willing to listen and do not impose your values, you can help.”

*Ava Ledford
SC Interviewers*

Training the interviewer

Most FIMRs link with qualified trainers such as another experienced FIMR program interviewer or their state SIDS center to arrange training sessions. Role-playing the home visit and interview is important in any training sessions. Content areas that should be addressed include how to (1):

- Track, contact and engage families
- Prepare to conduct the interview
- Provide bereavement support during the interview
- Listen and record, not interpret
- Conduct a standardized interview including eliciting responses with open-ended and close-ended questions
- Maintain confidentiality
- Recognize public health and safety codes related to home visiting and pertinent reporting requirements
- Handle difficult encounters and recognize personal safety issues and when to conclude or omit an encounter
- Avoid implications of mismanagement and liability
- Conduct a home assessment and refer for needed services

Fetal and Infant Mortality Review Program Home Interviewer (Part-Time)

PROGRAM DESCRIPTION

The FIMR program reviews individual cases of fetal and infant mortality to determine associated factors. Mothers who have experienced a fetal or infant death are asked to participate in a semi-structured interview to elicit information about their experiences during pregnancy and after delivery. This information, along with medical records data, is reviewed by a case review group that makes recommendations on how service systems and community resources can be improved.

JOB RESPONSIBILITIES

This position involves carrying out FIMR program tasks which include finding, contacting and interviewing the mother or another family member who has experienced the loss of a fetus or infant; gathering additional case information as needed; maintaining links with contract agencies and local providers; assisting in the development of case summaries; participating in case review group meetings; assisting in dissemination of program results to the community. Position will report to the FIMR program coordinator.

QUALIFICATIONS

Experience in home visiting, community outreach, case finding or conducting interviews. Excellent communication skills, sensitivity to needs and experiences of grieving families. Ability to work independently, with a flexible schedule, including some evenings and weekends. Knowledge of pregnancy and perinatal issues. Bachelor's degree preferred, with at least five years' experience in a community agency, health provider or similar setting. Must have car with valid insurance.

SALARY

Commensurate with skills and experience

Adapted from: the Perinatal Network of Alameda/Contra Costa Perinatal Network FIMR Program, Oakland, CA



Home Interviewers: The Art of Being Prepared

Why devote so much time and energy to being prepared? The initial “investment” pays off in the most important way. Once the details have been tended to, we are free to give our full attention to the interview and the mother being interviewed. We can listen sympathetically, with as few distractions as possible and better handle those that do come up. The preparations can be divided into three categories: physical, mental and professional.

Physical Preparation

- | | |
|--|--|
| <ul style="list-style-type: none"> ■ Checklist for briefcase: <ul style="list-style-type: none"> ■ sharpened pencils, pens ■ pad ■ note cards ■ business cards ■ permission/release forms ■ interview forms ■ pregnancy calculator wheel ■ calendars (last year and this year) | <ul style="list-style-type: none"> ■ Clip or mark unneeded pages of questionnaire in advance ■ Keep car in good repair and have plenty of gas ■ Dress appropriately, comfortably, not flashy ■ Lighten your load—avoid pocketbooks. Pocket organize items such as cell phones, beepers and keys. Remember to turn off cell phones and beepers during the interview ■ Bring Kleenex ■ Bring items for children to play with, i.e., basket of toys, coloring books and crayons, etc. |
|--|--|

Mental Preparation

- | | |
|--|--|
| <ul style="list-style-type: none"> ■ Know your own physical limitation ■ Stay focused on the objectives of program. Remind yourself why you are going there ■ Put superfluous thoughts from your mind and prepare to give full attention to this mother | <ul style="list-style-type: none"> ■ Enroute, review items such as how to pronounce family's name, child's name and other things you were told by the mother during your telephone call ■ Avoid making assumptions about mother's frame of mind; it may be different when you arrive |
|--|--|

Professional Preparation

- | | |
|---|---|
| <ul style="list-style-type: none"> ■ Research the best route to your destination, following safety and security guidelines enroute and after arrival ■ Be on time. Call if you are going to be delayed. A good response is: “It's a new area to me. I should be there at _____, but give me a few minutes” ■ Be flexible concerning mother's condition | <ul style="list-style-type: none"> ■ Be patient; don't expect her to always be logical or objective ■ Be non-judgmental. Be ready to listen, want to listen ■ Allow yourself to have feelings ■ Have a ready list of community resources and support groups (update periodically; keep current on subjects through sources such as the library, World Wide Web, etc.) |
|---|---|

Other Hints for During and After the Interview

- | | |
|---|---|
| <ul style="list-style-type: none"> ■ Develop ways to assure yourself that you recorded the information accurately, without asking the mother to repeat herself ■ Allow her to digress; one memory often triggers another ■ Avoid sharing your own values | <ul style="list-style-type: none"> ■ If the mother is an adolescent: Being aware of the developmental tasks and needs of adolescents can help us to accept, without judgment, behaviors and attitudes we might find unacceptable in adult parents ■ Exhibit sympathy, respect and genuineness ■ En route home, “replay” the interview in your mind. Something may emerge worth noting on a handy note pad or on a micro cassette tape recorder |
|---|---|

Adapted from: Wood J. FIMR Interviewer. Healthy Start Coalition of Hillsborough County, FL



Lessons Learned

Not every one who has the qualifications to conduct the home interview will necessarily have the empathy, skill or emotional stamina to be successful as a home interviewer. Nor will some of those possibly qualified actually want to take on this task. Home interviewers must volunteer and their most common characteristics are commitment and advocacy for the bereaved.



Maintaining confidentiality

The process of locating mothers requires sensitivity and attention to maintaining strict confidentiality because the mother might be living with people to whom she does not wish to reveal her experiences. She may have miscarried early in the pregnancy. Before the death, the infant may have been taken into protective custody or placed in foster care. To avoid inadvertently revealing her experiences to anyone, the home interviewer should not mention the fetal and infant review by name or describe the purpose of the interview. If the mother is not home, interviewers have asked neighbors or apartment managers when she might be home. The interviewer should only say something very general, such as: “I am _____ from the county health department. I am conducting a state-wide department of health survey and I would like to know when (person to be interviewed) will be at home.” For the same reasons, any mailings to the families or FIMR staff business cards left at the mother’s door should not include the name: Fetal and Infant Mortality Review Program. (2)

Locating families

Finding families after an infant loss can be difficult. Some families move after an infant loss because their home holds such powerful memories and reminders of their baby. Some move because of poverty, unemployment or homelessness and

do not leave much behind in the way of forwarding information. Moreover, while the death certificate is a good way of identifying cases, it does not always have the most useful or accurate information for locating families. Vital records generally have the family’s address, but not the phone number. It is highly probable that some may have moved from the address the home interviewer will have for them.

When families do move, FIMR home interviewers have been able to find the new address or telephone number by contacting other family members, neighbors, landlords, the post office, the local mail carrier, the telephone company, the electric or gas company, etc. Again, when contacting any of these sources, the home interviewer should not mention specific information about the purpose of the interview. As much detail as possible about the location of the family’s home such as the apartment number and zip code, directions such as north or south, the entire street name (e.g., Elm Circle Court, not just Elm) or county road rural route number should be gathered from these sources before the home interviewer sets out to visit the mother. A detailed local map and a compass on the car dashboard are important tools for the home interviewer. (2)

Ensuring the safety of the home interviewer in her travels is an important issue that should be addressed before interviews are begun. Networking with the local health department or home health agency that does the most home visiting in the community that FIMR is reviewing will provide some practical insights into the safety of individual neighborhoods. Safety is a relative issue and each community must identify local problems that put the home interviewer at risk. It may be just as necessary for one interviewer to know how to avoid attack by a flock of angry barnyard geese as it is for another to know how



to get past the drug dealer on the first floor to find the mother on the second.

How long does a home interview take?

The answer to this question depends on how long it takes for the mother to tell her story, and how long it takes to complete the standardized questionnaire. Some mothers have very much to say and many questions to ask as the home interviewer may be the first and only person that the mother has had an opportunity to talk to about her loss. The standardized NFIMR questionnaire takes about 45–60 minutes. The questionnaire has many items that can be skipped and probably no mother will answer every question in the questionnaire. The home interviewer must be able to balance the need to get the important family perspective via questionnaire with the mother's need to expound on her experiences. Both are important. It is safe to say that the whole process probably takes an average 1½–3 hours and may be done in one or two visits.

Home interview models

Two models for conducting the home interview have emerged: the early contact approach and the standard approach.

Early Contact Approach. The interviewer, having training and experience in maternal and child health and bereavement counseling, visits the mother as soon as possible after the loss, perhaps within 2–3 days. The purpose of the visit is to offer support, reassurance and needed referrals, usually as part of a specific public health service. The interview questionnaire is done at a later date and becomes a part of the bereavement process. Although the interviewer does not take on the responsibility of ongoing, comprehensive case management for these families in need, periodic contact with the family is maintained by telephone or letter and other visits may be done, if appropriate.

Standard Approach. The interviewer has basic knowledge of maternal and child health and bereavement support skills and has links to a trained and expert bereavement counselor mentor. Mothers who have lost an infant are sent a standard FIMR letter and brochure offering condolence and informing them of the FIMR program and proposed interview usually 1–3 months after their loss. Mothers are then contacted, usually by telephone, to explain the process in detail and to request their participation in an interview. If a mother has no telephone or cannot be contacted, a home visit is made to solicit participation in the interview. The interviewer tends to have more limited contact with the family after the interview, but needed referrals for service are made after the interview is complete.

Importance of the home interview

A common misconception holds that early losses are not important and quickly forgotten. A home interview with families who have lost a baby gives validity to that loss and helps them heal so that they can be better caretakers for themselves and their other children. One of the most important things to remember in talking with families whose children have died is that they long for an opportunity to talk about the child that they have loved and lost. Families want to find meaning and value in that child and to help someone else. Providing information to FIMR can give significance to that loss.

The ideal location of the interview is the home because it sheds light on the physical environment of the mother and infant. However, other locations may also be offered as options, as long as privacy and confidentiality can be maintained. Interviews have been conducted by telephone, at the health department office, coffee shops, parks, playgrounds or at the mother's place of business. The timing of the interviews should be as flexible as possible; the interviewer



should be able to schedule interviews during evenings and weekends for mothers who cannot be available during regular business hours.

The interviewing process

When the home interviewer greets the mother, she should introduce herself, tell the mother which agency she is from and show her official identification. The mother should be fully informed about FIMR and the significance of her involvement. The degree of privacy and confidentiality offered by the program should be emphasized. If the program has any FIMR pamphlets or brochures, the information should be shared with the mother (see sample). If the mother agrees to participate, the home interviewer should review the consent form with her and obtain her signature (see p. 25). The mother should be assured that she may refuse to answer any questions or may terminate the interview at any time without fear of loss of any current or future services.

Once a comfortable atmosphere has been achieved, the best way to begin the interview is to ask the mother to describe in her own words the events leading up to the loss of her infant. The interviewer should call the baby by its name, if given by the family. The mother may have already started telling the interviewer about the loss before the interviewer had to ask; she should be encouraged to share both positive and painful memories. When the mother has completed her initial comments and seems ready, the interviewer may proceed with a standardized questionnaire.

In the home, the interviewer must adapt to the life, space and activities of the whole family. This is in contrast to a mother having to adapt to a structured health care setting. The manner in which the family receives the home interviewer influences the tone of the early moments of the visit. More importantly, the manner in which

the interviewer responds to the family greatly influences the tone of the remainder of the visit.

A mother will be especially sensitive to any hint of criticism about her health, lifestyle habits or parenting skills. Unless there is a present danger to health or safety, any expression of critical attitudes should be avoided. The overall attitude of the interviewer should be understanding and neutral, avoiding expressions of surprise, pleasure, approval or disapproval at any answer or comment. (3) This “value-neutral therapeutic” interviewing technique or style will require some experience and skill.

When the interview is completed, the interviewer should thank the mother for her participation and give her the opportunity to relate any feelings she may have regarding the interview process. The home interviewer should discuss normal grief reactions (e.g., inability to sleep or eat properly, difficulties in interpersonal relationships, hearing the baby cry, aching arms, longing to hold the baby, reactions to other babies, babies on television, etc.). She should also provide information about local family support groups: Compassionate Friends, SIDS Alliance, hospital-based groups, etc. Written material may be helpful since the family may desire services or become engaged in a family support organization long after the home interview. If apparent health or safety crises are present, they should be addressed immediately (e.g., no heat in winter, no food available, critical health problems of mother or other children, etc.). Other referrals that the family may need and want may be given at that time or in a follow-up visit or telephone call. Some programs give the mother a simple evaluation form with a stamped, return envelope in order that she may have confidential input regarding the interview process. The interviewer should also send the mother a note of appreciation and condolence within a few days.



Ethics of interviewing grieving families

Interviewing families about the loss of their child or pregnancy can present ethical dilemmas for those who carry out FIMR programs. Families are vulnerable and extra care must be taken to be sure that no harm is done to them. Families must be able to give an informed consent and should not be coerced into participation in any way. Large financial inducement or other pressure to participate should not be used as leverage to encourage participation in the interview.

However, tokens of appreciation such as books of stamps, a plant or coupons to a local grocery store are sometimes given after the interview. A group composed mostly of social workers and psychologists has developed some guidelines for interviews of bereaved families. Some of their suggestions may be useful to FIMR programs. (4–7)

Lessons Learned

Offering a modest token of appreciation, especially a grocery store coupon, is appreciated by mothers and has helped garner support for participation in the interview.



How to handle home interview refusals

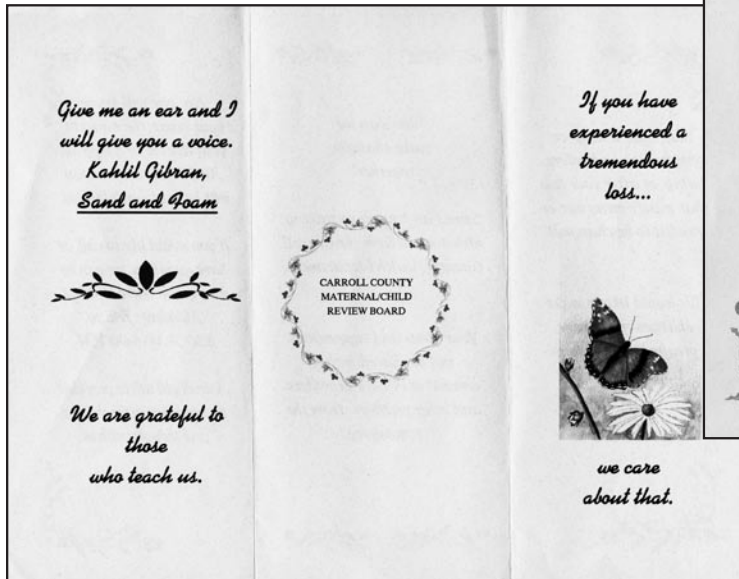
Successful FIMR programs have an ongoing, weekly dialogue between the FIMR coordinator and the home interviewer to evaluate success of tracking and interviewing. Although 5–10% of mothers may be lost to follow-up, successful FIMR programs interview about 60–80% of mothers that they do contact. However, because of the sensitive nature of the home interview, the interviewer should always be mindful of the needs of the mother when trying to encourage her to participate. When a mother says that she does not wish to participate, the home interviewer may try the following (3):

- Explain that it is important to complete interviews for as many mothers as possible in order to assure the most complete information about services and resources in the community from the family perspective.
- Explain that the information gathered from the interview will be used to look at prenatal and child health services and community resources to find ways to help families such as theirs in the future.
- Ask the mother to at least begin the interview and answer one or two sample questions on a trial basis. Assure her that she is free to stop the interview at any time and that she can refuse to answer any question that she chooses or feels is too sensitive. Many times, this approach encourages the mother to provide most of the information needed for the interview.
- Offer to call back later in the year to revisit the mother's decision not to participate.

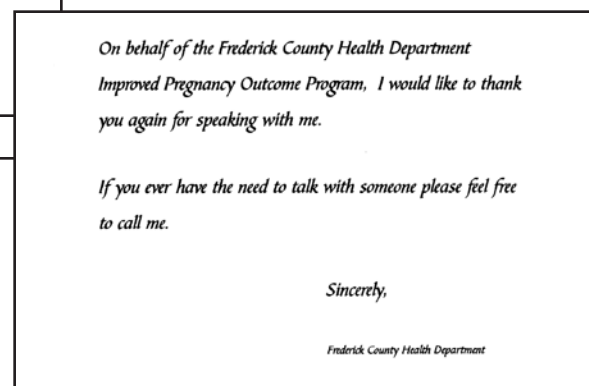
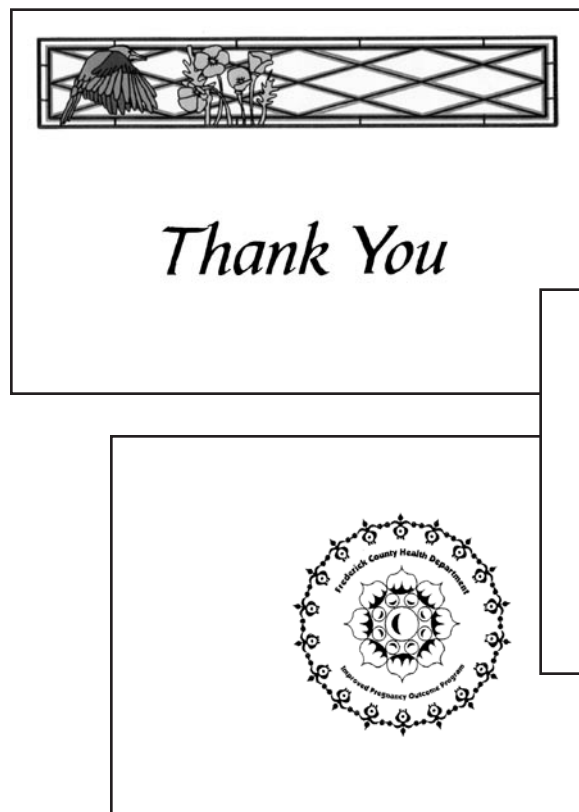
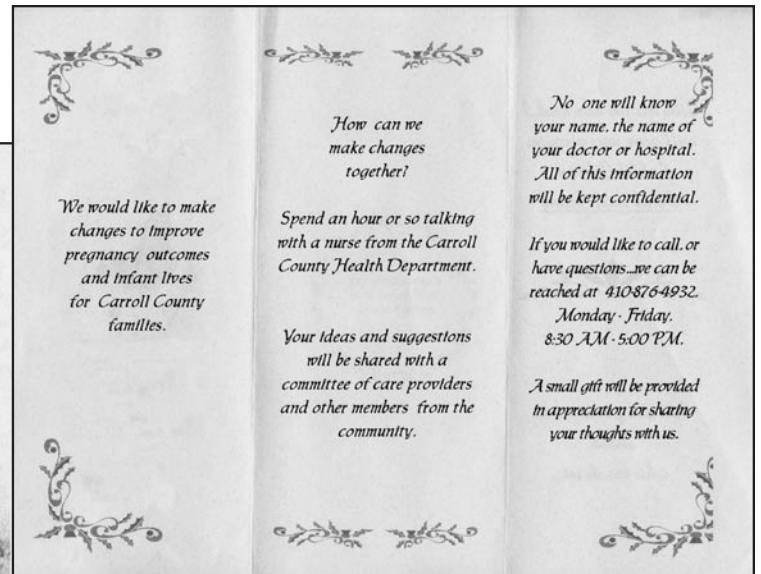
When interviewing is not recommended

Because of ethical or legal concerns, most FIMR programs avoid interviewing mothers in certain cases:

- Mothers hospitalized for psychiatric conditions
- Mothers who are in litigation with providers or institutions because of the circumstances of the infant's death
- Mothers who are under investigation or imprisoned for complicity in the death of their infant. FIMR programs have interviewed mothers who are incarcerated for other crimes (i.e., theft, bad check writing, etc.). These mothers have important stories to tell
 - All mothers during the holiday season, around the anniversary of the death, on Mother's Day or other sensitive times



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Reprinted with permission: Frederick County, MD, Health Department FIMR Program



Understanding Grief

The death of your baby is certainly one of the most painful experiences you will ever have.

Be patient with yourself. Grief has lots of ups and downs. It lasts much longer than most people realize.

There is no right way to deal with death. Everyone grieves in his or her own way — one person may be angry, another may be quiet and sad, while others might hide their feelings and seem not to care.

Crying and wanting to talk about your feelings are normal and can help you feel better. Share with others and allow your tears to come.

Friends and neighbors want to help you but sometimes don't know how. Tell them when you need to be held or hugged and talk with them about your baby so they know it's O.K. to do that.

Children need to know the truth. Don't tell them that the baby "went to sleep" or "went away on a long trip." That might make them afraid to go to sleep or go away from home. Be sure they understand that the baby's death was not their fault.

Decide what to do about your baby's clothes and toys when you're ready, not when others tell you to.

Guilt and anger are natural, normal reactions to grief. Again, it's best to share these feelings in ways that are healthy and not harmful to others. Holding your feelings inside will usually make you more depressed.



Ask questions to find out everything you can about what happened to your baby, but remember that sometimes there just are no answers.

Learn to forgive yourself when you have thoughts of "if only."

You may be tempted to use alcohol or prescription drugs to dull the pain, but this will only delay the grief process. To move through the pain of grief and loss, it must be faced head on.

Grief over the loss of a baby is emotionally, mentally, and physically exhausting. Some common physical reactions are not wanting to eat or eating too much, problems sleeping, sexual difficulties, and even aching arms. A balanced diet, rest, and some exercise are very important for you during this time.

Remember, healing from the pain of grief is a slow but certain process.



"Take heart, dear friend, and don't forget . . . the sunrise never failed us yet."



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Questions Respondents May Ask

Families may ask questions about the interview. Below are sample answers to such questions. Each program should develop questions and sample responses that relate specifically to their program circumstances.

Question: How did you learn my name?

Sample Answer: All infant deaths are routinely reported to the county health department by the Vital Statistics office.

Question: How did you know my phone number?

Sample Answer: Your number was found by
(a) Calling information or
(b) Looking in the local directory

Question: How did you know my unlisted phone number?

Sample Answer: Hospitals in our community routinely forward copies of records of infants who die to the health department. We obtained it from those records.

Question: What's in this for me?

Sample Answer: Health and medical care are important concerns for all of us in _____ County and the Department of Health can provide better health information by talking to families who have experienced the loss of a child. Also, I can arrange for health or social services that you and your family may need, if you wish.

Question: How do I know you represent the county Department of Health?

Sample Answer: Here's my official identification badge or I will be glad to give you a county number to call collect. I will also be glad to send you information by mail if you like.

Question: Why is the interview worthwhile?

Sample Answer: The information obtained will be used to look at prenatal and baby care, and mothers' health habits for both sick and healthy babies to find ways to help families such as yours in the future.

Adapted from: 1988 national maternal and infant health survey: Field representative's manual. Washington (DC): United States Department of Commerce, Bureau of the Census;1988.



Evaluation of FIMR Home Interview

COMMENTS	AGREE STRONGLY	AGREE SOMEWHAT	DISAGREE SOMEWHAT	DISAGREE STRONGLY
The interview gave me an opportunity to openly share my feelings.				
It was beneficial for me to answer questions about my loss.				
I felt that I could help other bereaved families by participating in the program.				
I gained some insight about my loss through participation in the program.				

Comments: _____

Thank you so much!!!

Adapted from: Cooke AS, Bosley G. The experience of participating in bereavement research: Stressful or therapeutic? *Death Stud* 1995;19 (2):157-70.

CHAPTER 4 REFERENCES

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CHAPTER 5

Basic Team Building and Group Process Concepts for FIMR Programs



CHAPTER 5

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Introduction

FIMR programs conduct their business and create community change through a series of ongoing meetings. Each meeting usually lasts from 2–3 hours. Over the long run, the quality and productivity of these discussions can make or break a FIMR program. To keep team members engaged, FIMR meetings must be well run and be interesting, stimulating and enjoyable. These meetings must also result in action.

Many FIMR program sponsors may not have had training in meeting management or group process. However, most of the people behind successful FIMR programs that have operated for a long time have had to learn the basic principles of these skills, identify team leaders who can best put these principles to work, and discover ways to harness the power that groups such as FIMR can wield. This chapter discusses some basic content about group process that may be useful for FIMR programs to know. (Also review Chapter 3.)

Leadership

To move from discussion to action, FIMR meetings require competent leadership. However, the team members must be equally responsible for meeting productivity and success. Each and every team member must also pledge to do their part to make meetings effective.

Leaders of the FIMR case review and community action teams come from many backgrounds including but certainly not limited to city and county health officers, high school principals, mayors, county executives, health professionals, bereavement professionals, Healthy Start Coalition chairs, community advocates, March of Dimes chapter chairs and Healthy Mothers/Healthy Babies Coalition directors.

Effective leaders all have some common characteristics, including (1):

- proven administrative skills in working with groups, setting agendas, running efficient meetings, garnering resources and delegating responsibilities
- knowledge and skill in resolving group conflict
- a democratic, non-partisan (i.e., without personal, professional or institutional agendas) leadership style
- overall respect from team members
- a degree of knowledge and competence in how communities work

Team Functions

When FIMR teams first come to the table, they expect to review cases, make recommendations or take recommendations to action. This is the task at hand or the “content” of the meeting, the main work of the FIMR teams.

However, team members and leaders alike must come to realize that there is more to a meeting than the main task. Experts tell us that team work involves additional process and maintenance functions which require time, energy and hard work. (2)

Team process function

Team process encompasses the “how” of the effort—focused on getting the FIMR group work accomplished. It includes the following (2):

- using decision-making and problem solving techniques
- clarifying roles and interdependencies
- setting priorities
- employing idea-generation methods
- using a meeting format (agendas, facilitation, time keeping, etc.)



- determining a set of goals and objectives
- developing and updating a program mission statement
- determining changes in organizational structure and team membership, when needed
- implementing strategic planning for the future

Team maintenance function

Team maintenance is probably the least anticipated aspect of group process. Team maintenance focuses on addressing the group's psychosocial needs, and facilitating the development of satisfying interpersonal relationships and meaningful personal experiences. Team leaders and members will have to spend time (2):

- clarifying common expectations
- building trust and relationships
- sustaining trust and relationships
- repairing trust and relationships (forgiveness and reconciliation)
- addressing issues of inclusion and participation
- dealing with problem members and ineffective behaviors
- understanding strengths, weaknesses, experience and styles
- understanding and meeting individual needs and values
- understanding and meeting organizational needs and values

Whether FIMR team leaders and team members actually know about the need for this maintenance function or not, successful FIMR programs do accomplish this task. It is common to hear FIMR team members say that they look forward to coming to meetings and that they personally enjoy the interaction of the FIMR team. As John E. Wright, MD, Pediatrician and FIMR Case

Review Team Leader, Broward County, Florida said, *"FIMR is the most fulfilling, interesting, satisfying, frustrating and important work that I have engaged in. Beyond selfish self growth, I firmly believe and have seen the changes in health care delivery that have been directly influenced by our team."*

70/15/15 rule of thumb

As a rule of thumb for a well-functioning, longstanding FIMR team, group process experts describe a 70/15/15 division in group functions. Team leaders and team members can expect to focus about 70% of the meeting time on the major task at hand, 15% on team process and 15% on team maintenance. Of course, a new team will naturally focus more time and effort on team process and maintenance. Any time new team members come on board, experts also say that incorporating them into the team may take additional process and maintenance time, as well. (2)

Resolving Conflict

In the beginning, FIMR sponsors and staff may dread conflict and disagreement at early team meetings and may actually view them as signs of failure. However, some conflict is expected as team members work toward developing their action agenda for several reasons.

First, FIMR programs make a deliberate effort to bring together diverse, energetic community agency directors and community leaders as well as outspoken community advocates and families. These members are bound to have different agendas and raise different points of view. Initially, they may not agree about which community actions are most needed.

Longstanding FIMR programs tell us that disagreement is not necessarily a bad development. Just the opposite—a lack of conflict may mean



that the group does not represent enough diverse opinions to have a meaningful discussion. A FIMR team that is truly diverse is almost always able to identify significant problems in health care and related service systems. They are also able to produce a wide range of high quality, community sensitive and culturally relevant FIMR actions to address them.

FIMR communities benefit when all members are diverse, feel equal, are free to voice their opinions and can disagree with others in the team. Establishing meeting ground rules that address appropriate ways to handle disagreements as well as other facets of the meeting have proved useful for effective FIMR teams.

Second, FIMR teams can be expected to evolve through stages of group development, which occur in any small group. (3, 4) This development is also likely to include some fairly active dissension and conflict. It is the

Sample Group Meeting Ground Rules

We will:

- begin and end our meeting on time
- listen respectfully
- be tough on ideas, not team members—no personal attacks
- ensure that every participant has the opportunity to speak and that one person speaks at a time
- use the nominal group process, if necessary to resolve difficult decisions about prioritizing recommendations or actions
- not tolerate the use of stereotypes and prejudicial comments
- take responsibility, each and every one of us, for making our meetings effective

Adapted from: A message to America from America's communities. Chicago (IL): The Coalition for Healthier Cities and Communities; 2000.

Stages of Group Development

Forming.

As a coalition comes together, feelings can range from excitement and enthusiasm to fear and resistance. The overriding tone is usually cordial.

Storming.

After the formative stage, issues and agendas begin to surface. Slight to severe differences in the perception of facts, goals, methods, values, etc. are uncovered. Responses can range from withdrawing to overt fighting. The atmosphere is often chaotic.

Norming.

Members stop talking at each other and start listening to each other. Needs, benefits and limitations of collaboration are realized. Roles and responsibilities are determined; agreements are made concerning ground rules and group procedures. Constructive compromises are found. The tone is usually relieved and hopeful.

Performing.

In this stage, the group produces. Members honor boundaries and agreements. Balance is maintained between content and process. Appropriate participation, respect and commitment characterize the tone of meetings.

Adapted from: Tuckman BW. Developmental sequences in small groups. Psychol Bull 1965; 63(6):384-99

FIMR leader's job to be prepared for conflict and disagreement at any time, but especially during the "storming" phase of group development. The more quickly and effectively any group, including the FIMR team, passes through that phase the better. During the "storming" phase, team ability to work collaboratively falls even below the beginning "forming" phase. Team members need to be prepared for dissension to reoccur. As new team members join the team and more experienced team members leave, some of the less productive group dynamics may resurface and need to be addressed again.



Lessons Learned

A FIMR team that is composed of members who are similar in profession, race, agency represented or socioeconomic status may not have much conflict but will most likely generate a narrow community vision, identifying only a few components of the problems. In so doing, they could fail to impact overall community service systems and resources. Lack of conflict for such teams is really a sign of inadequate breadth in membership and poor planning.



Compromise

Seasoned FIMR team members also become skilled at being able to compromise in order to move recommendations to action. FIMR teams will work best when the group decides at the outset how they will reach agreement on controversial or sensitive actions. Longstanding team members say that they have come to realize that the development of a plan for community action will probably not promote the opinion of one faction or another on the team. More likely it will reflect compromise or a middle ground among several different points of view.

FIMR programs consider compromise as one of the best ways to move from recommendation to action. Compromise encourages diverse, multi-professional, multi-cultural team members to come to a satisfactory workable plan and act for the community's good. For example, when it was difficult to sort out which priorities should be included in their action agenda, one FIMR program sponsored several weekend retreats for their CRT. During the retreats, the team members used the nominal group process (see p. 78) to reach consensus about their FIMR action agenda.

Rewarding FIMR Team Members

Successful FIMR programs always recognize and celebrate the work of their team members. FIMR team members are volunteers. In the long run, the ability of FIMR to produce meaningful community change relies on the continued enthusiasm and support of volunteer team members who do the work. Agencies sponsoring FIMR have all come to realize that showing appreciation for the volunteer team member's work is key to keeping members engaged in taking recommendations to action. As Dr. Rebecca Stauffer, former FIMR coordinator in Humboldt County, California remarked, *"We believe in thanking people for a job well done and believe that this too makes a difference in commitment to the process."*

Another approach that has worked well for FIMR programs is to build in opportunities to celebrate the positive actions that the team members have produced. As one community development expert explains, group activities really need to include some time dedicated to fun and affirmation of the strengths and joys of the community. One of the great gifts of effective groups to their members and to their communities is the gift of hope that evolves as they effectively address many local problems. (5)

Another way to honor the work of the team volunteers is to take advantage of opportunities to publicly acknowledge the work of the team members to the community at large. For example, some FIMR programs' annual reports display the names and organizational affiliations of the team members who do the work of FIMR. Other FIMR sponsors give members an annual certificate of participation. Team members like to display these in their offices. This small token of recognition has come to mean a great deal to them.



FIMR Over Time

Membership

What happens to team membership over time? Some core team members will stay involved with the program over the long haul. Karen Papachaud, former mayor and FIMR director in Aiken, South Carolina explained, *“We have wonderful FIMR members who believe in the process and continue to dedicate their time year after year”*.

Other FIMR team members can be expected to move out of the community, take new positions, retire or choose other volunteer activities. Recruitment of new, dynamic members is always critical to sustaining FIMR action. Another FIMR director, Georgia Modreck of Broward County, Florida, said *“One important lesson that we have learned is that we must keep bringing the community into our FIMR. FIMR needs fresh new people who are interested and passionate.”*

Ongoing process

Some FIMR teams have been in operation now for twenty years. What keeps them motivated and moving forward? Long lasting FIMR programs tell us that they have all come to enthusiastically embrace the idea that improving service systems and community resources for women, infants, and families is not a short-term job.

Rather than becoming discouraged that a problem that has been identified may not be addressed fully in one single stroke, these programs realize that the most meaningful change frequently occurs a step at a time. FIMR actions accomplished in one year often become the basis for building enhanced improvements down the road. A previous FIMR action may become a stepping stone to future actions.

FIMR programs also tell us to keep in mind that the FIMR process is a type of continuous quality improvement (CQI). In discovering the

benefits of incremental change over time, FIMR programs have validated one of CQI's most important principles. The Japanese call it *Kaizen*. Kaizen means small improvements made in the status quo as a result of ongoing efforts add up to the biggest and best successes. Kaizen also calls for identifying and holding on to past improvements which then become the stepping stones to future progress. Many important community actions are accomplished a step at a time. Kaizen is also a principle that embraces a long term journey of improvement. (6)

Serendipitous Benefits for FIMR Team Members

As an added benefit, the enhanced interactions among community FIMR team members are a valuable by-product of the FIMR methodology. Experts refer to the “law of unanticipated consequences” when discussing the phenomenon. (7) When a diverse group of people come together in a team (such as FIMR), they build both professional and personal relationships. Comprehensive information about community service systems and resources is provided to the team members. This in-depth knowledge about the community brings team members together, encourages new ways of thinking about the community, enhances respect and understanding of cultures different from their own and generates fresh partnerships to create innovative resources and service systems. Participation in FIMR also improves team member's competence and confidence in their professional activities

Simply by virtue of coming together and learning about the community, any team (including a FIMR team) builds unique local partnerships that can last a lifetime, nourishes disparate alliances and creates the opportunity for these unanticipated, yet community-strengthening consequences to unfold.



Nominal Group Process

The Nominal Group Process is a structured method of airing all of the issues and conducting a weighted vote to identify the priorities of any group. It requires a skilled facilitator, a recorder and a flip chart. The facilitator takes the group through the following steps:

- Each individual identifies, in writing, 3–5 needs or problems that s/he believes are the most important for the group to address.
- Each person shares one item from this list until all ideas are recorded on the flip chart. No discussion should be allowed during this time.
- Next, each item is clarified, as needed, and with permission of the group, items deemed duplicative can be removed and some items may be grouped. Each item or item cluster is numbered.
- Each person votes for the five items s/he believes are most important—the most important of the five is assigned a 5, and the least important is given a 1. After the ballots are collected, the sum of the priority scores for each item is multiplied by the number of times that item was selected. For example, if item #1 was selected three times with a score of a 5, a 2, and a 1, the sum of the priority scores (8) would be multiplied by three (the number of times selected) to give a total score of 24 for that item. Items are ranked on the basis of the total scores they receive.
- Once the group has agreed on the key issues, based on the top 3–5 scored items, these items can be rated in terms of likelihood of success. Starting with an item that has the greatest possibility of success is usually important for the morale of the group.

Adapted from: Striffler N, Coughlin PA, Magrab PR. Communities can workbook series: developing collaborative services for children. Washington (DC): Georgetown University Child Development Center;1994.

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CHAPTER 6

The Role of the Case Review Team



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Introduction

The case review team (CRT) is the information processor of the FIMR program. The CRT reviews and analyzes the information collected in interviews and medical data abstractions in such a way as to summarize findings and create recommendations to improve the community's service delivery systems and community resources.

The process for case review should reflect the FIMR mission statement drawn up at the first community meeting. The success of the team depends on the team's commitment to this purpose. Continued success also depends on the team leader's ability not only to keep the team focused on the work that needs to be accomplished, but also to engender a spirit of team pride and ownership for the work that the team members do through FIMR to benefit their community.

Membership of the CRT

Members of the CRT should have diversity, influence, and commitment to improve services. Appropriate consumer participation is also necessary to achieve the best results and to aid sensitivity to community and family issues (see Chapter 3). Diversity of representation on the CRT is key. In the past, FIMR programs thought that the CRT should have mostly physicians and nurses review cases because others would not have the background to understand the medical information.

However, over time programs have demonstrated that, in fact, teams that were broader in professional, organizational and consumer composition have much more to contribute to community improvement. Program teams also report that the broader the representation on the CRT, the more relevant the proposed interventions to the community will be. Across

the country the size of FIMR CRTs varies from 12–25 members. If teams are too small, the element of diversity is lost; if teams are too large, the group dynamics become unwieldy.

Professionals and agencies on the team should include those that provide services or community resources for families in the community as well as community advocates. For example, members could include representatives from the local health department, both primary and tertiary care obstetric and pediatric providers, Medicaid supervisors, WIC nutritionists, family planning providers, educators, drug treatment centers and hospital administrators. Other representatives might include a perinatal epidemiologist, pastoral counselors, minority rights advocates, a member of the Chamber of Commerce health committee and a member from the local SIDS community (see Chapter 3).

A midwest FIMR program has developed a diverse case review team that includes members from the health department, representatives from the university medical school department of OB/GYN and neonatology, the federally supported Healthy Start program, the medical examiner's office, the African–American health coalition, the Latino health organization, and the state Maternal and Child Health Division. Also included are a perinatologist from the tertiary care center, the Sudden Infant Death Center coordinator, WIC and social service representatives, a family member who has experienced an infant death, the prenatal care coordination provider, a family planning provider and an alcohol and drug abuse counselor.

What FIMR Case Review Does Not Accomplish

In the first meetings, some CRT members look to the FIMR process for results that



FIMR was never designed to accomplish. Knowing some of these most common misconceptions may help future programs avoid them. FIMR program members have come to accept that (1):

- They are not reviewing cases to determine individual causes of death or to categorize the deaths; that information is already available from autopsy, vital records or hospital reviews
- They are not fault-finding or assigning blame for the death. Blame cannot be determined with the subsets of medical information that FIMR abstracts, nor should it be attempted. Comprehensive local and state professional peer review and public health and institutional quality assurance programs are already in place and respond to this issue
- They are not conducting research on the etiology of infant death. Population-based literature exists on that subject. In addition, the information collected about individual cases may not fulfill requirements necessary to contribute to this scientific knowledge base
- They are not attempting to classify the death as preventable; that is often fraught with definitional issues, or key information for such decisions may be lacking or inconsistent

Determining Preventability of the Death

It is especially important to emphasize that CRTs are advised not to use preventability as a criterion for death review and delve into determinations of preventable versus non-preventable deaths, i.e., focusing attention on deciding if the occurrence of the death could have been prevented. Over the years, FIMR programs have found this approach to be both time consuming and counter-productive because of the following (1, 2):

- The overwhelming majority of fetal and infant deaths are not due to typical preventable causes (such as unintentional injury).
- Defining the term “preventability” is difficult; it may mean different things to various individuals and may be applied differently in diverse situations
- A community FIMR process goes beyond examination of medical care to asking about other social, economic, and system factors associated with the death. While a few cases may initially seem preventable, many of these cases will have a number of interrelated factors that are associated with the death and there is no one deciding factor, which if corrected, might have changed the course of events
- Labeling deaths “not preventable” may allow reviewers to overlook important correctable systems factors in these deaths. For example, the death of a child with a severe congenital anomaly may not be considered preventable. However, issues about cultural competence, access to care and lack of insurance could arise in the review of the case. These are issues that a review team would not want to overlook just because the death itself may not have been preventable
- Lengthy case review team debates about whether a case was preventable take valuable time away from the overall important discussion of whether the service system or community resources available were optimal or could be improved

In addition, FIMR programs have found that medical factors make the assignment of preventability even more problematic:

- The medical definition of a “preventable” death is quite different than a public health definition. The medical definition of pre-



ventability presumes culpability of the medical practitioner or the hospital and is definitely not in the purview of FIMR. FIMR is not a peer or institutional review process

- In the case of the same fetal death, the obstetric view of the preventability of the pregnancy loss and the pediatric view of preventability of the infant loss may vary

Keeping in mind this cautionary advice, FIMR programs do not totally ignore notions of prevention in their work. However, rather than spend their efforts deciding if the death per se was preventable, they focus their attention on identifying correctable system factors and implementing remedies for deficiencies in systems and resources with the expectation of preventing future occurrences similar to those uncovered in the case reviews.

The CRT Orientation

It takes time for the individuals on the team to develop a process by which they can work together. In the beginning, the team leader is usually the FIMR Director, or another senior-level policy maker in the agency sponsoring FIMR (see Chapter 2). In some teams, over the years, while the FIMR director continues to play a meeting leadership role, the team members rotate the task of presenting the cases and leading the discussions about them. In any case, the team leader or facilitator should be someone skilled in leadership so that the team members will feel comfortable with the FIMR process and one another (see Chapter 5).

The team leader's ultimate goal is to strike a balance between creating a comfortable atmosphere for team members to voice their opinions and engage in constructive discussions and, on the other hand, keeping the process moving so that the team does not get

bogged down in tangential issues. By attitude and action, the team leader should

exemplify the democratic nature of the team. The team leader can try the following to create the proper atmosphere:

1. Ensure that the team adheres to established ground rules
2. Solicit everyone's opinion, not only the opinions of individuals who have expertise on subjects applying to particular cases, but also those who may have more general knowledge about the community
3. Support the notion that all contributions are valuable. If a team member expresses an opinion that goes against the grain of the team's overall philosophy, the team leader should remind the team that all opinions are valuable and try to point out some aspect that perhaps can be incorporated into the discussion

Every effort should be made to ensure that the participants are comfortable and relaxed. Depending on the time of day, refreshments or a light meal may be served. The seating arrangement for CRT meetings helps set the tone of cooperation and sharing for this first (as well as subsequent) meetings. Chairs should be arranged around a meeting table so individuals face each other and can readily begin a dialogue. FIMR programs suggest that it is also important to assign seating for the first few meetings—placing name tent cards on the table. That way like groups of professionals (e.g., physicians, nurses, social workers, etc.) will not cluster together.

Members of new CRTs (or new CRT members of established teams) will need time to become acquainted with the FIMR program goals and objectives, to become familiar with the case summary format and to become comfortable



with one another. This will take at least several team meetings to accomplish. In anticipating the need for this introductory period, FIMR staff should save the bulk of the cases until after the team is sufficiently oriented.

The first team meeting should be devoted solely to orientation. Activities for this meeting should include the following:

- Give each team member a packet of information. This should include a brief description of the FIMR program, FIMR staff and CRT rosters, a CAT roster if available, program mission statement, sample case summaries and forms, useful articles and other literature, the community resource guide if available and a glossary of technical terms (see Manual Appendices A and B). These materials can be presented to each member in a binder to which additional information can be added over time
- Have team members introduce themselves individually, telling their personal and professional backgrounds and current positions. Placing the tented name cards on the table beforehand will help distribute members around the table and allow members to link names and faces more quickly during the meeting
- Repeat any pertinent information from the town meeting (see Chapter 3)
- Explain the need for absolute confidentiality and review the confidentiality protocol; members should sign and return their confidentiality oaths at this and at every meeting (see Chapter 2, p. 28–29).
- Review the specific objectives for FIMR case reviews and describe how the review team will carry them out
- Describe how case information is collected and summarized
- Distribute the Guide for Case Review Discussion (see p. 96–97), and perhaps a sample case (see p. 100–105), and discuss in detail the process for reviewing cases and making recommendations
- Review the roles of the CRT in developing recommendations and taking limited individual actions
- Explain the relationship of the CRT to the CAT, and the process for sending the CRT's annual recommendations to the CAT and subsequent community action

Once the CRT understands its role, the team should establish their operating ground rules (see Setting CRT Ground Rules). This activity most likely occurs at the second or third meeting after the team has been guided through a few reviews by the team leader.

Subsequent CRT Meetings

Preparing for subsequent CRT meetings

Summaries of 3–5 cases that include information from birth and death certificates, autopsy reports, hospital records, outpatient records, related social services records and the maternal interview, if available, are prepared by FIMR staff prior to the meeting. Using a case summary as opposed to actual medical records is essential to the FIMR process because it allows the program to de-identify the information.

On the practical side, the CRT members will have a much easier time studying the cases when they only have to read a 2–5 page summary, rather than sift through countless pages of forms or actual medical records. The format for the case summary varies from program to program and depends, to some degree—especially in the beginning—on the CRT's suggestions for information needed.



Setting CRT Ground Rules

FIMR CRTs need to decide on the following:

- Where, when and how often will the team convene?
- How will team members share responsibility for presenting the de-identified summaries of the cases?
- What happens if a disagreement or problem occurs at a team meeting?
- Will the CRT make decisions by simple consensus or a more formal majority rule?

Adapted from: Melaville AJ, Blank MJ. Together we can: A guide for crafting a profamily system of education and human services. Washington (DC): U.S. Government Printing Office; 1993.

Creating the case summary is one of the more time-consuming tasks for FIMR staff. NFIMR has developed a case generator within the 2008 NFIMR software package that electronically creates the summary. With a limited amount of editing by staff, the summary helps the team focus on systems issues.

The case summary should include the following information, if available:

- The family's situation during the pregnancy and at the time of the loss. The reader should understand whether the situation was stressful or stable, whether the living conditions were adequate, whether the family seemed strong or overwhelmed
- What happened, from the family's standpoint, from the medical providers' perspectives and from that of other agencies, if applicable. This information should cover the main points. Detailed medical information (blood gases, periodic vital signs, daily assessments, etc.) generally is not needed in the summary, except on very rare occasions when it directly relates to a systems problem presented in the case. Be aware, however, that information from the

family frequently contains non-medical system issues that should be included

- Services or community resources the family was known to have received or not received. If the family had obvious need for particular services, were referrals made? If referrals were given were they followed up? Were any particular reasons known why the family did not receive services?
- Any events since the loss that are relevant to the case, such as subsequent pregnancies, changes in the family, resolution of problems identified in the case, etc.

Tips for preparing case summaries:

- Most programs use the mother as the main subject of the summary
- Use the same format for every case. CRT members will more easily absorb the case when they know where to find the information that is important to them in each summary
- Separate interview information from records information. Programs may want to use distinct typefaces or use bold or italic type. This will allow for recognition of inconsistencies between interview and medical records information, and will give readers a sense of how different individuals perceive what happened in the case. This also helps the CRT members make judgments about the extent of relevant case information available

Many FIMR program teams have chosen to mail, courier or e-mail the de-identified summaries to the team members 3–5 days before the meeting (or whatever timeframe works best for the FIMR staff and team members) along with the Guide for Case Review Discussion (see p. 96–97). This allows members of the team time to read the cases beforehand and use the questions contained in this guide



to help determine what issues they want to raise during the case discussion.

If the summaries are paper copies, the envelope that contains the documents as well as each page of the summaries should be marked “confidential.” Members should be reminded not to make copies of the summaries. If the summaries are mailed electronically, the e-mail should be marked “confidential” and formatted so that the e-mail may not be forwarded to anyone else. The team members should also be instructed not to share the downloaded e-mail document with anyone else, and the document itself should be marked “confidential.”

At the end of the meeting, all paper copies of the cases and case summaries reviewed should be collected from team members and shredded by FIMR staff. Immediately after the meeting, any e-mailed cases should be retracted and deleted by FIMR staff.

Conducting subsequent meetings

FIMR staff will coordinate and schedule all the meetings of the case review team and prepare the summary of the cases. Every team member is responsible for bringing with them all written case summaries received prior to the meeting. Before the cases are presented, each team member must read and sign the pledge of confidentiality form.

At the first few meetings, the FIMR Program Director usually presents each case summary for discussion. Subsequently, responsibility to give the oral presentation of the case rotates among CRT members, with assignments being made in advance. As the summary is being presented orally by a team member, the CRT will listen and can refer to the somewhat longer written summaries.

A discussion of the case (approximately 30–45 minutes in length) follows and may follow the format suggested in the Guide for Case Review Discussion. Important FIMR discussion points that need to be raised include, but are not limited to:

- Did the family receive the services or community resources that they needed?
- Were the systems and services culturally and linguistically appropriate?
- What gaps in or duplication of service systems are apparent or suggested by this case?
- What does this case tell us about how families are able to access existing local services and resources?

The discussion of these key questions will in turn lead the team to develop a list of all possible issues related to the case. In the past and in some programs today a “white board”, newsprint pad, or other medium is used to record the team’s issues as they are presented. Sometimes this list may include 10–12 suggestions for systems improvement. When possible, it is important to narrow the list to three or four priority items. One way to narrow this list is for the team leader to ask: “What are the three or four most important issues that you as a team want to remember from this case?” This facilitates development of future recommendations and action plans based on the most important findings identified over time.

A FIMR CRT has much to accomplish during each meeting. In a two-hour meeting, 3–5 cases will be the average number reviewed. Prolonged discussion about any one case may hinder getting the work done. The team leader should keep an eye on the clock and gently keep the team on track.



Lessons Learned

Today, many FIMR coordinators now use a clean copy of the Guide for Case Review Team (CRT) Discussion and take notes and write group findings directly on that form during the meeting. That way the minutes are finished as the case is reviewed and can be placed on file. Another benefit is that the information can be entered into the NFIMR software and analyzed electronically.



Most FIMR programs ask their information abstractor and home interviewer to sit in on all meetings and be prepared to answer occasional questions that may possibly arise about information abstracted or obtained in the home interview, but not necessarily included in the case summary. For example, a medical provider might ask "Was a repeat sonogram done?" or a public health official may ask "Was a follow-up home visit made?" The best idea, however, is to anticipate these questions and include such information in the case summary.

On the other hand, the abstractor may know the answer from her or his memory of the case. In order to be prepared to answer such questions, FIMR staff have the complete copy of the abstracted records and the home interview nearby (but stored in a locked file) so that they can refer to it if necessary. When called upon to supply additional information, FIMR staff must be very mindful of the need to maintain the confidentiality of all concerned, as they convey additional information. These requests for the team tend to diminish over time as the abstractor becomes more familiar with information that the team would like to see and begins to include it in the case summary.

At the end of the meeting, all team members' copies of the de-identified case summaries and associated Guide for Case Review Team Discussion documents should be collected by the FIMR staff and shredded. FIMR staff are responsible for writing the minutes of the meeting in a timely fashion (within two weeks).

Meeting minutes

The meeting minutes are crucial because they summarize the decisions of the CRT and become the basis for their annual recommendations. Understanding what type of information ultimately will be used for the annual recommendations is useful when generating meeting minutes. Again a caution: When meeting minutes are written, care should be taken to preserve the anonymity of the case as well as the anonymity of comments or suggestions from individual team members.

Based on these minutes, the FIMR staff should prepare summaries of the CRT deliberations on a quarterly (or at least semi-annual) basis to share with CRT members. Some programs summarize the information only for the previous quarter, while others prepare their summaries in a cumulative fashion (e.g., the third quarter summary would reflect the experience of all three quarters).

Whichever approach is used, the summary should include the same content as that of the meeting minutes although format. Data in the Adequacy of Services Grids (see p. 99) could be combined (and converted from check marks) to present the cumulative findings. It is equally useful to identify service components for which there seem to be adequate services as it is to determine where there is room for improvement. In addition,



the FIMR staff should summarize the overall estimates of relevant case information available for review.

The annual review of cases provides the basis for formal recommendations. The CRT should use the summaries to review its work and refine the list of case-related issues that they will use to determine future recommendations.

What CRTs Can Accomplish

The overall goal of reviewing individual cases is to enhance the health and well-being of the community's women, infants and families through improving the service systems and community resources available to them. Specific actions that relate to this goal include the following:

Review cases

The case review process is a distinguishing characteristic of FIMR. The involvement of individuals from many disciplines and aspects of the community makes case review findings and opinions particularly valuable. What they discover about the way community resources and services were provided to a family that lost an infant becomes the basis for creative problem solving to improve the overall community health and related services delivery systems. Types of discoveries made by the CRT include sentinel incidents, trends, and incidental findings.

Sentinel Incidents. For the purpose of FIMR, sentinel incidents are those cases that alone alert the community to a glaring problem or situation with services or community resources that needs prompt improvement. Sentinel incidents are so outside the norm of what the community expects “best practices” of service delivery or re-

sources ought to be that swift action is warranted to correct the gap. The problem that a sentinel case exemplifies may be rare or relatively common; what distinguishes the case is the clarity with which it presents the problem. The sentinel case may also suggest a solution, for example:

A one-month-old infant is brought to the emergency department for treatment of persistent cough and congestion. The chart shows that staff knew the baby's mother had had no prenatal care and used crack cocaine during her pregnancy. The baby had never been seen by a pediatrician. The infant was examined and sent home with saline nose drops and a pediatric appointment was scheduled for two days later. The infant was not taken to that appointment and died several days later of pneumonia.

By itself this case compellingly presents gaps in pediatric services for high-risk infants. The CRT identified these important issues: patterns between utilization of prenatal care and utilization of pediatric care, the need for adequate risk assessment and referral by emergency department staff, and the need for swift home follow-up by public health nursing.

Based on this case, the CRT immediately recommended to the CAT that poor use of prenatal care, or none at all, should be considered a risk for poor or no use of pediatric care as well. Moving into action mode, the CAT was able to bring about the following community interventions: institute a hospital protocol in labor and delivery to refer all women who deliver with a history of no or late prenatal care for a public health nurse home visit; and establish a protocol in all emergency departments to make urgent



public health nursing referrals in cases where an infant arrives in the emergency department for services and the mother had received no prenatal or the infant no pediatric care.

This kind of case vignette, with the details obscured enough to protect confidentiality, can be a powerful tool in presentations to policy makers and can be a rallying point to motivate systems changes.

Trends. Over the course of time, several cases will illustrate similar problems or situations. Together the cases may be more illustrative of a particular problem, for example:

A major trend identified by one CRT was lack of available prenatal records, particularly when pregnant women were seeking care at emergency centers as a result of perinatal complications. Case reviews found multiple reasons why records were not available, including: 1) the records were lost; 2) the hospital staff could not gain access to the prenatal records; and 3) deliveries were occurring outside of the clients' health plan service system.

This trend was significant and worth reporting to the CAT. In response, the CAT decided to develop a Prenatal Health Card/Passport that contains essential information about a woman's health history. The card that was developed has proved so useful over the past 10 years that its use has spread to their entire perinatal region.

Incidental Findings. Incidental findings are uncovered through the FIMR process but are not necessarily part of the case review findings. In addition to case review findings, the FIMR staff or team members may uncover gaps in

the services delivery system that should be addressed, for example:

As part of the early program development, before any cases had been reviewed, the staff developed a list of community resources for families that experience the loss of a fetus or infant. Program staff discovered that virtually no grief and bereavement services existed in the FIMR program area. Moreover, of the few services in the larger region that dealt with infant loss, most were not culturally appropriate for the population in the FIMR area.

The FIMR program's first "finding" in this case was the lack of appropriate grief and bereavement services in its target community. Program staff alerted the CRT and CAT of this finding and the CAT worked with local maternal and child health staff to develop proposals for funding services and bereavement training for family agency staff in the region, and eventually to initiate a program that dealt specifically with infant loss for families in the program area.

Develop initial recommendations for eventual action

The heart of the FIMR process is a careful, thorough study of every case by the CRT to determine the adequacy of local systems of care and community resources for women, infants and families and to make recommendations for their improvement. Preliminary discussion of recommendations occurs at each case review session; however, the team does not finalize them at that time. The team should be encouraged to think creatively and not be dissuaded totally by feasibility. In making recommendations, the team should ask one another: "Do we need to design more responsive service systems?"



What should they look like? Are there resources that the community should have?” Refining and overseeing the implementation of recommendations is the job of the CAT and will be discussed in the next chapter.

The FIMR coordinator usually provides an brief update on the reviews at the CAT quarterly or semiannual meetings. This brief update usually includes information about the process, e.g., number of meetings held in the time period, number of hours spent in review, number of cases reviewed by age at death (fetal, neonatal, postneonatal). However, CRT recommendations are only forwarded to the CAT on an annual basis.

On an annual basis, the CRT should develop and formally report their recommendations for action to the CAT. This means that the CRT must take time to meet and study their findings and the summaries of their meetings. Usually the FIMR coordinator has prepared periodic synopses of their work to facilitate the CRT’s examination of their opinions and suggestions (see previous sections on minutes and periodic summaries). Looking at the aggregated analysis of team findings about individual cases helps focus the team’s thinking and aids their decision-making. Examining the prior years’ recommendations with the findings in the current year helps assist CRT members determine whether trends exist (e.g., repetition of issues from year to year), and if so, the frequency of the issue in the cases. This comparison (and longer-term view) also provides an opportunity to assess whether previously identified issues are no longer cropping up in reviews, and perhaps indicate resolution. A word of caution: finding that an issue is not surfacing does not mean that remedies previously put into place

should be discontinued. It may be that the presence of the particular resource or service in the community is having a positive effect.

After reviewing their findings, the CRT must identify the major trends recognized through the reviews that require systems change and prioritize the most important ones as recommendations to be transmitted to the CAT.

FIMR programs often ask how many recommendations should be moved forward? There is no set number but a range of 6–10 separate recommendations seems reasonable. If there are more than 10, the CAT may be overwhelmed and not know where to begin. However, this upper limit can be somewhat flexible, because the CAT will have to decide what they feel they can accomplish, as well. If the CRT has trouble streamlining their list of recommendations, they can use the nominal group process to narrow it down (see p. 78). If there are less than six, the CAT may not have enough work to keep them motivated to make change happen. If possible, the CRT should provide the CAT with a range of issues and potential actions, not just one or two.

The CRT should try also to aim for a mix of long-term (more than one year) and short-term (less than one year) recommendations to move forward. If all the recommendations will take several years to accomplish then the whole FIMR program becomes bogged down and has no completed actions to report to the community. For example, one CRT formally recommended that the community hospitals should find a way to bring at least one pediatric pathologist on board, while also suggesting development of an annual memorial service for bereaved families, a follow-up system for pregnant women discharged from



the county jail, training for health professionals on use of a standardized domestic violence screening tool and a system for SIDS risk reduction training for child care providers. The first recommendation actually took five years for the community to implement, while all the others were completed within the next year.

A consideration for the CRT regarding the presentation of their recommendations is whether or not the CAT has developed standing subcommittees on particular issues. For example, one larger city FIMR program has six CAT subcommittees based on continuing problems in the community. These include: 1) preconception planning and pre-pregnancy health; 2) access to perinatal and infant health care; 3) adequacy of perinatal and infant health care; 4) perinatal social support; 5) infant safety in child care; and 6) perinatal grief and bereavement support services. (Note: FIMR programs should recognize that selection of subcommittee themes, if desired, depends on the particular circumstances and issues of the community.) If so, recommendations could be subdivided to fit subcommittee categories, but that should not deter the team from making recommendations that do not readily fit into them.

Take some limited action

Findings from review of cases may prompt CRT members to initiate some limited actions individually or jointly with other members and their organizations.

Individual. Many CRT members are powerful members at their own agencies or worksites and can stimulate or make changes in communication, availability of services and access in their community. As cases are reviewed, one member may consider

whether identified barriers to care or gaps in services present issues in his or her own agency. However, Acting as a change agent, a team members will subsequently examine systems of care within his/her own organization with an eye to improving services, for example:

A series of cases points out provider insensitivity to families accessing well-baby care. The director of pediatrics returns to the university hospital and institutes four, three-hour cultural sensitivity seminars that become mandatory for all pediatric residents.

Until recently, FIMR teams did not take credit for these types of systems changes or even acknowledge that they were happening. However, this individual advocacy and action, while not a part of the formal FIMR process, contributes to the continuous quality improvement in the community and should be encouraged and documented, if possible and team members agree. Team members tell us that this participation in FIMR also improves their competence and confidence in their own employment activities.

Caution: Any specific information about FIMR case histories or proceedings of the individual CRT meetings that pertain to issues identified at a particular agency always remain confidential and cannot be shared by the team member as a rationale for encouraging his or her own agency's system change.

For local FIMRs that have been reviewing individual cases for 18–24 months, a simple questionnaire could allow the program to poll team members about their individual activities (see p. 92) Of course, in some cases a team member may choose not to reveal activities



Insights From Participating On The FIMR Case Review Team

1. Has membership in the case review team benefited you in any way?

☐ YES ☐ NO

Please explain:

2. Have you made any changes in your own practice or in policies/procedures in your institution as a result of your participation in the case review team meetings?

☐ YES ☐ NO

Please explain:

3. Has your understanding of the health and human services available for women, infants and families in your community changed since you became a member of the team?

☐ YES ☐ NO

Please explain:

4. If you had to make one statement about your participation as a member of the FIMR case review team to a team member just getting started, what would you say?

Please describe:

if the disclosure could reflect negatively on a participating agency.

Interagency or Joint Interventions. Sometimes review of cases points out a simple problem that rallies some or all of the CRT members to develop a limited action together, for example:

After review of several SIDS cases, each agency representative sitting on the CRT decided to develop at least one mechanism in their agency to disseminate the new American Academy of Pediatrics recommendations regarding infant sleeping position to pregnant and parenting families.

It is important for the CRT members to consider what the overall community outcomes of their decision could be and to advise the CAT of their actions at the quarterly meetings. The CAT can then begin to consider whether to expand the scope of this intervention to other service providers or agencies.

Report to the CAT

Every year the CRT team leader, FIMR director and/or a delegation from the CRT should formally report their recommendations for action to the CAT. This report usually involves an oral report with an accompanying Power Point presentation. Suggested components of this report might include, but are not limited to:



- Number of meetings held and number of hours spent in review
- Number of cases reviewed by age periods of death (fetal, neonatal, postneonatal) and total number of cases
- General availability of relevant information for the cases (includes family interview information)
- Trends—in issues, adequacy of services relative to the cases reviewed
- Priority recommendations
- CRT members' limited action (if available)

Much of this information will already have been written in the course of developing the periodic summaries for the CRT and can be inserted into the annual report for the CAT.

Most importantly, the CRT should take great pride in reporting their recommendations to the CAT. This formal report is the culmination of a year's worth of serious examination and hard work. These agreed-upon team recommendations provide a sound basis for improved services and resources for women, infants and families.

Group Process and the CRT (Refer also to Chapter 5)

When a deliberate effort is made to bring diverse individuals together, disagreement is bound to result eventually. One of the healthiest signs of group process is when all members feel free to speak up and voice their opinions, especially if they do not agree with others in the team. The team leader should not treat such disagreement, or even argument, as poor group process but rather should encourage open expression of opinions as an important step toward high-quality findings. An obvious limit exists at the point

of personal attack. The team should be aware of that limit and avoid it.

Another important role of the team leader is to maintain balance in the team and to ensure its flow. The team leader should closely assess each member's interaction with the rest of the team and try to draw out those who may be feeling intimidated or tentative. Rotating case presentations, though some people may be nervous about the prospect, is one of the best ways to ensure that the quieter team members learn to speak up. The team leader should also call on those who have special knowledge or expertise that pertains to a particular case.

Team members need to feel that they and their work are valued. One way to do this is to ensure that the meetings are as effective and efficient as possible. Meetings should begin and end on time. Food and snacks at the meeting are always appreciated. Those FIMR program teams that send case summaries to the team before the meeting should do so with plenty of time (3–5 five days or whatever works for the FIMR staff and CRT members) for reading and study. The FIMR coordinator and staff should plan ways to acknowledge the team's work at least once a year. Some suggestions are sending cards or taking the team members to lunch. Also, the FIMR staff as well as the agency sponsoring the program should make certain to acknowledge the team in any written or oral presentation of FIMR information. Every gesture that signifies the importance of the team to the FIMR program makes it more likely that the members will take their commitment seriously and value their service to the community.

Rare is the team in which every member comes to every meeting. Despite the best



efforts at recruitment and motivation, the reality of professional life is that other commitments will from time to time prevent members from attending. Some FIMR programs have solved this problem by having two professionals share one team seat (e.g., two pediatricians rotate every other meeting). On the other hand, it is important to emphasize to team members that the invitation to participate in team discussions is issued to each member personally and that the member may not delegate that responsibility without prior approval. One or two absences a year is understandable. More absences than this, especially over several consecutive months, should be examined closely. Is this member able to make the commitment? Is there some way to make it easier for this member to attend every meeting?

Over the long run, team membership may change. Some members may assume other job responsibilities or move from the community. Vacant spaces on the team should be filled as quickly as possible. The impact of changing team membership is felt most on the group's ability to have a consistent process from meeting to meeting. New members need to be oriented to the process, the expected outcomes, and the mission statement. It might be helpful to have new team members observe a meeting prior to active participation. Reviewing the CRT's mission statement and objectives with new team members and maintaining consistency in the case discussion format are two ways to ensure consistency over time.

Common Questions the FIMR Staff May Have Regarding the CRT

What should I do when one of the review team members has been involved with the case?

FIMR involves not only medical or nursing or social services review, but all the systems of care that were involved in the case. At each meeting, before the case review, make a practice of telling the team that if any of them think they were providers for the case, or know who the providers for the case were, not to identify themselves, others or the institution. Emphasize that if they know other information about the case that has not been presented, or if it has been presented incorrectly, not to identify themselves or give out the additional information, but to contact the FIMR coordinator separately after the case review. If requested, the FIMR coordinator can inform the team that the case will be re-abstracted for clarification or to correct misrepresentation. However, the case can only include information found in the medical records, not anecdotal information from team members which is not in the chart.

A team member wants to know the names of all the physicians involved with the cases. What should I tell him/her?

Tell the team member that this information cannot be shared because of the confidentiality pledge you have signed. All FIMR staff and team members have signed a pledge of confidentiality and cannot divulge this information. In addition, cases are anonymous and provider identifiers are never on file or written on abstracted forms, and all forms are shredded after case review, so names of providers will be impossible to determine. There is really no reason that the team member needs to know the names of



all the physicians involved. As previously stated, FIMR is not a peer review but a systems review. In general, the fewest number of FIMR staff members with identifying knowledge, the better. Your chair may be testing to see if staff are really able to keep the information confidential.

What should I do if a team member identifies her/himself at a meeting as involved in a case?

Self-identification as one of the providers on a case can and does happen. If it does happen, stop the conversation right away and reiterate the confidentiality standards. Do not allow information not abstracted to be shared. Ask the person not to share other names or providers. Usually, this confrontation will stop further loss of confidentiality.

In what circumstances would the name of the family or the mother in a FIMR case have to be revealed?

In the case of suspected child abuse or neglect, the mother or family would have to be reported to appropriate authorities. Because each geographic area may have a different system to accomplish this, the method should be determined before the review begins. Mothers consenting to an interview are notified of this before the interview. There is never a reason, however, to reveal the name to the CRT.

In what situations is it appropriate for a CRT member to share information about FIMR findings prior to their formal presentation to the public?

At times, review team members who are leaders in community institutions hear discussions in CRT meetings that stimulate ideas for system changes in their own institutions. Since a summary of the FIMR findings and recommendations is presented

to the community only on an annual basis, review team members hearing information about a needed system change during the FIMR process can and do elect to initiate the system change sooner in their institutions. However, any specific information about FIMR case histories or proceedings of the individual CRT meetings that pertain to issues identified at a particular agency are confidential and cannot be shared as a rationale for encouraging his or her own agency's system change.



GUIDE FOR CASE REVIEW TEAM (CRT) DISCUSSION

Goal of Case Review: At the heart of FIMR is a case review of a fetal or infant death. The overall goal of reviewing individual cases is to enhance the health and well-being of women, infants and families in your community by improving the service systems and community resources available to them.

Case Review Team: CRT members play a distinctive role in the FIMR process. Team members represent a broad range of professional organizations, public and private agencies (health, welfare, education) that currently provide services and resources for women, infants and families, as well as community advocacy groups and family representatives.

Case Review Team Discussion: Obtaining CRT members' opinions about the issues associated with each case is the crux of the case review discussion. As the CRT examines each case, the team should ask and answer such questions as:

- Did the family receive the services or community resources that they needed?
- Were the systems and services culturally and linguistically appropriate?
- What gaps in or duplication of service systems are apparent or suggested by this case?
- What does this case tell us about how families are able to access the existing local services and resources?

Aggregate CRT Findings and Recommendations: Usually quarterly and on an annual basis, the CRT examines their aggregate case review findings and reviews their priority barriers to care, gaps in services, and negative trends in service delivery systems. At the end of the year, the CRT will then develop recommendations for actions to improve services, resources, and policies that affect women, infants, and families. These recommendations are subsequently presented to the community action team (CAT).



GUIDE FOR CASE REVIEW TEAM (CRT) DISCUSSION (CONTINUED)

Percent of Information Available for This Case Review

Estimate the percentage of relevant information that was available for review of the case:

- ☐ 0–25% Minimal information available
- ☐ 26–50% Major gaps in information available
- ☐ 51–75% Minor gaps in information available
- ☐ 76–100% Substantially complete: medical information and maternal interview available

Was a maternal interview for this case obtained? ☐ Yes ☐ No

Personal, Community and Service Delivery Strengths

Identify personal strengths, community resources, or service system features that supported the success this family had in accessing services.

Issues Associated With This Case

Listed below are a variety of issues you may find present in this fetal/infant case. In your discussion you will want to identify all that are present.

1. Culture

Language barriers
Cultural beliefs re: pregnancy/health
Concern re: citizen status
Other: _____
☐ Unknown ☐ None

2. Environment/Occupational Hazards

Second-hand smoke
Substandard housing
Overcrowding
Improper infant bedding
Other environmental hazards
No care seat
Heavy lifting (greater than 40 lbs.)
Other occupational hazard
Other: _____
☐ Unknown ☐ None

3. Family Planning

Never used
Not used; intended pregnancy
Failed contraception
Other: _____
☐ Unknown ☐ None

4. Family Violence/Neglect

Partner abuse
Child abuse
Child neglect
Other: _____
☐ Unknown ☐ None

5. Gaps in Care

Critical gap in care identified
Specify _____
Missed appointments
Other: _____
☐ Unknown ☐ None

6. Homeless/Transient

Frequent Moves
Living in Public Shelter
Living on the streets/homeless
Other: _____
☐ Unknown ☐ None

7. Medical: Fetal/Infant

Intrauterine growth retardation
Congenital anomalies
Substance exposure
Infection
Prematurity
Other: _____
☐ Unknown ☐ None

8. Medical: Mother

Cord problem/abruption
Diabetes
Incompetent cervix
Infection
Insufficient weight gain
Multiple gestation
Obesity
Poor nutrition
Pre-eclampsia/eclampsia
Preterm labor
PROM
Previous fetal loss
Previous infant loss
Previous LBW delivery
Previous preterm delivery
STI
Other: _____
☐ Unknown ☐ None

9. Mental Health/Stress

Divorce/Separation
Jobless, involuntary
Parent in prison/parole or probation

10. Need for Health Education

Critical information not provided
Specify _____
Other: _____
☐ Unknown ☐ None

11. Need for Health or Psychosocial Referrals

Critical referral not made
Specify _____
Other: _____
☐ Unknown ☐ None

12. Payment for Care/Services

No insurance/not Medicaid eligible
Medicaid eligibility unclear
Other: _____
☐ Unknown ☐ None

13. Poverty

Present
Other: _____
☐ Unknown ☐ None

14. Prenatal Risk Assessment

Not done
Inadequate
Not followed
Other: _____
☐ Unknown ☐ None

15. Problems with Pediatric Care

No pediatric care
Missed appointments
Multiple providers/sites
Other: _____
☐ Unknown ☐ None
Single
Teen pregnancy
Maternal history of mental illness
Mental illness during perinatal period
Multiple stresses during perinatal period
Possible dual diagnosis
No/Inadequate grief support after loss
Other: _____
☐ Unknown ☐ None

16. Problems with Prenatal Care

No prenatal care
Late entry
Missed appointments
Multiple providers/sites
Other: _____
☐ Unknown ☐ None

17. Provision/Design of Services

Unavailable in area
Mother/child non-eligible
Lack of communication among providers/services
Fear of/dissatisfaction with system(s)
Other: _____
☐ Unknown ☐ None

18. Screening for Health

or Psychosocial Problems
Screening not done, critical problem not identified
Specify _____
Other: _____
☐ Unknown ☐ None

19. Social Support

Lack of supportive friends/family
Negative influence of friends/family
FOB not supportive
Other: _____
☐ Unknown ☐ None

20. Substance Abuse

Tobacco
Alcohol
Illicit drugs
Prescription drugs
Other: _____
☐ Unknown ☐ None

21. Transportation

Inadequate _____
Other: _____
☐ Unknown ☐ None

Other: _____

Other: _____

COMMENTS:

Of all the systems issues that the team has listed above, which seem to be the most significant? Please comment.

Adequacy of Services Grid. Looking back at this case, put a check in any cell in the first two rows to indicate where additions to system changes seem needed and whether or not existing systems changes needed were minor or major. Put a check in the third row if the services needed are currently not available in your community.

	PRECONCEPTION	PRENATAL	LABOR AND DELIVERY	NEWBORN	INFANT	GRIEF
MINOR additions to the services provided would have been useful to this family.						
MAJOR additions to the services provided would have been essential for this family.						
This family needed important services NOT currently available in our community.						

Comments: _____



CASE # NFIMR 2007 Fictitious Fetal Death Case*

Vital Statistics Fetal Death Certificate Information:

Sex: Male

Cause of Death: Placental abruption

Weight: 8 pounds 7 ounces

Weeks Gestation: 40

Mother: 20, White, 12 years education, single

Previous Pregnancies: none

Father: 22, white, 12 years education

Prenatal Care: 1st month, 17 visits

Weight Gain: 25 pounds

Substance Use: none

Delivery: vaginal

Cases summary synopsis: (information from medical record and interview)

The mother was 20, gravida 2 para 0010, single, 12 years education, homemaker. She entered prenatal care at six weeks at an OB private office with 17 visits. Medical history was significant for termination of pregnancy age 15. Prenatal history was significant for anemia treated with iron and multiple hospital ER visits for complaints spotting and discharge after 28 weeks. Prenatal referrals to WIC and Healthy Start. At 40 weeks she presented to a Level I hospital with contractions and complaints of abdominal pain. Fetal demise was noted on ultrasound. Four hours after admission she had a vaginal delivery with small placental abruption noted. Birth weight was 8 pounds 7 ounces. An autopsy was requested but refused by family. Day after delivery, mother left hospital against medical device with her boyfriend. Bereavement support was documented. Mother agreed to FIMR interview 8 weeks after delivery. Interview took place at her parents' house. She requested boyfriend never know of the interview. During the interview she told nurse that he had threatened to harm her during her pregnancy and she was worried that was what "killed her baby."

*This case is a work of fiction. It was developed by Ms Dani Noell, ARNP, MSN, NFIMR Consultant, as a training tool for the FIMR basic training track at the National FIMR conference.



MEDICAL RECORD	MATERNAL INTERVIEW
<p>1. Medical: Mother Prenatal Medical record: Mother 20, white, USA, gravida 1 para 000 Previous Pregnancies: none LMP: 10/10/06 EDC: 7/17/07 by dates, 7/20/07 by sonogram at 12 weeks HIV: tested negative, pre- and post-test counseling documented Prenatal labs: A+, GC neg., Chlamydia neg., Rubella immune, Hep neg., urine culture neg. PAP wnl. Initial H/H 12/36.2 Results unremarkable except for elevated GTT 146, 3 hour GTT wnl. Repeat H/H 9.8/30.2 Treatment was Iron tabs bid. Repeat H/H 11/32. Pre-existing medical problems: none Medications: PNV, Iron Problems developed: none Nutrition: assessment not documented</p> <p>Pre-pregnancy Weight: 176 Height: 5'4" Identified nutritional factors: none Gained: 40 pounds by 40 weeks. Body Mass Index: 30 (obese) Nutritional referrals: WIC Other testing/Procedures: HIV, urine C&S, 1 hour GTT at 30 weeks wnl, AFP 17 week's wnl.</p> <p>Prenatal Hospitalizations: Level I ER (Abstractor Note: All visits between hours 11PM and 3 AM)</p> <ul style="list-style-type: none"> ■ 28 weeks for abdominal pains and complaints spotting. Labor check only, then discharged. ■ 32 weeks for abdominal pains and complaints spotting. Labor check, not in labor. Boyfriend noted in record as having alcohol on breath and acting impatient, wanting her to be discharged to drive him home. ■ 35 weeks for complaints yellow vaginal drainage. Vaginal culture negative, not in labor. ■ 37 weeks complaints abdominal pains and vomiting. US normal, good fetal movement, not in labor. ■ 39 weeks: c/o spotting, vomiting and abdominal pains. US wnl. + fetal movement. Not in labor. Sent home with instructions. 	<p>1. Medical: Mother <i>She was single, 20 years old, born in USA, and is white. She completed 12 years of education and is attending night school for her GED. Her baby was a singlet. Prior to this pregnancy she had a termination at age 15 but her boyfriend and parents don't know.</i></p> <p><i>She was 4 weeks when she thought she might be pregnant. She was 6 weeks when she was sure she was pregnant. She was satisfied with her care. During her pregnancy she did not attend parenting or childbirth classes. Her boyfriend did not want her to go.</i></p> <p><i>She took no special precautions to prevent preterm labor. She describes her health during her pregnancy as good but she said she always worried something would happen to her baby. The ending weeks of her pregnancy she was scared something was happening to the baby as her boyfriend kept threatening her. She went to the ER frequently to be checked.</i></p> <p><i>She was not on a special diet. Her prepregnancy weight was 165, and she gained a total of 36 pounds and she is 5'4". She craved ice.</i></p>



MEDICAL RECORD	MATERNAL INTERVIEW
<p>Labor and Delivery Medical Record: Hospital Level: I Date/Time: 7/21/07 at 11:20PM Gestational Weeks: 40 weeks Reason for Admission: Admitted 11:20PM to L&D triage with abdominal cramping and sent to L&D. Onset labor 9:30PM. Had been visiting with friend when pains began. Waited for a ride. Admission History: 11:20PM: BP 132/60, temp 98.7, pulse 119. Dilated 4cm, effaced 70%/Floating. Vaginal spotting. Sonogram done by OB on call at 11:30PM notes no fetal activity. Last fetal movement at 4:00PM. LABS: admission: WBC 15.6 H/H 9/29.6 Discharge: WBC 16 H/H 8.8/27 Membranes: SROM 11:45PM, meconium Monitoring: External monitoring no tracing noted. Fundal height 36cm. US confirmed fetal demise. Problems in labor and delivery: fetal demise Referrals: none Medications: Demerol and Phenergan, Pitocin Anesthesia: none Delivery: 7/22/07 at 1:22AM, spontaneous vaginal delivery of 8 pounds 7 ounces, male with cord around neck x3, small abruption. Resuscitation: none. Apgars 0/0 Discharged: Home after 1 day with clinic F/U in 6 weeks. Placental exam: 770 grams, Third trimester, meconium stained. 3 vessels cord, area infarction and abruption.</p>	<p>Labor and Delivery: (Maternal Interview) She was not transferred from one hospital to another. She was never refused admission. She delivered on 7/22/07. Her due date was 7/20/07.</p> <p>She describes her delivery: Contractions began at 9:30PM. She didn't get to the hospital until 11PM because she was waiting for her sister to pick her up. When she arrived at the hospital the nurse was unable to find a heart beat. She waited to have the ultrasound done. While she was waiting her water broke and she was leaking everywhere. A nurse told her baby was dead. She spent 1 night in the hospital. After her delivery her boyfriend wanted her home.</p> <p>She says what happened is: The baby's father was to take her to the hospital but he did not show up. They had had a fight that morning and he had left. She called her sister who lived in another town. She then went to the hospital as her stomach hurt and she did not feel the baby was moving as much. After her baby was born she got to hold him and pictures were taken. She was scared but he was so beautiful and perfect. Her parents were with her. Everyone was helpful. When her boyfriend came he didn't want to see the baby and would not talk to her very much. He told her she needed to come home the next day. She left as she was worried he would do something.</p>
<p>2. Medical: Fetal/Infant Fetal demise. Weight 8 pounds, 7 ounces. Cord wrapped around neck. Small placenta abruption noted. Autopsy: Refused by family.</p>	<p>2. Medical: Fetal/Infant She does not know why her baby died. She thinks her boyfriend "killed the baby" by threatening her so much during her pregnancy.</p>
<p>3. Payment for Services: Medical Prenatal & L&D: Managed Care.</p>	<p>3. Payment for services Prenatal & L&D: Her parents' insurance.</p>
<p>4. Problems with Prenatal Care Prenatal care: First visit at 6 weeks, private provider with 2 health care givers. Prenatal Appointments: 17 with 1 missed appointment. Followed up by telephone call. Visits: BP ranged 90/60 – 120/80. Instructed to monitor fetal movement three times a day. Last visit 7/14/07 wnl.</p>	<p>4. Problems with Prenatal Care She received prenatal care as early as she wanted. It was not difficult obtaining prenatal care. Her first prenatal visit was at 6 weeks at a private provider's office. She saw the same provider and did not change providers during the pregnancy.</p>
<p>5. Problems with Pediatric Care: N/A</p>	<p>5. Problems with Pediatric Care: N/A</p>



MEDICAL RECORD	MATERNAL INTERVIEW
6. Substance Use Healthy Start: denies usage. Prenatal: denies usage. L&D: denies usage.	6. Substance Use <i>She did not smoke or drink. She took only vitamins and iron. She was asked if she smoked and was told how it would affect her baby. She was asked if she was drinking and was told how it would affect her baby. Her boyfriend drank a lot and said mean things to her when he drank.</i>
7. Prenatal Risk Assessment Healthy Start Screen Score: 4 Prenatal risk factor: single, 12 years of education, transportation difficulties. Healthy Start Coordination: unable to locate after 2 telephone calls and one home visit.	7. Prenatal Risk Assessment <i>Her doctor told her she was a low risk pregnancy.</i>
8. Infant Risk Assessment: N/A	8. Infant Risk Assessment: N/A
9. Social Support Prenatal: single mother with involved boyfriend. L&D: single. Family and boyfriend listed as support persons. Father of baby not present during delivery.	9. Social Support <i>If a problem had come up in the 12 months before the baby was born her sister or parents would have helped. The baby's father completed 12 years education and is 22 and white. She describes her relationship with the baby's father as good but it changed frequently and she was not satisfied with his contributions financially. During the pregnancy the baby's father had problems with his job and finances. She describes her relationship with the father now as poor. She feels their relationship changed for the worse during the end of her pregnancy and after the baby died. Her parents have been very helpful though.</i>
10. Homeless/Transient Healthy Start: has housing, feels safe Prenatal: lives with boyfriend in an apartment. L&D: Has housing, air conditioning, and heat.	10. Homeless/transient <i>She felt satisfied with her overall living situation. She lived with her parents and her boyfriend and did not have to pay rent each month. She did not live in public housing. She moved three times in the past year. There was never a time when she couldn't afford a place to stay or when she couldn't afford the rent or mortgage and she was never evicted from her home and her utilities were never turned off.</i>
11. Poverty No source data.	11. Poverty <i>During her pregnancy she felt she never had to cut down on the amount of food she bought. There was never a time there wasn't enough money. Sources of family income were wages from family members and her boyfriend and her estimated yearly income was unknown. Before the baby died, she never worried about not having enough money from one month to the next.</i>



MEDICAL RECORD	MATERNAL INTERVIEW
<p>12. Mental Health/Stress Healthy Start: No to receiving mental health counseling. Prenatal: No history of postpartum depression.</p>	<p>12. Mental Health/Stress <i>During the 12 months before delivering her baby she lost a family member, moved, changed jobs and met her boyfriend. During the pregnancy he experienced job difficulties, drank a lot and had financial problems.</i></p> <p><i>In the last month she has not felt good about her ability to handle her personal problems and felt her difficulties were piling up so high that she thought she could not overcome them. She often feels depressed. Since her baby died she and her partner have not received counseling or joined a support group for parents who have lost a baby. Her boyfriend does not want to talk about the baby.</i></p>
<p>13. Family Violence/Neglect Healthy Start: No to being hit or hurt in past year. Prenatal Record: Negative for domestic violence on prenatal record checklist. L&D: Negative history of domestic violence on nursing admission assessment.</p>	<p>13. Family Violence/Neglect <i>She was physically pushed by her boyfriend during her pregnancy. He yelled at her a lot during the pregnancy and she went to live with her parents. She moved back with him her last trimester because he was sorry and wanted her back. She almost left him again but he kept threatening her and she was scared to leave and scared he would do something to hurt the baby.</i></p> <p><i>Her family wanted her to stay with them as they were worried about her. She was scared to stay as her boyfriend threatened to harm her family. She didn't know what to do.</i></p>
<p>14. Culture Prenatal: English speaking. L&D: No to "cultural or belief issues affecting care." Religion: Baptist.</p>	<p>14. Culture <i>No issues expressed</i></p>
<p>15. Transportation Healthy Start: transportation difficulties Prenatal: Missed one visit due to transportation difficulties. L&D: No personal transportation. Had to wait for a ride to come to hospital.</p>	<p>15. Transportation <i>She traveled by bus or taxi to get to prenatal appointments and it took 30 minutes. Sometimes her boyfriend took her.</i></p>
<p>16. Provision/ Design of Services Documented education Prenatal: Education section blank in prenatal records. Documentation of HIV pre- and post-test counseling and fetal movement noted in prenatal notes. L&D Education: Self care. Bereavement: "Family in to see mother and baby. Pictures and footprints taken. Bereavement information given." Referrals Prenatal: WIC & Healthy Start Care Coordination. L&D: none.</p>	<p>16. Provision/Design of Services <i>Education discussed with her during her prenatal care included getting tested for HIV, preterm labor signs, complications of pregnancy, sexuality, fetal movement, labor and delivery process, infant care seat and infant sleep positioning. She was asked if she had enough food to eat. She did not attend any classes, as she did not have transportation at night and her boyfriend did not want her to go. Nutrition was discussed with her. She did not see a dietician.</i></p> <p><i>She had WIC. Advice given at WIC included eating properly, how to buy food, to cut down or stop smoking. It was easy to get WIC vouchers.</i></p>



MEDICAL RECORD	MATERNAL INTERVIEW
17. Environment/Occupation Hazards None, unemployed.	17. Environment/Occupation Hazards <i>She did not work during the pregnancy.</i>
18. Family Planning: Intended pregnancy. Used birth control pills prior to pregnancy.	18. Family Planning <i>She remembers feeling that she wanted to be pregnant earlier. She never considered not continuing her pregnancy. During the three months before she became pregnant she was not using birth control, as she wanted to get pregnant. She expects to have more children and plans to wait a few years. She is currently not using birth control.</i>
19. Other issues: Interviewer note: The mother showed the baby's pictures and footprints to the interviewer. Mother talked about how perfect baby looked. Information regarding community support groups requested and given to her. Mother talked about being depressed but says she is doing better and that talking about what happened has helped. She is glad to know somebody cares. She is staying with her parents right now but hopes to get back with boyfriend. Her family has been very supportive. She does not want "her boyfriend to know she did this interview. He does not like to talk about the baby."	19. Other Issues: <i>Thinking back on the entire experience, she feels it would have made things better if she had not gone back with her boyfriend at the end of her pregnancy. She also thinks that her boyfriend would have been happier and more involved if he had less stress and drank less during her pregnancy. She thinks joining a support group or going to counseling might be helpful to women and families who experience the death of a baby. She would also like to share that she is thankful she got to hold her baby in the hospital and that she has pictures of him to keep forever.</i>

CHAPTER 6 REFERENCES

1. Brustman B, Buckley K, Cohen M, Medvesky M. Infant mortality review: Progress report. Albany (NY): New York State Department of Health; 1993.
2. Draft infant mortality review manual. Rockville (MD): Health Resources and Services Administration, Office of Maternal and Child Health; 1988.



CHAPTER 7

The Role of the Community Action Team



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Introduction

NFIMR promotes the use of a two-tiered FIMR process employing two teams to separate the functions of review of cases and drafting of preliminary recommendations from those of determining and implementing actions that address identified systems and resources issues. The team carrying out or facilitating the latter functions is the Community Action Team (CAT); Chapter 6 explains the role of the Case Review Team (CRT).

In the national evaluation of the FIMR program, about half of the surveyed FIMR programs (36 out of 74) described utilizing a two-tiered structure. Evaluation findings indicate that a two-tiered structure for FIMR appears to enhance the program's effectiveness. FIMR programs organized as a two-tiered process (separate CRT and CAT) as opposed to those with a joint CRT/CAT team or a single CRT were significantly more likely to (1):

- Report a greater variety of key FIMR program attributes, e.g., serving as a base for advocacy about perinatal problems
- Carry out a greater number of roles in supporting perinatal health, i.e., perform an increased number of activities in all five of the measured essential Maternal and Child Health (MCH) services. Differences were largest in the categories of quality assurance and policy development
- Address a greater number of perinatal health issues
- Implement a higher mean number of recommendations to address 10 perinatal topic areas. The data show that two-tiered programs executed 88% of their recommendations compared with 71% for those using a CRT only or 48% for those with a joint CRT/CAT

Because of these advantages, including the potential of accomplishing a more robust action agenda, FIMR teams should strongly consider implementing the two-tiered structure.

Community Action Team Role

Despite some variation in the manner in which a CAT is constructed, the ongoing role of the CAT is to:

- Develop new and creative solutions to improve services and resources for families from the recommendations made by the case review team
- Enhance the credibility and visibility of issues related to women, infants and families within the broader community by informing the community about the need for these actions through presentations, media events and written reports
- Work with the community to implement interventions to improve services and resources
- Determine if the needs of the community are changing over time and decide which interventions should be added or altered to meet them
- Safeguard successful systems changes initiated by FIMR that have been implemented from being discontinued in the future

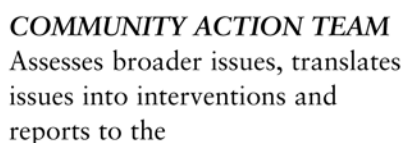
In the course of their work, the CAT may respond to issues that are broad or politically complex, that change over time, and that require substantial time and resources to implement change.

FIMR Community Action Team Sponsor

Every successful FIMR CAT has to have a core sponsoring organization that will choose the team members, chair the meetings, and encourage team action with enthusiasm. For FIMR programs, the most common sponsor is the local health department. Others sponsors



CASE REVIEW TEAM
Reviews cases, identifies gaps in service systems and resources and reports to



COMMUNITY



Action Occurs:

Creating Solutions Where None Exist:

- Within Provider Groups and Organizations
- Between Providers and Organizations
- Across the Community

Adapted from: South Carolina FIMR

Relationships Among the CRT, the CAT and the Community

The CRT reviews health care and related service systems to determine if gaps in services or community resources exist, to document opportunities for improvement and to report findings to the community action team. For example, one CRT reviewed several cases in

The CAT does not necessarily have to be sponsored by the same agency that sponsors the CRT. For example, in one FIMR program, the CRT was located in the health department and reported its findings to the CAT, which was a blue ribbon infant mortality panel in the mayor's office. In another FIMR program, the CRT was a part of a regional perinatal coordinating council and the CAT was a subcommittee of a local Healthy Mothers/Healthy Babies Coalition.



which domestic violence was a significant factor. The CRT reported this trend to the CAT and recommended that screening for domestic violence should become a routine part of intake for prenatal care and that resources for battered



women should be increased to accommodate the need for more services that community-wide prenatal screening would engender.

Acting on the CRT's domestic violence recommendations, the CAT was able to broker agreement among all public and private prenatal care providers to begin using a standardized domestic violence screening tool. Over a two-year period, the CAT also worked with the mayor and the local Commissioner of Social Services (both members of the CAT) to identify and target resources to fund additional services in the local shelter for battered women.

In response to findings reported jointly by these two groups, the broader community may act through the development of individual actions, new coalitions, legislative committees or other local organizations to improve service delivery and resources for women, infants and families.

Lessons Learned

Some FIMR programs are now asking their CRTs not to report specific recommendations until the CAT has developed an action plan. That way, the larger community will have no doubt about the way forward and the FIMR program speaks with one voice.



Membership of the CAT

The CAT is composed of two types of members: those who have the political will and fiscal resources to create larger-scale systems change, and those who can define a community perspective on how best to create the desired change in the community. Across the country, the number of CAT members depends on the size and complexity of the community and ranges from 15–35.

Lessons Learned

As the FIMR process moves forward to action, the CAT needs to take charge and help the process stay focused on the big picture, which is improving and/or restructuring existing resources and services. FIMRs should not confuse short-term gains with systems change. For example, consider a FIMR program that develops a patient education pamphlet regarding the signs and symptoms of preterm labor as an action. This pamphlet may be an extremely worthwhile short-term action if the CAT also considers that they need to: 1) ensure provider buy-in so that all prenatal providers use the pamphlet to routinely initiate and reinforce this message; and 2) coordinate institutional planning so that triage of the expected increased number of women who would read the pamphlet and report these signs can occur. These actions taken together help ensure that a system-wide plan will be effective and endure over time.



One example of a FIMR CAT has 25 members. These include the mayor and members of the city council, presidents of local hospitals, the director of the local medical society, directors of several local government agencies (the Housing and Redevelopment Authority, social services, the schools), the local Commissioner of Health, the CEO of the managed care organization, and representatives from the Chamber of Commerce, the state Resource Mothers program, the state Maternal and Child Health program, a military parenting program, the perinatal data unit, the state Child Abuse Prevention Services, a family member who represents the local bereavement support program, the Urban League, the local March of Dimes chapter, the Kiwanis Club, the community health center advisory board, the AME Baptist Church and the Hispanic health services coalition.



Lessons Learned

Think outside the box! Today, there is a place at the table for truly diverse community partners who might not usually be associated with the FIMR CAT.

For example, parks/recreation departments, faith communities, educational institutions, libraries, big businesses, small businesses, community-based organizations, tenants' associations, artist schools, or co-ops all can potentially help create community change. The more diverse the team, the more action is possible.



Experience tells us that many communities already have a functioning group that has the characteristics to fulfill the role of the CAT, such as a prenatal/perinatal regional consortium, a community advisory board, a mayor's or county executive's blue ribbon panel on infant mortality, a Healthy Mothers, Healthy Babies Coalition, etc. In these situations, the CRT would report its findings to that existing group with the understanding that that group would work to create the change. It is most important not to form a new and separate FIMR CAT unless no other comparable group exists in the community. The members would certainly overlap and be asked to do much more work. For that reason, the team members may then give less than optimal attention to FIMR.

Given the strong working relationship between the CRT and the CAT, some CRT members may also be members of the CAT (e.g., Commissioner of Health, Director of Social Services, etc.). In addition, some members of the CRT may rotate onto the CAT after several years of service and vice versa.

The CAT Orientation

The person chairing the CAT meetings must set the tone for overall community collaboration. The chair may be the director of the FIMR lead agency or another individual. Ideally, a chair should be chosen who is knowledgeable about and skilled in dealing with diverse groups, is non-partisan and is well respected by all as a community leader.

Members of a new CAT will need time to become acquainted with the FIMR goals and objectives, to become familiar with their role and responsibilities, and to become comfortable with one another. The first team meeting usually occurs three or four months after the first CRT meeting and should be devoted solely to orientation. Activities for this meeting are somewhat similar to the CRT orientation meeting and should include the following:

- Give each team member a packet of information. This should include a brief description of the FIMR program, program mission statement, FIMR staff and CRT rosters, the CAT roster, useful articles and other literature, the community resource guide if available and a glossary of technical terms (see Manual Appendices A and B). These materials can be presented to each member in a binder to which additional information can be added over time
- Have team members introduce themselves individually, telling their personal and professional backgrounds and current positions. Have tented name cards available on the table so that members may link names and faces more quickly
- Review the specific objectives for FIMR and describe how the CAT will carry them out. It may be a good idea to give team members the introduction section to this chapter. Some FIMR programs ask the CAT members to



sign a pledge detailing the ground rules or norms that the team will abide by.

- Describe how the case findings are developed by the CRT and how the CAT develops action plans based on these findings and generally approaches implementation of the actions

At this first meeting, every effort should be made to ensure that the team members are comfortable and relaxed. Depending on the time of day, refreshments or a light meal may be served. The seating arrangement for CAT meetings helps set the tone of cooperation and sharing for this meeting as well as subsequent ones. Chairs should be arranged around a meeting table so individuals face each other and can readily begin a dialogue.

CAT Meetings During the First Year

However a note of caution: During the first year, it is important not to let the momentum of the CAT flounder while waiting for the first annual review of cases to be completed by the CRT. The sequence described below seems to work best:

To avoid losing momentum and community support, an enthusiastic CAT typically develops complementary FIMR activities that will assist them at the end of year to begin developing their informed action plan. For example, as a first activity, many CATs have taken time to further expand the community resource guide, which had been originally drafted by the FIMR program staff for internal use (see p. 17–18). The CAT may familiarize themselves with community resources, identify striking gaps in services or resources, mobilize or establish additional culturally relevant resources for the community and subsequently circulate the revised directory of services and resources to the entire community. The Directory will be an important contri-

Fetal and Infant Mortality Review Community Action Team (CAT) Norms/Ground Rules

1. The Carroll County Fetal and Infant Mortality Review CAT includes dynamic community leaders such as public and private non-profit agency heads, business owners, public health professionals, health care providers, community members and others interested in and able to take the lead to actively implement community specific, culturally competent actions that will lead to healthier mothers and babies.
2. All CAT members will strive to serve in a capacity which meets the Mission of the FIMR program, with strict attention to professionalism and respect in working with other team members and community groups to implement change.
3. All CAT members will agree to serve a 2-year term with the option of extension of that term of office.
4. The Carroll County Health Department will apply for and administer a grant from the Center for Maternal and Child Health of the Maryland Department of Health and Mental Hygiene. The Health Department will also supply to the CAT or ensure the presence of the FIMR Coordinator and a Meeting Facilitator.
5. Meetings will start and end on time and will be held quarterly on the first Friday of the month unless otherwise designated by the FIMR coordinator. All meetings will be held at the Carroll County Health Department, 290 South Center Street, Westminster, MD 21157 from 12:00 to 2:00 with a light lunch provided.
6. Meetings will be facilitated to ensure that:
 - all members will listen respectfully and be tough on ideas, not team members
 - every participant has the opportunity to speak and that one person speaks at a time
 - nominal group process will be used to resolve difficult decisions
7. Each team member must pledge to work actively to implement annual changes in service systems and resources for women, infants and families.
8. Each team member must pledge to participate in developing the annual FIMR report and present the report findings back to their agency, as well as to other similar agencies that may be appropriate.

Signature: _____

Date: _____

Adapted from: Carroll County MD FIMR



Lessons Learned

Some FIMR programs have waited to convene the CAT until a full year after the CRT has been meeting and the CRT has produced its first formal recommendations. While the idea may be appealing on some levels, in practice, this strategy generally has not worked very well. The few programs that did wait have indicated that they tended to lose the broader community support and commitment in that interim. The link between the reviews and action weakened, the CAT became an after thought or was never set up properly and the opportunity for real systems change was decreased. Rather than go down this less successful road, experience tells us that it seems to work better if the CRT and the CAT teams are both set up and working in tandem during the first year of the program.



bution to agencies, counselors and providers and becomes the CAT's first successful action.

About four months after the orientation meeting, a second CAT meeting is usually held (eight months after the CRT began its reviews). At that meeting the CAT can receive an interim report from the FIMR Director. This report may include information about development of the Resource Directory, any survey results or general community forum feedback or standard information about the ongoing CRT process, e.g., number of meetings held in the time period, number of hours spent in review, number of cases reviewed by age at death (fetal, neonatal, postneonatal). CRT case findings are generally not included in these interim reports to avoid premature response on the part of the CAT.

The next meeting would be scheduled 4 months later (at the end of a 12 month period of CRT case reviews). By this time, the CRT

will have conducted their total review of all cases occurring in the prior 12-month period (or a pre-determined subset of them), analyzed the findings and prepared their recommendations to present to the CAT.

Subsequent CAT Meetings

In subsequent years, the CAT continues to receive a formal CRT summary of the findings and recommendations of all of the cases reviewed in the prior 12-month period. In response, the CAT prepares an action plan. On an ongoing basis, the CAT generally meets quarterly to report on and discuss the progress of implementing their agreed-upon action plan. At the end of each year, the CAT produces a report for the larger community about progress made and plans for the future year. As the process continues over the long term in the subsequent years, these meetings provide an opportunity to review the progress

Lessons Learned

Some community oriented CATs are also setting up and convening a series of Community Forums or agency community boards to talk with the broader community about maternal and infant health issues and concerns. The team can then use that input to help them begin their action agendas with a better understanding of how to maximize a link between the community's priorities and the FIMR findings. The CAT will then be able to begin their action agenda starting at the level *where the community is*.

Other CATs have developed and circulated a provider questionnaire to elicit their knowledge, attitudes and beliefs regarding causes of infant mortality, barriers to care or other issues. FIMR programs have said that comparing and contrasting these initial survey results with future findings of actual case reviews has been very useful.





of previous successful actions that have been implemented by the CAT, and to celebrate these achievements.

Translating Recommendations Into Actions

Following the annual receipt of recommendations from the CRT, the CAT is then responsible for ensuring that proposed recommendations are translated into local action. The CAT must decide who will do what, when and with what resources to improve services and resources for families.

The CAT generates their annual action plan by identifying a series of actions and a plan for achieving them. Over the years, the CAT must compare and contrast new findings with previous findings and determine if the needs of the community are changing. If so, the CAT must decide which actions should be added or altered to meet them.

Creating the Action Plan

The CAT works through several steps to create a succinct action plan:

1. Develops a list of actions or interventions responsive to the issues. This involves considering a range of actions (see next section), taking into account prior recommendations and actions, refining the CRT recommendations if necessary and/or including additional action strategies. Ideally, the plan should be:
 - Limited to a reasonable number of actions
 - Able to specify a person/agency that should be accountable for the action
 - Realistic in terms of resource requirements
 - Time-framed: short term (less than one year) or long term (more than one year)
2. Prioritizes the actions, as needed. Occasionally, the ideas for improvement may exceed

Lessons Learned

In recent years, some longstanding CATs have discovered it is also important to pay special attention to what has been accomplished in the past and keep track of successful FIMR systems changes to see that they are sustained. In effect, FIMR programs become the “historians” of past local systems change. FIMR programs have found to their dismay that sometimes new local health and human service policy makers may not know the reasons for a previous intervention and unwittingly discontinue it. For example, in one local community with high rates of late or no prenatal care, a special walk-in system for new prenatal patients was implemented. All high-risk patients were seen the day they presented and all others were seen within five business days. After about a year, the majority of prenatal patients were seen in the first trimester. At that point, a new hospital administrator was hired. She came to the conclusion that since there was no problem with late entry, the special walk-in service was not needed and that service was discontinued. Within the next two years, the rates of late or no prenatal care returned to the previous high levels. In this example, a local FIMR program able to track their system changes could have pointed out what the past situation was and why an existing service system was still important, and thereby possibly have prevented that unfortunate decision.



the resources and capacity available for the year and priorities have to be established.

3. Formulates a simple workplan for achieving the actions (see p. 130–132). In order to move forward on their priority actions the CAT also needs to determine:
 - A CAT team member/subgroup who volunteers to be responsible for overseeing the action
 - A practical means to check the ongoing status of the activity



Lessons Learned

The CAT most always focus on the taking the CRT's specific case review findings and recommendations to action. CATs that disregard the CRT's findings and recommendation and instead go off on a tangent to implement another unrelated action proposed by an out spoken member(s) will be divided in their efforts and usually fail to produce any meaningful systems change. Many times, FIMR programs that have fallen into this unproductive pattern of operation have not sustained their activities.



Categorizing FIMR actions

Some FIMR programs report developing an array of descriptive categories for identifying and grouping their actions. Doing so serves as a reminder to think broadly about the variety of strategies to employ. In addition, consistently grouping FIMR actions into more descriptive categories may help the community better understand the work of FIMR. An example of FIMR program actions using one classification scheme is displayed on 117–118. (Note: Other FIMR groupings and actions are also possible and this listing of FIMR actions is not limited to these examples.)

Prioritizing FIMR actions

All CATs face the tough decision of identifying which of the many recommended actions will have priority for implementation. Use of group techniques such as nominal group process and the likelihood/impact matrix for prioritizing actions may assist the overall process (see p. 129). Additional ideas communities should consider in prioritizing their decisions include but are not limited to the following:

Building on Existing Initiatives. Whenever possible, the CAT should choose actions that can build on the foundation of existing com-

munity services and resources. Building on existing initiatives helps ensure that actions can be sustained over time and that the FIMR process is integrated into the existing community infrastructure. This means that the CAT must be very knowledgeable about a wide range of available services and resources in the community chosen for FIMR and the larger surrounding community.

For example, a CAT choosing to put forth smoking cessation strategies for pregnant women initially could not identify any resources to support this action. Several team members pointed out that their community had a local American Lung Association (ALA) who might help. Indeed, when asked, ALA was willing to conduct an ongoing series of smoking cessation classes for pregnant women free of charge.

Linking Community Action to Population-Based Information. The process of finalizing an action plan can benefit from a review of community-specific vital statistics (population-based) information. That way proposed actions based on case findings can be readily linked to similar problems documented in the larger population, if present. For example, if infant death rates due to car injuries in a community implementing FIMR are higher than the state rate and the CRT found that in all infant car accident cases reviewed the car safety seats were not properly installed, the CRT might propose an education campaign for parents on installing car safety seats. Then, CAT actions targeted to infant car safety seats' installation would be consistent both with case findings and data on vehicular injury deaths to infants. Armed with this information, the CAT may then assign the proposed action a higher priority.

The other suggestion is to have a basic understanding of clear-cut socio-behavioral problems already identified in the literature that influence



FIMR Action Categories

Community-Based Education

These actions address messages that need to get out to the public. Selected FIMR program actions include:

- | | |
|--|---|
| <ul style="list-style-type: none"> ■ Conduct a media campaign to encourage early and continuous prenatal care ■ Conduct a media campaign to promote SIDS risk reduction ■ Conduct a media campaign to promote family planning or STD screening ■ Conduct a media campaign to address disparities in infant health ■ Enhance the local March of Dimes Prematurity Campaign | <ul style="list-style-type: none"> ■ Promote breastfeeding through education, training or advocacy ■ Hold a town health fair ■ Convene a FIMR town meeting ■ Develop culturally relevant health education materials ■ Publish an annual FIMR report ■ Publish a FIMR newsletter |
|--|---|

Professional Training

These actions address specific training needed by health providers, service providers and agency representatives. Selected FIMR program actions include:

- | | |
|--|---|
| <ul style="list-style-type: none"> ■ Conduct provider training on prematurity/pre-term labor management ■ Conduct provider training on use of screening tools (e.g., substance use, domestic violence, etc.) ■ Implement cultural competency training for providers | <ul style="list-style-type: none"> ■ Implement SIDS training programs for first responders ■ Develop a community resource directory for providers ■ Implement bereavement training for pastoral or other professional counselors |
|--|---|

Service System Improvements/Linkages

These actions address needs regarding service system components and improvements in linkages or communication between components. Selected FIMR program actions include:

- | | |
|--|--|
| <ul style="list-style-type: none"> ■ Develop a 24/7 prenatal hotline ■ Eliminate a duplication of MCH services ■ Eliminate a gap in family planning services ■ Improve transfer of prenatal records for availability at delivery | <ul style="list-style-type: none"> ■ Improve referral patterns among agencies ■ Implement “one-stop-shopping” prenatal care ■ Develop public transportation routes to MCH services ■ Increase public safety around MCH service sites ■ Develop a 911 system |
|--|--|

continued on next page



FIMR Action Categories (Continued)

Organizational Practices

These recommendations request that agencies consider making an internal change in their practices or protocols. Selected FIMR program actions include:

- | | |
|---|---|
| <ul style="list-style-type: none"> ■ Initiate or expand public health case management ■ Expand hospital quality assurance standards ■ Decrease response time of emergency vehicles ■ Expand services to homeless women and children ■ Expand services to pregnant substance abusers ■ Enhance services to bereaved families | <ul style="list-style-type: none"> ■ Expand family planning services ■ Implement standardized prenatal risk assessment ■ Improve cultural competency protocols ■ Implement screening for domestic violence ■ Implement screening for postpartum depression |
|---|---|

Policy/Advocacy

These actions address the political body that has the ability to make policy change and take action. Selected FIMR program actions include:

- | | |
|--|--|
| <ul style="list-style-type: none"> ■ Initiate a mayoral or governor's proclamation of a day or week promoting MCH ■ Report FIMR findings to the mayor, county executive and/or other officials on an annual basis ■ Include the mayor or county executive as a FIMR community action team member ■ Invite the mayor, county executive or other elected official to chair a FIMR town meeting ■ Invite the Mayor or County Executive to contribute to the FIMR annual report | <ul style="list-style-type: none"> ■ Enact regulations to streamline MCH Medicaid application process ■ Institute a Mayor's Task Force on Domestic Violence ■ Report the FIMR findings to the state Maternal and Child Health program director ■ Promote and develop a policy to ban smoking in public buildings ■ Develop local or state legislation |
|--|--|

Individual Knowledge and Skills

These actions address the approaches to increase individual knowledge and strengthen individual skills in the community. Selected FIMR program actions include:

- | | |
|---|---|
| <ul style="list-style-type: none"> ■ Conduct infant car seat installation checks ■ Go into the home to teach parenting skills ■ Go door-to-door to distribute SIDS risk reduction messages | <ul style="list-style-type: none"> ■ Conduct home infant safety checks ■ Develop a mother-to-mother parenting support program ■ Develop a mother-to-mother bereavement support program |
|---|---|

Adapted from: Humboldt County (CA) FIMR Program, and the NFIMR Directory summary and Reference (4)



health outcomes for women, infants and families. It is well known that maternal smoking is one of the most preventable determinants of low birth weight and increases the risk of stillbirth. Studies also show that passive smoking increases the infant's risk of respiratory infection and is associated with increased incidence of SIDS. If the CRT review of cases documents high maternal tobacco use and infants' exposure to second-hand smoke, then CAT actions related to smoking cessation strategies would be consistent with findings both from the cases as well as from the scientific literature.

Taking Stock of the Political Reality. Taking a totally different approach, political analysts like to say that politicians, more so than scientists, civil servants or advocates, shape policy (a compelling reason to involve local legislators on the FIMR community action team). According to one expert, those actions that surface and are implemented by politicians meet several criteria: the actions are technically feasible, the actions fit with the dominant community values, the cost is reasonable, the political support for the action is high or opposition the action may encounter is low. (2)

Therefore, the CAT members must be politically astute and ever ready to seize all opportunities to promote their chosen actions when they emerge in the political arena. On the other hand, the CAT members might also need to ask whether proposed actions make sense in the local or state political climate and, of course, whether that answer needs to deter them from their proposed course.

Relying on Common Sense and Community Wisdom. What if the CAT members decide that an action recommended by the CRT should be pursued even though it may be very difficult to achieve? If their local FIMR program is configured to include community

legislators, leaders, services providers, advocates and consumers and is reviewing comprehensive case reviews with home interviews, they can be sure that they are looking at the big picture of service systems and community resources in their community. The team members should be confident that the FIMR process is an effective perinatal systems approach that can identify systems failures and instigate the appropriate actions needed to correct them.

Grouping people for action

By having the right decision-makers on the CAT committee, some actions that might have taken an individual agency or provider group an extended period to accomplish can be initiated in minutes around the CAT meeting table. This quick start to the action can be very characteristic of FIMR, for example:

The CAT is reviewing a CRT recommendation that suggests something needs to be done to facilitate Medicaid enrollment for pregnant women and that this problem seems to have been at least partially the reason for some women entering care late or not at all over the past year. A CAT member involved with the Medicaid program says "Continue with the other recommendations, let me make a call and follow-up on this now." The member comes back in five minutes and reports that an expedited eligibility system is, in fact, in place, explains how it works and gets additional constructive feedback from the CAT members on how best to make that system responsive to the needs of pregnant women and their providers.

Other actions will be much broader in scope and may take several years to accomplish. Larger-scale activities also need to be handled more deliberately. For example, one local FIMR developed a common psychosocial assessment form for use by all caregivers and institutions that



provide prenatal care. Several meetings were held to discuss the proposed form and the protocol for its use with all prenatal care providers and institutions. FIMR provider and institutional team members worked slowly and carefully over a period of two years to ensure support and to obtain administrative approvals for implementation of the proposed screening tool.

There also may be situations for which the CAT creates a subcommittee of the CAT to move specific actions or convenes an issue-specific task-force. This latter situation can occur in instances where the issue requires expertise not available on the CAT.

Lessons Learned

A danger to avoid in any community collaborative effort such as FIMR is calling only on the most reliable and productive CAT members who volunteer again and again. While it is tempting to use these members repeatedly, the team not only will exhaust the members who volunteer but also marginalize the other members who do not volunteer. An effective team leader can encourage a fair sharing of the work, thus motivating wider support, enthusiasm and commitment. (3)



Characteristics of Effective FIMR CATs

FIMR programs and their CATs that have functioned successfully for multiple years demonstrate a number of characteristics.

Address a Wide Range of Community Actions. (4) Rather than choose a single focal issue for action, longstanding FIMR programs can point to a wide array of issues that they have identified and a comparable range of activities they have accomplished. They are flexible, capable of developing an action agenda on many different fronts at the same time and able to enact plans that change over time, as well.

How do FIMR programs have the energy to identify so many issues and take action on numerous different fronts at once? The group motivation and passion for the betterment of woman, infants and families creates the momentum. A sentiment expressed by FIMR leaders suggests that the interaction among diverse community participants generates ideas for action that exceed the imagination and influence of an individual provider or agency.

Some FIMR programs also divide into subcommittees to move multiple actions forward. Subcommittee can be standing or ad hoc. Standing committees have been created to address issues that continue to confront the CAT or particular types of strategies. FIMR programs should recognize that selection of subcommittee themes, if desired, depends on the particular circumstances and issues of the community. One FIMR program established standing subcommittees on teen pregnancy, domestic violence, professional education, community education, legislation and community advocacy. Another had six subcommittees directed toward preconception issues, access to care, adequacy of care, perinatal social support, infant safety, child care, and perinatal grief and bereavement counseling. FIMR programs utilizing standing committees should periodically assess their continuing need for attention to the specified topical areas.

Ad hoc committees form to undertake a specific action issue and dissolve once that issue is satisfactorily addressed. One FIMR program had a special ad hoc subcommittee dedicated to find ongoing support to bring a pediatric pathologist to their community. As soon as they were effective in getting that physician on board, they disbanded.

View Improving Services and Resources as a Continuing Journey. (4) Long-lasting FIMR programs have all come to embrace the fact



that improving service systems and community resources for women, infants and families is not a one-time job. Rather than becoming discouraged that a problem that has been identified cannot be addressed fully in one single stroke, these programs realize that the most meaningful change frequently occurs a bit at a time. FIMR actions accomplished in one year often become the basis for building enhanced improvements down the road. A new FIMR action may advance and expand the previous actions.

Securing resources and saving costs

The CAT must come to the table being aware that all proposed FIMR actions will require resources. Resources can mean identifying staff, volunteers, products or services that can be leveraged for the good of the community or donated in-kind as well as allocating existing local dollars or generating new funding sources. For each action that the CAT proposes for the community, members must think about what kind of resources are needed and where they can be secured. In these days of diminishing financial resources, it is important to ask local companies and organizations, and other entities viewed as community assets, to get involved in the action, including:

- Local March of Dimes chapters
- Networks of charitable organizations focused on communities
- Community-based foundations
- Pediatric and obstetric professional groups, medical societies or academic institutions
- Hospitals and MCOs
- Local businesses
- Local schools, churches, libraries and community leaders

Besides pulling in additional dollars, in-kind contributions and services to implement

FIMR actions, the CAT should actively look for opportunities to produce some cost-saving solutions for problems identified. For example, communities tell us that the FIMR review of cases is one of the most successful ways to pinpoint duplication of services as they relate to individual families. Upon learning of this duplication from the CRT, the CAT is in a unique position to reason together and implement potential interagency partnerships or other strategies among their own members, as well as in the broader community. Such strategies will make better use of existing local resources, eliminate duplication of efforts and save local dollars. These actions are very compelling to policy makers and business leaders.

Costs of FIMR actions/interventions are not usually borne by the FIMR program. Typically, the CAT mobilizes agency, institutional and community policies, programs, resources, capital and/or services to accomplish proposed changes.

Lessons Learned

Costs of FIMR actions/interventions are not usually borne by the FIMR program. Typically, the CAT mobilizes agency, institutional and community policies, programs, resources, capital and/or services to accomplish proposed changes.



Monitoring the Progress of FIMR Interventions (Also See Chapter 8)

Critical to the FIMR process is the notion of assessing the status of proposed actions to ensure their implementation and securing information about system change in the community as feedback for the process. The continuous nature of the case review process provides a means for ongoing monitoring and feedback; however, it is up to the members



of the CRT and CAT (with assistance from FIMR staff) to make this happen.

Examination of new cases over the long term by the CRT can shed light on whether a system or resource problem has been resolved, and reveal that new action has indeed been incorporated into systems of care. In the same vein, the CAT will need to check periodically on the extent to which they are able to obtain the desired information for their quarterly updates on pending actions. It is anticipated that input from the members on the CAT who represent the most important systems for women, infants and families will make this possible.

FIMR programs are creative and the additional monitoring strategies they use take some different forms. Some programs have developed an anonymous survey method to check on status of an action. For example, one FIMR program assessed the presence of bereavement services for families in hospital-based maternity services by distributing an anonymous questionnaire (in a self-addressed, stamped envelope to avoid inadvertently getting an answer back in an envelope with identifiers, such as a hospital logo). Program staff were subsequently able to report the percentage of hospitals offering bereavement services as a result of the FIMR proposed action without revealing hospital-specific performance. A caveat: Monitoring FIMR actions should never mean that FIMR staff or CAT members single out specific providers or institutions for censure. General principles related to confidentiality apply to this component of the FIMR process as well as to review of cases.

Another strategy FIMR programs recommend is that the CAT try to incorporate monitoring for selected actions into periodic community needs assessments (such as those conducted by the local health department) whenever possible. In this way, the FIMR monitoring

process becomes a part of the larger community assessment process.

However, there is still work to do to achieve a system for keeping track of actions in progress. As part of the national FIMR evaluation, FIMR Directors/coordinators were asked about monitoring the implementation of their four most important recommendations (in the evaluation they were required to identify the four recommendations they felt were most important). Of the 231 recommendations reported overall, slightly more than half were monitored formally (i.e., specified data were collected or structured feedback was sought from involved agencies or individuals), and a small percentage were monitored informally

Lessons Learned

A few FIMR teams have floundered because the CAT assumed that FIMR program staff would take on their work, delegating the staff to look after completion of their proposed actions. This situation causes the team members to lose interest and momentum and the staff to become overwhelmed. More importantly, because FIMR staff cannot broker the large-scale systems change that the CAT members can by virtue of their diverse leadership positions, this role reversal usually spells failure for the local FIMR process. In fact, successful FIMR programs report that their staff have few additional assignments related to CAT activities.

If FIMR staff continually find themselves trying to implement most of the actions proposed by the CAT, staff and CAT members need to meet to understand why this is happening and to resolve this issue. Even if it may mean that the CAT will have to reduce the number of proposed actions, having CAT members take responsibility to move most of the actions forward is always the right decision.





(i.e., assessed by unplanned, sporadic and non-specific communications). For the remaining almost one-third of the recommendations, there was neither formal nor informal monitoring in place. (5)

Role of FIMR Staff

FIMR staff coordinate and schedule all CAT general meetings as well as subcommittee meetings, write the minutes in a timely fashion and assist the CAT in keeping the information in their documents current. The FIMR director or coordinator will work with the CAT to draft the annual report and make sure that all CRT and CAT members have the opportunity to have input into the document. Behind the scenes, the staff may find that they act as facilitators helping to smooth over an occasional misunderstanding between the powerful CAT members.

Recording the CAT Decisions and Progress on Actions

It is important to keep track of decisions about the CAT actions, workplan and subsequent progress. The CAT members responsible for each action can incorporate this information into an informal workplan (see p. 130–132). Some kind of standard document of this type that identifies the responsible person/agency, how the action will be tracked and its status can serve as a practical tool to track progress on the actions and any changes in the plan. Irrespective of the particular style of the form, the important thing is to keep track of the program's decisions, actions and outcomes.

Getting the Word Out

FIMR programs tell us that a key to longevity and success is making sure that their efforts are publicized throughout the larger community. These FIMR programs have

developed ongoing, effective communication with the broader community as a continuing strategy in their CAT action plan. Some savvy CATs have even designated several CAT team members as their standing media subcommittee with the purpose of exploring multiple opportunities to get the word out to local policy makers, funders, providers, the committee at large and the community most at risk for poor outcomes. (4)

Such publicity can:

- Promote broad-based community ownership and pride in the local process
- Help recruit new and diverse team members for the future
- Keep action stories on the community's radar screen over time
- Gain financial support and community buy-in
- Enhance visibility of maternal and child health issues and credibility of the program (6)

Findings from the national evaluation of FIMR document the importance of a broad dissemination plan. Results showed that while almost all FIMR programs disseminated their recommendations to their local and state health departments, less than half of the programs disseminated them to the offices of state and local officials (e.g., governor, mayor, county executive, city or county council member). However, the most disturbing finding was that not many community members outside of the teams knew about FIMR's actions to improve service systems. (7, 8)

FIMR programs can utilize a variety of communication tools; however, no one communication strategy works for every person or entity. The CAT needs to figure out who it is the program wants to reach, what information would be important to them and the best way to reach them



(see p. 133) Suggestions for written reports, presentations, etc. are described below. Additional information on communication tools and techniques can be found in the NFIMR document, *Sustaining the FIMR Program: A Toolkit*, accessible at www.nfmr.org. (9)

Lessons Learned

Circulation of FIMR recommendations and successful actions to the public is a CAT responsibility. Activities to publish FIMR successes are very important to sustaining FIMR. A local community cannot rally around a FIMR program that no one knows about or appreciates.



Writing an annual FIMR report for the community

On an ongoing basis, the CAT is responsible for enhancing the credibility and visibility of issues related to women, infants and families within the broader community. The most effective strategy identified by FIMR programs is to prepare and publish an annual report detailing findings, actions proposed and progress to date. It is important to share the results with a number of audiences, such as the community at large, professional groups and agencies, business leaders, elected officials, and funders.

Today some FIMR programs are developing power point presentations as their annual report, in lieu of a written document. Regardless of report format, for best results, the reports should be customized to suit the audience. The depth and breadth of information will vary with the audience and the purpose for which it is being shared. It usually is advantageous for FIMR reports and recommendations to be sent to the state Title V director level, as well.

In practice, the CAT usually works together with the FIMR program director and staff to draft a report. This document, with each page of the report stamped “draft,” is circulated for review among both the CAT and CRT members and then finalized. The annual report may include the content below as well as any other that the program may choose:

- FIMR program purpose (or community FIMR mission statement)
- Overview of the FIMR process
- Findings including infant mortality trends over time and anything of special concern locally
- Progress to date on actions/recommendations (and any prior years’ if applicable)
- Names of CRT and CAT members
- Acknowledgement of all sources of funding and in-kind donations

Once there is agreement on the final report, any needed adaptations can be prepared. For instance, for the community at large, the report may need to be written at an appropriate literacy level, be reasonably short and visually pleasing. In addition, some FIMR programs have found that concise, one-page summaries of each key recommendation and the subsequent actions taken to implement it may be more appropriate to capture the interest of elected officials.

It is very important to note that the annual report should not be an unpleasant surprise that reflects negatively on any individual or agency. Every effort should be made to present service systems and resources in the community in the best possible light, with suggestions being made for enhancement of existing services or resources.

If recommendations target an agency or service not currently represented on the FIMR teams, the FIMR program director should personally discuss the findings with leaders of that agency



Style #1:

- Issue (brief statement of issue identified)
- Discussion (short description providing explanation for the issue)
- Case vignette (a de-identified composite of several actual cases) illustrative of the problem, if appropriate
- Action(s) proposed
- Time-frame for implementation: short term (less than one year) or long term (more than one year)
- Status of each action (brief descriptions of activities/accomplishments associated with each action; can be listed under each action or grouped following all of the proposed actions)

The following example illustrates Style #1.

ISSUE: Lack of comprehensive child care services

DISCUSSION: Lack of child care services was cited as an important barrier to receiving prenatal care by 40% of the mothers interviewed.

VIGNETTE: Several mothers from different prenatal care sites could not get anyone to care for their children and therefore only went for one prenatal visit. At the visit, the clerks were angry and told them never to bring children to an appointment again.

ACTIONS PROPOSED:

1. Train appointment gatekeepers (e.g., receptionists and clerks) about the importance of their role in encouraging attendance at prenatal appointments. (Short term)
2. In local clinics, work out a system with pediatric services to share child care facilities and offer at least one prenatal clinic after working hours so that a spouse or friend may be able to provide care for children. (Short term)
3. Require that any county approvals for new health clinics or social services sites for pregnant and parenting women include child care facilities. (Long term)

STATUS:

- Hospital and clinic managers agreed to conduct in-service training for personnel working with prenatal patients about the importance of early and continuous prenatal care and customer service approaches
- Local health department has expanded the number of clinics and is offering one prenatal clinic on Thursday evening
- Met with key individuals about requirements for acquiring county approval for a new site and discussed the child care issue

before the report is released. These discussions can become an opportunity to expand the base of support and composition of the FIMR teams. Any service system that is not represented on the CAT and that is targeted for an intervention may be a candidate for inclusion on the CAT, at least on an ad hoc basis.

If FIMR comes to be seen in any way as an antagonist in the community, rather than as a constructive part of the system, its effectiveness, as well as its very survival, are imperiled. On the other hand, if FIMR can identify a significant problem in a non-threatening manner without singling out any group or person for blame, propose useful actions and be seen



Style #2:

- Problem (brief statement of problem)
- Recommendation (general description of recommended solution)
- Intervention (concise statements of proposed actions)
- Progress (brief descriptions of activities/accomplishments)

The following example illustrates this style (9):

PROBLEM: Lack of referrals to substance abuse treatment, smoking cessation, nutrition counseling and other services was noted in 54% of at-risk pregnant women.

RECOMMENDATION: Care coordination and referrals to specialty services, such as substance abuse treatments, should be made by providers and documented for at-risk mothers and infants.

INTERVENTIONS:

- Increase completion rate of State Prenatal Program screenings
- Inform providers about services available for all mothers through State Prenatal Program, including care coordination, nutrition counseling, breastfeeding, childbirth and parenting education and other community services

PROGRESS:

- State Prenatal Program screens were sent to all providers
- FIMR program staff held meetings with providers to review screening components of State Prenatal Program. The suggestion was made to mail out information again to providers under the Medical Association letterhead

as a part of the solution, then its effectiveness and stature in the community are enhanced.

Formatting FIMR actions in written reports

As described in Chapter 6, the method of detailing FIMR actions is a local decision. Some programs decide to utilize a similar format throughout the process (CRT to CAT to Annual Report) to facilitate transfer of information from one step to another. Two format styles are presented with an example of each.

Actions that indicate sensitive problems

On rare occasions, the CAT might have to deal with findings that seemingly point up significant problems in service delivery. With such findings, the first inclination may be to adopt a negative, blaming attitude and possibly carry that over to a community report. However, in all circum-

stances it is to the FIMR program's advantage to develop constructive solutions that do not in any way demean or undermine the credibility of local services or providers. Instead, every effort should be made to couch the need for improvement in terms of educational actions that suggest enhancing provider skills or service delivery protocols. The confidentiality of providers and institutions should be maintained. For example:

ISSUE: Lack of awareness about cultural norms and beliefs of clients seems to be a barrier to client access to family health care services.

ACTION PROPOSED: Establish a series of training programs for family health care providers that explores the new skill-building strategies for working with culturally diverse populations.



Notice in this example that the following were carefully not mentioned: the type of professional groups (pediatric or obstetric service; or nurse, physician or social worker professionals, etc.) or the names of individual providers; the type of institution (hospital, clinics or private office, etc.) or the names of individual institutions. Even if individual institutions (e.g., hospitals) are targeted, their names, especially if there are only one or two, are best not mentioned, for example:

Encourage hospitals that serve our community to expand their quality assurance programs to include patient satisfaction questionnaires or focus groups.

This wording makes it likely that the CAT could have meant not only the one local hospital, but also the referral tertiary care unit two counties away.

Finally, on a very rare occasion, the CAT may carefully weigh all the options and decide that the best course for a serious and extremely sensitive problem is to work with one or two agency members to try to effect change. In this instance, as a first course of action, the CAT may decide to table public reporting of this problem and work quietly behind the scenes to correct the situation.

Writing a FIMR report for funders

In contrast to the FIMR community report, additional program reports may be prepared by the agency sponsoring FIMR for outside FIMR grant funders, other agencies or professionals, or state maternal and child health (Title V) program directors. These reports will typically be more complex and longer than the community report, and will involve other sources of population-based information such as vital statistics and perhaps greater details regarding actions. Formats for funders' reports are usually

suggested by the agency requesting them. It is important that the FIMR program staff incorporate basic information about the FIMR process and prominently describe the successes of their local teams into these reports. An information-filled report may be a way to encourage wider support from such agencies as state Title V or others.

Presentations and other activities

On a periodic basis and at a minimum, in conjunction with the release of the annual FIMR report, it is important for the CAT and FIMR program to keep key issues related to FIMR findings and actions in the public's eye. An important strategy for enhancing the credibility and visibility of these maternal and child issues within the broader community is to delegate to each CAT and CRT member the task of reporting the findings and proposed actions back to their respective member agencies as well as any others associated with them, such as:

- Local medical society and specialty societies
- Local hospitals or hospital associations
- Professional nursing organizations
- Social services organizations
- Other community services representatives (as appropriate)
- District health commissioners
- Local government—elected officials
- Health systems agency
- State health agency
- Community leaders
- Consumer organizations
- Focus groups of consumers
- Business leaders
- Civic groups
- School boards



- Clergy
- Law enforcement officials
- Others, as appropriate to individual communities

Another strategy is to put a copy of the Annual Report on the sponsoring agency's website. The program may also decide to initiate a radio or television appearance, a television public service announcement or a newspaper press release as a means of disseminating its findings. Building a working relationship with the media takes knowledge about different media outlets. More importantly, it takes experience and skill to actively manage these opportunities so that they do not damage the program, but work for its benefit. Locally, experts in the community such as the county public health media coordinator may be very helpful. (9)

Going Beyond the FIMR CAT Action Agenda: Action in the Broader Community

Once the FIMR findings and proposed actions have been promulgated throughout the community through the written report, CAT and CRT presentations and the media, the impact of a successful FIMR program has a wider effect. FIMR programs report that the actions they undertake translate into local accountability and pride and become part of a larger pattern of change. Like "ripples in a pond," the FIMR momentum spreads out into the larger community, for example:

- A philanthropist hears about FIMR findings related to domestic violence from a close friend who attended a Junior League luncheon FIMR presentation and donates a large sum to the women's crisis center.
- The county mental health department professional staff hear a FIMR report from their director and decide to volunteer together to set up an after-hours domestic violence hotline. This hotline later becomes a funded project through that agency.
- A group of staff nurses hears about lack of support for single teen mothers after delivery in a staff report about FIMR findings and devises a system for telephone follow-up and referral, as needed. This system becomes the model of follow-up for all hospitals in the community.
- A physician hears the FIMR report in grand rounds and returns to his/her private practice and designates a staff nurse to act as an ombudsman to see that patient barriers that interfere with compliance are identified and actively addressed before they become problematic.
- A business person, who owns a furniture store, attends a Chamber of Commerce meeting where FIMR actions related to SIDS prevention are discussed and now checks to make sure that every crib sold in his store meets National Safety Council Guidelines.
- A restaurant owner reads a newspaper article about FIMR efforts for homeless families and decides to donate food to a shelter for homeless pregnant and parenting women.

This list could continue. Through the new and locally important information that FIMR provides, the community itself is enabled to own the problem and act through the development of new coalitions, legislative committees, other local organizations or individual actions to improve service delivery and resources for women, infants and families.



Decision-Making Techniques

Ideas to help communities generate and develop recommendations can be found in almost any text that describes group process. The following techniques adapted from work reported by Georgetown University may help some teams finalize and prioritize ideas.¹

1. Nominal Group Process

The Nominal Group Process is a structured method of airing all of the issues and conducting a weighted vote to identify the priorities of any group. It requires a skilled facilitator, a recorder and a flip chart. The facilitator takes the group through the following steps:

- Each individual identifies, in writing, 3–5 needs or problems that s/he believes are the most important for the group to address.
- Each person shares one item from this list until all ideas are recorded on the flip chart. No discussion should be allowed during this time
- Next, each item is clarified, as needed, and with permission of the group, items deemed duplicative can be removed and some items may be grouped. Each item or item cluster is numbered
- Each person votes for the five items believes are most important—the most important of the five is assigned a 5, and the least important is given a 1. After the ballots are collected, the sum of the priority scores for each item is multiplied by the number of times that item was selected. For example, if item #1 was selected three times with a score of 5, a 2 and a 1, the sum of the priority scores (8) would be multiplied by three (the number of times selected) to give a total score of 24 for that item. Items are ranked on the basis of the total scores they receive

Once the group has agreed on the key issues, based on the top five scored items, these items can be rated in terms of likelihood of success. Starting with an item that has the greatest possibility of success is usually important for the morale of the group

2. Likelihood/Impact Analysis

Likelihood/Impact Analysis is a way of looking at the barriers to recommendations and evaluating the likelihood of removing that barrier and the impact of resolving the particular problem on the service delivery system. The process proceeds as follows:

- Brainstorm all of the barriers to the recommendation
- Clarify each barrier and consolidate items

- Rate each recommendation on the list for two things. First, the likelihood that the barrier could be resolved, and second the impact that the recommendation would have on reaching the team's goals. (1 = Low; 4 = High)

Example:

ITEM	LIKELIHOOD				IMPACT			
	1	2	3	4	1	2	3	4
Implement a new prenatal care clinic on Maple Street								

- Total all responses for the likelihood of each item (note the number of respondents for each item)
- Total all responses for the impact of each item (note the number of respondents for each item).
 - Calculate the mean score for the likelihood of each item
 - Calculate the mean score for the impact of each item
- Write the action item identifier (number, letter) into the appropriate cell of the Likelihood/Impact Matrix
- For action planning, select recommendations that have a high likelihood of resolution and that will have high impact on reaching the team's goals
- Any need or problem that has been deemed low likelihood for resolution will probably require more time for completion. However, if the same need is of high impact, the group may choose to work on this activity, with the understanding that resolution may take more time

LIKELIHOOD/IMPACT MATRIX

IMPACT	HIGH	4					
		3					
		2					
	LOW	1					
		LOW	1	2	3	4	HIGH
LIKELIHOOD FOR RESOLUTION							

¹Adapted from: Striffler N, Coughlin PA, Magrab PR. Communities can workbook series: Developing collaborative services for children. Washington (DC): Georgetown University Child Development Center; 1994.



Community Action Team Work Plan

Goals: The goals of the community action team (CAT) are to 1) receive the findings and the recommendations from the case review team; and 2) develop an action plan based on those recommendations and implement the actions. The overall goal of the action plan should be to enhance the health and well-being of women, infants and families in your community by improving the resources and services systems available to them.

Purpose: The CAT is composed of two types of members: those who have the political will and fiscal resources to create large-scale systems change, and those who can define a community perspective on how best to create the desired change in the community. The process of the CAT should include:

- Prioritizing recommendations. Based on the findings and recommendations presented by the case review team and review of vital statistics data, what are the overarching needs present in the community? Are there any needs particular to one or only a few cases that are so pressing they must be addressed at once?
- Developing an action plan. How can the recommendations be addressed? What organizations represented at the CAT have jurisdictions over these issues? What issues are outside the jurisdiction of the entities present? Who else should be involved?
- Setting a time frame. Action time frames may be short term (less than one year) or long term (more than one year)
- Maintaining some type of workplan for action. Each year selected delegate(s) from the CAT should volunteer to complete and update the action plans as they develop.
- Monitoring progress. Team members report to the team on progress of implementing actions at each quarterly meeting
- Informing the larger community about the need for action and FIMR successes. When and how will the community hear about the plan for improvement?
- Keep track of successful ongoing FIMR systems changes to see that they are sustained, as needed
- Determining if the community's needs are changing over time and deciding which actions should be added or altered to meet them. How do current findings build on past activities? Are the communities needs changing? Or are old problems recurring?



Interventions and Workplan

For each community action identified, complete a brief workplan such as the one found on the next page. Identify the action steps necessary to effect change, the person or agency that will be responsible for implementing these action steps, the timeline for action, the resources required or needed for action and leave space to document the status of the proposed action at later meetings.

FIMR Community Action Team Work Sheet

Action:

Action Steps	Person/Agency Responsible	Time Line	Resources	Status of Proposed Action
1.				
2.				
3.				
4.				
5.				

Adapted from: a FIMR/HIV CAT workplan developed by CityMatCH, NFIMR, the American College of Obstetricians and Gynecologists (ACOG), the Maternal and Child Health Bureau at the Health Resources and Services Administration, and the Division of HIV/AIDS Prevention at the Center for Disease Control and Prevention and is currently being piloted by the City of Detroit, MI Department of Health and Wellness Promotion, the Northeast Florida Healthy Start Coalition, Inc. in Jacksonville and Family Services of Greater Baton Rouge, LA. This project is supported by cooperative agreements 1U65PS000813-01 and #U50/CCU300860 from the CDC Division of HIV/AIDS Prevention.

continued on next page



Interventions and Workplan (Continued)

Annual Community Communication

The CAT must document its decisions and successes and bring this information to the wider community on an annual basis. Consider the following questions as you develop a communication plan:

How will team members present the FIMR action plan to their agency?

How will the larger community learn about the FIMR action plan and FIMR successes?

Are there existing community events or forums where FIMR information can be shared?

Past Findings and Actions

Finally, think about prior action plans from this team (refer to meeting minutes, as needed).

What prior actions have been executed and have become successful systems changes?

What prior actions are still in progress?

Are any prior actions tabled because they cannot be accomplished at the present time? Why?

Action Log

Community development experts suggest completing a form such as the one below for each action a program like FIMR accomplishes and filing it along with any program materials developed as a permanent record of program accomplishments.

Briefly describe the following:

1. Issue (why the action was implemented)

2. Recommended Action (include category of action, if use classification scheme)

3. Action Steps (list each activity as it is implemented to accomplish the action; indicate the involved agencies/organizations and date when completed. Attach any materials developed for this action, such as pamphlets, policies, screening tools, training agendas, etc.)

4. Lasting Effects in Community (identify what has happened in the community as a result of the FIMR action)

Adapted from: Community Toolbox. Gathering information: Monitoring your progress. Lawrence (KS): University of Kansas, 2007. Available at http://ctb.ku.edu/tools/en/sub_section_tools_1364.htm. Retrieved May 25, 2007.



Communication Approaches to Community Groups

FIMR program volunteers—Keep them up to date on FIMR activities, findings and problems. Send an annual report; invite to meetings and special events.

MCH leaders—Keep state Title V and local MCH officials in the loop. Invite participation in planning and share findings, system issues and recommendations. Annual report, invite to meetings, preliminary findings as appropriate.

Local physicians and hospital OB unit staff—Keep them apprised about medical-related findings and other system issues. Grand Rounds, articles for medical society bulletin.

Elected officials—Keep them up to date on findings, systems issues and needs. Annual report, invitation to special events, personal briefings.

Businesses—Link improved pregnancy outcomes with the “bottom line.” Share findings and recommendations. Get on the speaker’s list for the Chamber of Commerce and other business-related groups.

Agency directors—Keep them up to date on findings and systems issues. Share problems and search for solutions together. Annual report, invitation to special events and meetings, speakers for meetings, in-service training.

Key community leaders—Share findings, recommendations. Listen for solutions and resources from the community. Look for partners. Invite to special events and meetings, speakers for meetings.

Foundations—Keep them informed of successes and barriers. Annual report, invite to special meetings, Grand Rounds.

Media—Annual report, news releases and requests for coverage.

Consumers—Individuals involved in CRT and CAT carry message to others; identify community “authorities” to invite to meetings and mail updates.

Adapted from: Kerr D, Hutchins E. Sustaining the FIMR program: A toolkit. Washington (DC): National Fetal and Infant Mortality Review Program. American College of Obstetricians and Gynecologists. 1998. Available at www.nfmr.org.

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CHAPTER 8

Taking Stock of the FIMR Process



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Taking Stock of the FIMR Process



Introduction

A key measure of success for most FIMR programs is the community action that they generate. Many FIMR programs also produce an annual report that further describes their progress in implementing successful actions to create systems change and their plans for the future. This report is a program description and to some degree, many FIMR programs think of the report as the opportunity to reflect and take stock of their efforts to date.

Other FIMR programs may need or want to document additional information about what their program has done and describe their value for the community in more depth. This interest may originate from within the program, or more likely, be requested from an external source such as a sponsoring agency or external funder wishing to document program accomplishments.

Armed with additional information from a program evaluation, FIMR programs are able to tell the key stakeholders and the public more about their activities and successes, thereby heightening awareness of the program and encouraging continued support for the program. The feedback can also prompt programs to modify and fine-tune their activities to improve their overall functioning when the findings indicate a need for some adjustment.

It is beyond the scope of this chapter to present an exhaustive commentary on program evaluation or a detailed plan for assessing a local FIMR program. Rather, this chapter offers a number of resources and ideas to assist FIMR programs to think about how they might approach an examination of their program and the contributions they are making. Note that throughout the chapter the terms take stock, assess or evaluate are used interchangeably and relate to program evaluation.

What Is Program Evaluation?

One widely used definition for program evaluation describes the process as

“...the systematic collection of information about the activities, characteristics and outcomes of programs to make judgments about the program, improve program effectiveness and/or inform decisions about future program development.” (1)

Program evaluation takes time and resources. A critical first step for a local FIMR program is to decide what it wants to accomplish with its evaluation and why (i.e., what it wants to find out about the program, how the information will be used, by whom and for what purposes) and what capacity exists within the FIMR program and the agency sponsoring FIMR to implement such an evaluation.

For instance, the focus of the assessment may be to:

- Find out what effects the program is having in the community
- Identify whether the program is meeting its goals and objectives
- Determine how the program components are functioning
- Assess some combination of the above

The reasons or uses for a program evaluation also vary and may include the following:

- Improve the FIMR program's operations
- Expand the community's awareness of the program and build community support
- Improve the program's opportunities for increased funding

If the rationale for a local evaluation is crystal clear, timely and compelling, these program decisions will begin to guide the evaluation



process and methods. If the rationale does not meet the criteria above, the program should think again about the real need for a program evaluation.

FIMR Program Evaluation

In general, evaluating systems-oriented or public health interventions that address fetal and infant mortality (such as FIMR) can be challenging for a variety of reasons:

- Infant mortality is a complex problem, and the mechanisms associated with several of its key contributing factors (e.g., low birth weight, preterm birth) are poorly understood
- Fetal and infant deaths occur infrequently in most communities resulting in the issue of small numbers when doing analysis of rates
- Measuring outcomes of FIMR programs presents the challenges of dealing with the multi-faceted array of community activities and interventions produced by the initiative, and teasing out FIMR's effects from those of other community perinatal initiatives may be difficult
- Unexpected or far-reaching events or circumstances that disrupt or alter health-related services and systems in the community could possibly influence local FIMR efforts to improve services and resources for women, infants and families

In the face of these challenges, how can FIMR staff take stock of their FIMR program?

A key bit of information to start: Nationwide evidence shows that FIMR is an effective perinatal systems intervention.

A national evaluation of FIMR, conducted and reported on by researchers at Johns Hopkins University Bloomberg School of Public Health, has systematically documented that

FIMR is effective. The focus of FIMR on systems of care and identifying gaps in care results in action being taken in a way that interpretation of vital statistics alone does not necessarily promote. Moreover, the presence of FIMR appears to significantly improve a community's performance of public health functions (using essential maternal and child health services as measures) as well as enhance the existing perinatal care system's goals, components and communication mechanisms. Additionally, a heightened performance of public health functions was found in communities where both a FIMR and another type of perinatal system initiative were present. The findings reinforce the concept that FIMR makes its contributions being a part of a system of services. (2–5) (also see Chapter 1)

That said, it is also important to recognize that evaluations done at a national level generally differ in purpose than assessments carried out at a local level. The national evaluation essentially asked whether FIMR as a public health intervention in this country can make unique contributions at the community level. It did not focus on all aspects of FIMR programs and how they function, nor did it ask all of the questions that might be appropriate to determine local impact. However, the national evaluation reports (accessed online at www.jhsph.edu/wchpc/projects/fimr.html) can provide background information and ideas about measuring community-level perinatal systems interventions that a local FIMR program may find helpful when it decides to assess its program. Other resources, some related specifically to the FIMR process and others pertaining to evaluation of generic or other community programs, also have the potential to be useful to local programs and will be discussed later in this chapter.



How should a local program begin?

In preparation, FIMR programs that feel uneasy about the prospect of program evaluation or those desiring a refresher on the subject may want to review several available website resources that explain in detail the overall process for evaluating a community-level program. Examples of website resources include the:

- Community Toolbox at http://ctb.ku.edu/tools/en/part_J.htm
- CDC Evaluation Working Group at www.cdc.gov/eval/
- CDC's Steps to a HealthierUS Cooperative Agreement Program's foundational elements for program evaluation at www.cdc.gov/pcd/issues/2006/jan/05_0136.htm

These websites describe general elements and frameworks for program evaluation, present a “how-to” guide for planning and implementing evaluation activities, provide a practical tool for engaging community stakeholders in program evaluation, clearly distinguish academic research from program evaluation, as well as identify other relevant resources.

Involving stakeholders (including culturally diverse community advocates and consumers) in the process from the start is also key to developing a culturally competent evaluation. Community members should be asked their opinions about the various phases of the evaluation including what they want to find out about the FIMR program through the evaluation.

Overall, what methods and resources can be used?

A variety of methods can be employed to acquire the information needed to address the specific purpose(s), including surveys,

interviews, focus groups, documentation, etc. Selection depends on what information the program is seeking and its sources, the time-frame associated with needed feedback and extent of resources and expertise available for undertaking the task. (6)

With regard to evaluation capability, program staff may want to seek assistance from experts when skilled input is required. On the other hand, they should not underestimate what they can contribute or accomplish through their typical activities (see next section).

Ideas for Assessing the FIMR Program

Keeping track of FIMR program activities and accomplishments

Instituting ongoing mechanisms to document program activities and track accomplishments greatly facilitates taking stock. This may involve building in some time on a periodic basis to summarize information from program records (e.g., CRT meeting minutes, CAT meeting minutes, rosters of team members, etc.) or taking some time to create a system that will allow the program to track recommendations and their implementation. On a day to day basis, the tracking and compiling of some information can be spread out among several staff and become part of their ongoing assignments. The home interviewer could keep track of the number of interviews completed, and the data abstractor could keep track of the number and type of records abstracted and their completeness. A FIMR secretary might be delegated to keep the rosters of the FIMR teams current.

Systematically keeping track of each program action using a standardized form, such as an Action Log (see p. 132), improves the program's ability to document the FIMR action



Insights From Participating On The FIMR Case Review Team

1. Has membership in the case review team benefited you in any way?

☐ YES ☐ NO

Please explain:

2. Have you made any changes in your own practice or in policies/procedures in your institution as a result of your participation in the case review team meetings?

☐ YES ☐ NO

Please explain:

3. Has your understanding of the health and human services available for women, infants and families in your community changed since you became a member of the team?

☐ YES ☐ NO

Please explain:

4. If you had to make one statement about your participation as a member of the FIMR case review team to a team member just getting started, what would you say?

Please describe:

Name (Optional): _____

NB: A FIMR program that uses this form should tell members ahead of time if information they forward would be shared with the public or kept confidential—regardless if the name of the team member is used. The opportunity to fill out the form itself and the team member's signature on the form should always be optional.

Lessons Learned

Keeping a record of FIMR actions over the long run, including retaining actual hard copies or pdf files of materials developed to implement the action (e.g., pamphlets, protocols, brochures, public service announcements etc.) is key to documenting success. Saving this information should be part of FIMR staff activity. When programs operate for many years, these files become the “institutional memory” of the program's successes. For example, even if all FIMR team members and program staff from 15 years ago have moved on, the program itself will have ongoing documentation of what accomplishments have gone before. Failure to keep track of the work of the FIMR program may result in activities being lost or forgotten and be detrimental to sustainability of the program.



agenda and its effects in the community. The documentation would provide a deliberate way to identify changes made to community systems. Information recorded would also allow a program to examine patterns or trends. For instance, a program could determine if only certain types of actions are implemented or if there appear to be barriers for implementation of specific types of actions or among particular community sectors.

Additionally, a CRT that has been reviewing individual cases for 18–24 months may want to document any activities that the individual members have initiated in their own practice, for their professional colleagues or within their agency or institution as a consequence of participating in the FIMR process. This periodic poll of team members may capture further accomplishments that can be shared with the community or in the program's annual report. Of course, in some cases the need for change



could reflect negatively on a participating agency and the team member may choose to keep it confidential.

Using FIMR-specific evaluation tools

In 1997, the 13 California FIMR programs developed a list of qualities they felt were characteristic of long-lasting FIMR programs.

These characteristics still ring true today. FIMR programs can use this tool as a checklist to identify the presence or absence of the qualities and gauge their progress over time. While the checklist does not produce a summary measure of “success,” it can direct FIMR staff to areas of the program they may wish to strengthen (see p. 142). In addition, the program (or its evaluators) can draw on the content in the tool to prepare other types of evaluation instruments.

FIMR programs might also wish to use an additional NFIMR tool, *Fostering Local Community Support and Buy-in—A FIMR Program Checklist*, for an annual review of the various facets of community involvement. Detecting a need for more community awareness about FIMR or more community input to the FIMR process may then prompt the FIMR program to expand its team composition or increase its efforts to broaden community support.

In addition, community development experts say that community programs such as FIMR can benefit from conducting an annual survey to monitor the satisfaction of team members. The FIMR team survey instrument can be tallied and results used as a basis for discussion and planning for future directions and activities with the FIMR sponsors and teams (see p. 143–144).

Fostering Local Community Support and Buy-in— A FIMR Program Checklist

To gauge the community’s awareness of FIMR and promote community buy-in, take a moment to review the checklist below:

YES NO

- | | | | |
|-----|-----|-----|--|
| ___ | ___ | 1. | In the beginning stages of your program, were you able to make adequate time to “lay the foundation” and recruit influential leaders and consumers from key sectors of the community to help plan and build your FIMR program? |
| ___ | ___ | 2. | Does the composition of your team reflect the cultural diversity of your community? |
| ___ | ___ | 3. | Should you recruit additional team members who bring added disciplinary or sector leadership and new points of view to the FIMR case review team? |
| ___ | ___ | 4. | Should you recruit additional team members who bring added leadership, the power to create change and new points of view to the FIMR community action team? |
| ___ | ___ | 5. | Can your FIMR document a positive impact on local problems? Have many successful actions been implemented as a result of FIMR recommendations? |
| ___ | ___ | 6. | Do you use multiple strategies to promote broad community awareness about FIMR’s contribution to improving health service delivery systems and resources in the community? |
| ___ | ___ | 7. | Does your mayor or county executive know about the FIMR program and its successes in taking recommendations to action? |
| ___ | ___ | 8. | Do ordinary people in the larger community know what FIMR stands for? Do they know about actions that FIMR has implemented? |
| ___ | ___ | 9. | Have you identified community leaders and organizations that can bring funding and other resources to help take recommendations to action? |
| ___ | ___ | 10. | Do you make sure to formally say thank you to all community members that have supported the FIMR process in even small ways? |
| ___ | ___ | 11. | Do you make sure to thank your FIMR team members for a job well done and make time to celebrate their successful efforts in taking recommendations to action? |



Qualities of Successful and Less Successful FIMR Programs—A Self-Assessment Tool

More Successful

Successful actions and community impact

- FIMR can document a positive impact on local issues
- Many solutions/changes have been implemented as a result of FIMR recommendations
- FIMR is “hooked into” the community’s power structure
- Policymakers participate in or are accessible to FIMR
- An institutional and fiscal base of support sustains FIMR
- The community takes ownership of perinatal health problems and FIMR process

Successful process

- The program contributes to the community’s capacity for assessment
- FIMR has found problems and created solutions
- People in the larger community know what FIMR stands for and are proud of the process
- The CRT communicates about process and recommendations with the CAT
- FIMR deliberations maintain a good balance between medical, public health and community viewpoints
- Communication among community agencies and institutions improved
- Culturally diverse consumers are involved in the process
- The team finds great value in the maternal interview
- FIMR maintains a strict anonymous and confidential process
- Local institutions contribute to record abstractions
- Both human and fiscal resources support the program

Less Successful

Little evidence of success

- The process stalls at the point of prioritizing recommendations
- Legal aspects of FIMR cannot be resolved
- FIMR cannot externalize findings because of malpractice concerns
- The process stalls at obtaining and abstracting medical record data
- The primary FIMR focus is research or medical review
- Personal or interagency agendas interfere with the program’s development
- The community resists the FIMR process and does not see its value

Adapted from: “Qualities of Successful FIMR Programs,” developed by the 13 CA FIMR programs and Sean Casey, MSW, MPH, former director of the California FIMR Support Program; 1997.



SAMPLE SATISFACTION SURVEY FOR COMMUNITY FIMR TEAM MEMBERS

We welcome your feedback on how well this FIMR team is doing. For each item, please circle the number that best shows your satisfaction with that aspect of the FIMR team. Provide additional comments if you wish.

Your SATISFACTION with the PLANNING AND COMMUNITY ACTION

	very dissatisfied			very satisfied	
1. Clarity of the mission for where the FIMR team should be going	1	2	3	4	5
2. Planning process used to prepare the FIMR team's objectives	1	2	3	4	5
3. Follow through on FIMR team activities	1	2	3	4	5
4. Strength and competence of staff	1	2	3	4	5
5. Processes used to assess the community's needs	1	2	3	4	5
6. Quality of FIMR collaborative actions	1	2	3	4	5
7. Number of systems changes carried out by the FIMR team	1	2	3	4	5

Your SATISFACTION with the LEADERSHIP

	very dissatisfied			very satisfied	
8. Strength and competence of FIMR team leadership	1	2	3	4	5
9. Sensitivity to cultural issues	1	2	3	4	5
10. Opportunities for FIMR team members to take leadership roles	1	2	3	4	5
11. Willingness of members to take leadership	1	2	3	4	5
12. Trust that FIMR team members afford each other	1	2	3	4	5

Comments:

Your SATISFACTION with the: COMMUNITY INVOLVEMENT IN THE FIMR TEAM

	very dissatisfied			very satisfied	
13. Participation of influential people from key sectors of the community	1	2	3	4	5
14. Participation of community residents	1	2	3	4	5
15. Diversity of FIMR team membership	1	2	3	4	5
16. Help given the community in meeting its needs	1	2	3	4	5
17. Help given community groups to become better able to address and resolve their concerns	1	2	3	4	5
18. Efforts in getting funding for community programs	1	2	3	4	5

Comments:

continued on next page



SAMPLE SATISFACTION SURVEY FOR COMMUNITY FIMR TEAM MEMBERS (Continued)

Your SATISFACTION with the COMMUNICATION

	very dissatisfied			very satisfied	
19. Use of the media to promote awareness of FIMR's goals, actions, and accomplishments	1	2	3	4	5
20. Communication among FIMR team members	1	2	3	4	5
21. Communication between FIMR and the broader community	1	2	3	4	5
22. Extent to which FIMR team members are listened to and heard	1	2	3	4	5
23. Working relationships established with elected officials	1	2	3	4	5
24. Information provided on FIMR issues and available resources	1	2	3	4	5

Comments:

Your SATISFACTION with the PROGRESS AND OUTCOME

	very dissatisfied			very satisfied	
25. Progress in meeting the FIMR objectives	1	2	3	4	5
26. Success in generating resources for FIMR	1	2	3	4	5
27. Fairness with which funds and opportunities are distributed	1	2	3	4	5
28. Capacity of FIMR members to give support to each other	1	2	3	4	5
29. Capacity of FIMR and its members to advocate effectively	1	2	3	4	5
30. FIMR's contribution to improving health and human service systems in the community	1	2	3	4	5

Comments:

Adapted from: Kaye G and Wolff, T. From the ground up: A workbook on coalition building and community development. Community Partners, Inc. Amherst, MA: pp 180-183

Examining components of the FIMR process

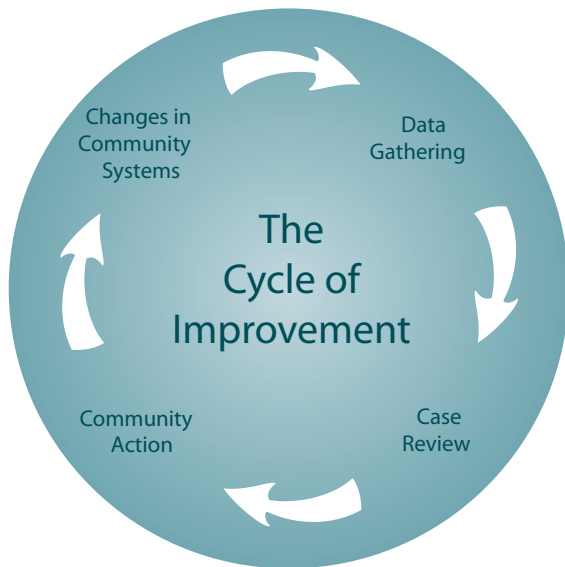
Program evaluators frequently use logic models to guide their work conceptually. Logic models schematically depict the linkages between program inputs, activities, outputs and outcomes. The FIMR Cycle of Improvement provides the basis for development of a logic model.

FIMR programs could collect additional data and information that can be used both to describe the basics of their process and examine its functioning. Programs will find it helpful to pose the questions they want to ask about each step or feature of its process. For example: How many cases did the team review? What proportion of the total fetal/infant deaths in the FIMR program community did the cases reviewed



represent? What actions were implemented? Once FIMR programs identify their questions, it is then appropriate to determine what program information or other mortality review program information will provide the answers. (6, 7)

Ideas for types of information to collect relative to each component of FIMR's Cycle of Improvement follow. Programs may have other suggestions as well. Each indicator on the list suggests a question the program may want to ask.



Data collection

- Cases identified for review—number; distribution by any targeted or specified categories; number and percentage of initiated cases with complete data; number and percentage of initiated cases summarized for case review; reasons for difficulties obtaining data or incomplete case data
- Home interviews—number lost to follow-up, number attempted and percentage of the cases initiated; number and percentage of attempted home interviews completed; reasons for not completing home interviews

Case review

- Membership of the case review team—number of members; distribution by orga-

nizations/agencies represented; distribution by professional background; distribution by race/ethnicity; consistency of attendance; length of team members' service

- Number of meetings held annually; reasons for additional meetings or cancellations of scheduled meetings
- Number of cases reviewed by CRT
- Percentage of the total fetal/infant deaths in the FIMR program community the cases reviewed represent
- Number and types of recommendations proposed by the CRT
- Number and types of recommendations submitted to the community action team annually
- Trends in recommendations identified through case review—changes or not in content or focus of recommendations over time
- Anonymity of cases and confidentiality of process maintained; reasons for any additional measures to ensure anonymity and confidentiality
- Characteristics that enhanced or interfered with CRT process

Note: Much of the above information should be available in the CRT de-identified meeting minutes.

Community Action

- Membership of the CAT—number of members; number and type of leadership roles; distribution by organizations/agencies represented; distribution by professional background; distribution by race/ethnicity; consistency of attendance; length of team members' service; reasons for turnover
- Number of meetings held annually; reasons for any additional meetings or cancellations of scheduled meetings



- Number of recommendations received by the CAT
- Number of recommendations reviewed by the CAT
- Number and types of actions planned by/through the CAT; percentage of recommendations reviewed for which actions were planned; number of particular actions of interest to program (e.g., actions that increase cultural competence in services or health education messages; actions that address health disparities)
- Number and types of actions being implemented by/through CAT; percentage of actions being implemented of those planned
- Number and types of actions fully implemented by/through the CAT; percentage of actions fully implemented of those planned
- Trends in planned actions—content themes, intent of system change; community agency or sector involved
- Trends in fully implemented actions—content themes, intent of system change; community agency or sector involved
- Characteristics that enhanced or interfered with CAT functions or implementation of actions

Note: Much of the above information should be available in the CAT meeting minutes (or could be available in the action logs).

Changes in Community Systems

FIMR programs need time for their program to operate and initiate actions before attempting to measure related changes in community systems. Selection of measures for this category will depend on the issue-driven actions promoted by the program.

Lessons Learned

FIMR programs tell us that attribution of systems change solely to FIMR may be inherently difficult (and perhaps counter productive) in that FIMR is a broad community-based process. By its nature, FIMR involves multiple agencies, institutions, providers, advocates and consumers in every system change that is implemented. FIMR programs wishing to attribute community changes solely to the process should do so cautiously, gratefully acknowledging the contributions of every team member.



Examples of measures might be

- Expansion of needed services available in community— number and type of new services instituted during a selected time period (e.g., past three years); increase in utilization of these services over time; percentage of previously instituted services that are still sustained, e.g., decrease in late entry to prenatal care
- Elimination of duplication of community resources—number of FTEs and/or dollars saved
- Improved linkages among services/facilities—increase in percentage of women who have lost an infant being offered in-hospital bereavement support
- Changes in providers' or agencies' performance—increases in proportion of pregnant women being screened for domestic violence; decrease in length of time to enroll in Medicaid program
- Positive shifts in community issues—declines in sudden unexplained infant deaths in which back sleeping was not employed; declines in fatal house fires in which kerosene heaters were used



Note: Some of the above information might be available in the CAT meeting minutes. It is possible, however, that a program (or its evaluator) would need to take deliberate steps to collect or obtain information of this type (e.g., from vital statistics, anonymous surveys of facilities and agencies, etc.). Other organizations or programs may have collected information that could be used for FIMR evaluation purposes. For instance, a health department that has instituted a community screening initiative following a FIMR program recommendation may subsequently evaluate its effects. These findings could then be used to document system changes that the FIMR program's actions stimulated.

Besides the program elements listed above, there are other activities or features programs might wish to track. Some of these include: mechanisms to disseminate accomplishments (type, frequency of dissemination and to which community members, organizations and leaders); funding or in-kind services (amounts, types or sources, new contributors).

Other qualities related to FIMR structure and linked with improved functioning might

Lessons Learned

A valuable indicator to keep track of is the total number of hours per year that the team members volunteer to review cases and promote community action. The number of hours can easily build up, and represents an asset that legislators and potential funders can appreciate. A FIMR program might ask team members to fill out a simple form at the end of each meeting. A less time-consuming solution might be to ask team members once a year just to estimate the average number of hours donated per meeting. Staff can then multiply the number of meetings/year attended by the team members to tally volunteer efforts.



be assessed. The national evaluation revealed that a two-tiered structure (separate CRT and CAT) for FIMR enhances its effectiveness with respect to implementation of reported recommendations as well as performance of essential maternal and child health services. It also found that training for both the FIMR director/coordinator and staff in how to use case review findings was significantly associated with greater implementation of FIMR recommendations in specified perinatal content areas. (8)

In-Kind Services and Hours Donated To the FIMR Program for Each Meeting

DATE: _____

PERSON DONATING

TIME: _____

☐ CRT MEMBER

☐ CAT MEMBER

☐ OTHER

AGENCY: _____

PURPOSE: _____

ACTIVITY TIME

PER MEETING: _____

TRAVEL TIME

PER MEETING: _____

TOTAL TIME DONATED

PER MEETING: _____

SIGNED: _____

COMMENTS: _____

Adapted from: the Northeast Florida Healthy Mothers/Healthy Babies FIMR Program, Jacksonville, FL



Thinking more expansively about FIMR program effects

A number of FIMR programs, especially those that have been in existence for several years, have talked about a wider spectrum of effects in the community. Some of these effects likely evolve from the community coalition aspects of the program or from the role the program plays in improving service systems. The list below offers some ideas adapted from a community development perspective. (9) Knowledge about community development theory as well as the FIMR process may assist a local FIMR program to select indicators or measures to document these notions, thereby further describing the program's effectiveness.

■ **The community's capacity to act increased**

- FIMR team members learned more about important community issues
- Some or all of the broader community learned about maternal and child health issues and effective FIMR activities to address them
- Involved individuals had opportunities to be heard in ways that expanded their influence
- Commitments to act were secured from elected officials and others in positions of influence
- Broad-based coalitions of community leaders in support of productive activity addressing women, infants and families expanded

■ **The community's pool of resources for women, infants and families increased**

- Effective or exceptional people in the community became more visible to potential supporters
- The FIMR efforts attracted funds or other resources

- Allocation of resources improved so that less money was wasted
- Approaches identified made resources go further or have more impact

■ **A broader base of voices helped determine community strategies and the use of resources**

- Links among like-minded groups or organizations grew stronger
- New and emerging leaders received encouragement
- The management and technical skills of organization partnerships grew stronger
- Overall FIMR improved the quality of service for women, infants and families

Using the Evaluation Findings

After evaluation information about the program is collected, compiled and explained, what should happen next? A key activity is preparing and disseminating the findings. FIMR programs may determine it is important to share the results with a number of audiences based on the original intent and content of the evaluation. The depth and breadth of information will vary with the audience and the purpose for which it is being shared. Reports of findings may range from a separate document describing the evaluation and its results to inclusion of selected findings in the FIMR program's Annual Report or in its various presentations.

Familiarizing the FIMR staff and team members with the findings is essential in order for them to fully utilize the information in their future activities in the program. It may be necessary to schedule a separate meeting with the teams to assure that adequate attention is given to the evaluation. Once apprised, CRT and CAT members can also incorporate



selected results when they update their agencies annually on the progress of the FIMR program (see p. 123).

FIMR programs should think about the preparation, publication and dissemination of the evaluation information during the early planning for the evaluation and determine how it will be accomplished. For instance, if an outside evaluator is to carry out the evaluation, include the preparation of the report(s) as part of the evaluator's responsibilities. Planning for this activity should never wait until the last minute lest it be abandoned.

While dissemination is important, it is most vital that the FIMR program thoroughly consider the information that comes out of the evaluation. To conduct an evaluation and then not use the findings is imprudent. FIMR programs realize they can capitalize on demonstrated accomplishments of the evaluation to sustain their efforts. So too, they can benefit from new ideas suggested by the findings that might enhance their program's efforts.

Conclusion

Taking stock of a FIMR program on a periodic basis may be critical for the success and longevity of the process. A program evaluation lets programs and sponsoring agencies or funders know how the program is working and more importantly, what effects it is bringing about in the community. Successes spark enthusiasm, community involvement and at times, increased resources. Noted breakdowns in the process provide incentive for remediation. While a key measure of progress for most FIMR programs is the community actions they produce, there are many other measures that can help local communities appraise their development and more fully tell their story.

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CHAPTER 9

Other Maternal and Child Case Reviews and Related Processes: Opportunities for Collaboration



CHAPTER 9

Other Maternal and Child Case Reviews and Related Processes: Opportunities for Collaboration



Introduction

At both state and local levels there are now several types of case review processes that examine adverse events occurring to women, children and their families with the intent of improving the health and welfare of this population over time. This chapter provides brief descriptions of the most common case review processes, and identifies resources that provide additional details about each process. The descriptions reflect the recommended approach or model published by national organizations or resource centers providing support for each of the processes. Comparisons of various case review processes (some contrasting general features and others specific to a particular state) and reports of integrated processes have been published and are available at www.nfmr.org. (1–6) It should be mentioned, however, that variations in implementation of each type of case review process exist across the country with no one model being used in all states or communities.

Descriptions of several other programs or techniques that do not employ case review but have relevance for FIMR and similar processes also are included. Finally, the chapter discusses opportunities for coordination and collaboration in the presence of multiple processes, and offers some useful suggestions that have emerged over time.

Case Review Processes

Child death review

Child death review (CDR), also known as child fatality review, typically undertakes a comprehensive, multidisciplinary review of child deaths to better understand how and why children die, and to use the findings to prompt action that can prevent other deaths and improve the health and safety of children. Although CDR developed initially to address

issues of child abuse and neglect, many CDR teams today have broadened their attention in examining child death to encompass both accountability issues and a preventive, public health approach. Because unintentional injury is still the leading cause of all childhood deaths (ages 1-19), CDR teams may give special consideration to those preventable injury cases, as well as other public health concerns, such as teenage suicide.

Objectives of the CDR process may relate to making improvements in the following:

- Accurate identification of the cause of death, risk factors and trends in child deaths
- Agency responses to investigation of deaths
- Criminal investigation and prosecution of child homicide
- Protection of siblings and families in homes of deceased children
- Delivery of services to families
- Increased public awareness
- Advocacy for needed changes in policies, legislation and practices addressing health and safety of children

CDR programs operate at state and/or local levels (e.g., in health departments, child welfare services), frequently under laws or rules that provide varying degrees of legal protections as well as mandates for the process. A prominent difference between FIMR and CDR is that CDR reviews are confidential but not anonymous; CDR team members bring their agencies' individual case records to the review for discussion. Family interviews are also not part of the CDR process. Recommendations and actions about a case range from management of individual cases to general suggestions for system changes. Reports of CDR program findings (in aggregate form)



may serve as vehicles to educate the public and policy makers alike. (4)

The National Center for Child Death Review, funded by the Maternal and Child Health Bureau, Health Resources and Services Administration, serves as a national resource center for CDR, and offers a range of services including resources and tools (e.g., the program manual can be accessed on their website); technical assistance, training and support for CDR programs; and coordination with other review processes. The Center may be contacted at www.childdeathreview.org or 1-800-656-2434. A list of state contacts is available at <http://www.childdeathreview.org/state.htm>.

Citizens review panels for child abuse and neglect

Citizen Review Panel's (CRP) performance as a review group frequently is closely linked with CDR. States receiving federal grants under the Child Abuse Prevention and Treatment Act (overseen by the Administration for Children and Families) to improve a state's child protective services system must establish CRPs. The CRP function, as amended in 2003, is to examine the policies, procedures and practices of state and local agencies and where appropriate, specific cases, to evaluate the extent to which state and local child protection system agencies are effectively discharging their child protection responsibilities. CRPs have the authority to review cases of child fatalities and near fatalities (an act that, as certified by a physician, places the child in serious or critical condition). Membership on the panels is voluntary, but must broadly represent the community and include child abuse and neglect expertise. In numerous instances, an existing entity, such as a CDR, is designated as the CRP. (4, 7)

Resource materials, including state-specific information, and access to a CRP listserv are available on The National Citizens Review Panels Virtual Community website (www.uky.edu/socialwork/crp) maintained by the University of Kentucky's College of Social Work.

Maternal mortality review

Maternal mortality review (MMR) examines deaths that occur to women during pregnancy or within one year after pregnancy to prevent future maternal deaths and improve women's health. The terminology and definitions used to characterize a maternal death vary, however, by jurisdiction, and relate to differences in length of time following the termination of pregnancy and the cause of death. MMRs originated out of hospital- or state-based reviews that focused solely on medically related causes of death and clinical issues. A more recent trend indicates that MMR committees are broadening their focus and involving multidisciplinary teams to study both medical and non-medical aspects of the case and identify system factors that need improvement. To date there has been little experience in the U.S. with family interviews.

Because of the relatively low incidence of maternal deaths in the U.S., most MMRs are organized at the state or possibly a large sub-state level to ensure the anonymity of cases and efficiency of the process. MMRs tend to be placed within state health departments, although some are located within academic institutions or medical societies. The possibility of legal action to subpoena review committee members to testify about the review finding for an individual case or the minutes of the case review meetings themselves has been a concern for MMRs. Depending on state statutes, substantial protection from discovery may be accorded to MMR committees functioning under the auspices of a state health department. (8, 9)



Although there is no national resource center per se, the Centers for Disease Prevention and Control's (CDC) Division of Reproductive Health (DRH) has provided leadership and technical assistance for the MMR process for many years. Key CDC resources about MMR include a guide, *Strategies to Reduce Pregnancy-Related Deaths: From Identification and Review to Action*, that summarizes best practices about the basics of the MMR process (8), and a document providing greater detail about selected components of MMR (especially information on setting up committees, data collection and instruments, and dissemination). (9) Online access to CDC's DRH is available at www.cdc.gov/reproductivehealth/DRH. A pdf version of the *Strategies* document is located under Publications and Products at that website.

The state of Florida has developed a unique MMR process based on core concepts of the FIMR methodology. The process is called Pregnancy Associated Mortality Review (PAMR). The CDC *Strategies* document mentioned above contains the data abstraction forms used by the PAMR abstractors and more program information about PAMR is available at http://www.doh.state.fl.us/Family/mch/pamr/pamr_info.html.

Domestic violence fatality review

Domestic violence fatality review (DVFR) has emerged within the past 15 years in an effort to reduce injuries and prevent deaths associated with domestic violence. DVFR teams (situated at state, regional or local levels) systematically examine circumstances surrounding a case to increase their understanding of the factors that increase or decrease risk for injury or death, identify gaps in community systems, raise community awareness, enhance coordination among agencies and recommend

improvements in prevention strategies, policies and practices.

The multi-agency, multi-disciplinary teams (including representatives from the justice system) commonly employ a non-blaming approach to their review of identified cases, drawing on information from family members and agencies that have had contact with the case. The teams consider how the community or state can improve their accountability for prevention. Types of cases may be limited to intimate partner violence cases only or include other forms of violence as well. Some teams only review closed cases while others will review a case still pending in the justice system. Confidentiality of findings is stressed, and many states have enacted statutes to provide legal protection for DVFR. A number of DVFR programs publish annual reports with aggregate findings and recommendations. (10, 11)

The Department of Justice's Office on Violence Against Women funds the National Domestic Violence Fatality Review Initiative (NDVFRI), a clearinghouse and resource center dedicated to domestic violence fatality review. The NDFVRI website provides details about the process and state-specific information; contact them at <http://www.ndvfri.org/>.

Maternal and child health (MCH) morbidity reviews

Selected communities have initiated case review processes to examine a broader range of sentinel events affecting the MCH population that may result in significant morbidity but not necessarily mortality. Examples include but are not limited to: prenatal domestic violence, preterm/low birth weight births, birth defects in infants such as neural tube defects or suspected fetal alcohol syndrome disorders, infectious diseases in infants such as perinatal HIV transmission or syphilis.



Generally these reviews seek to improve the overall services and resources for women, children and families in the community as well as to improve specific services for families most affected by the adverse outcome or event. In a number of communities, the method or process for conducting these reviews has been patterned after the action-oriented, quality improvement approach used in the FIMR method, and the reviews are confidential and anonymous.

Communities adapting an existing FIMR process to conduct MCH morbidity reviews report they have had to undertake one or more of the following modifications: (12)

- Obtain additional legal authority or institutional review board approval to access medical records for cases other than infant mortality
- Create additional or more complex case-finding strategies
- Develop broader strategies for locating and engaging mothers or infants with the specific morbidity
- Expand existing data abstraction tools and accompanying software to collect new information pertaining directly to the specific morbidity
- Increase institutional capacity and staff to implement the adapted process
- Reach out to develop new partnerships with other entities beyond the usual MCH provider community, institutions or agencies
- Convene a separate case review team specifically to review the morbidity event

Making such modifications is possible, although communities should anticipate the time and effort required.

Relevant Programs or Methods Not Employing Case Review

Sudden infant death syndrome (SIDS) programs

SIDS is the sudden death of an infant less than one year of age that cannot be explained by information collected during a thorough investigation, one that includes a complete autopsy, thorough examination of the death scene and a review of the clinical history. Annually, half of all sudden, unexplained infant deaths are due to SIDS, and SIDS is the leading cause of postneonatal deaths. (13) Typical activities of SIDS programs, located at state and local levels, focus on risk reduction and prevention efforts, bereavement support services for families and training of professionals. (14) SIDS professionals frequently serve as team members for FIMR.

SIDS is a diagnosis of exclusion, and accurate death scene and medical examiner information is a necessity. To that end, the Centers for Disease Prevention and Control launched an initiative in 2004 to improve the investigation and reporting of sudden unexplained infant deaths, including SIDS death. This effort was undertaken in collaboration with a wide array of experts and parents who have experienced a death of an infant. Resources developed through this effort include the new Sudden, Unexplained Infant Death Investigation Reporting Form for state and local use in infant death scene investigations (released in 2006), and a comprehensive training curriculum and materials for infant death scene investigations. (13)

Multiple organizations, federal agencies and resource centers offer assistance around SIDS and related issues. A pdf version of the *SIDS & Infant Death Program Manual and Trainer's Guide* can be found at the first website listed



below. The four federally funded SIDS resource centers include (14):

- The National SIDS and Infant Death Program Support Center www.firstcandle.org/psc/manual.html
- The National SIDS and Infant Death Resource Center www.sidscenter.org
- The National Center for Cultural Competence SIDS/ID Project <http://www11.georgetown.edu/research/gucchd/nccc/>
- The National SIDS & Infant Death Project Infant Mortality Policy and Communication Tools (IMPACT) <http://www.sidsprojectimpact.com/>

A list of state contacts is also available at <http://www.sidsprojectimpact.com/programs/map.cfm>

Perinatal periods of risk (PPOR) approach

The PPOR approach developed in the U.S. to enable communities to better understand and respond to fetal and infant mortality and improve the health of women and infants. A key feature is the use of an analytic framework to divide deaths (based on combinations of birth weight and age at death) into four “periods of risk” groups that are labeled to suggest the primary preventive direction for community strategies: maternal health/prematurity, maternal care, newborn care and infant health.

PPOR focuses extensively on analysis of vital statistics data to determine the contribution of each of the four groups to the total problem and identify if there are excess deaths when compared with a reference group. The approach requires a certain number of fetal-infant deaths overall, as well as for every subpopulation or geographic region examined to have sufficient numbers to calculate rates. Large cities and counties with highly accurate

vital statistics data sets are better able to use this method.

When excess deaths are identified, PPOR refers to them as “opportunity gaps” and indicates the need for a second phase of analysis to find out the reasons for the deaths and assist with identifying prevention strategies. PPOR experts point out that limiting analysis to the first phase may be problematic as the broad findings may not provide sufficient specificity for targeted action. Communities can pursue further epidemiologic studies, death reviews such as FIMR, program and policy reviews, and other community assessments for follow-up investigations to provide additional explanation and focus direction to prevent fetal and infant mortality. A number of communities use both vital statistics findings from PPOR and aggregate findings from FIMR case reviews to guide their efforts. (15–17)

CityMatCH provides the leadership for technical support and continued development of the PPOR approach. Further details about PPOR and materials, such as protocols for selected analyses, can be accessed online at www.citymatch.org/ under Products & Services.

Opportunities for Collaboration

Collaboration among case review and other processes established to improve aspects of health and/or safety for women, children and their families at the community or state level seems to have many advantages, including the following:

- Communication of information between the processes enhances team awareness and understanding
- Joint review of each team’s aggregate findings can improve recognition of system gaps and identification of issues



- Combining similar findings boosts their magnitude and encourages greater community response
- Joint findings may produce unique information to enlighten community-wide assessment and planning
- Linkages between review processes facilitates the dissemination of information at the local and state level

FIMR programs often ask how they might approach initiating or improving coordination and collaboration with other processes. A beginning step is to identify which processes operate in the FIMR community as well as at a regional or state level. Talk with staff associated with these existing programs to find out the specific program purpose, how each functions, especially noting commonalities and differences. Discuss steps in the process to identify possibilities for and feasibility of coordination.

During this exploration FIMR staff may also find it useful to review available information about processes or collaboration in the literature or on national websites, including the NFIMR website at www.nfmr.org (see references). A number of publications present schematics to depict models of coordination between two processes (FIMR and CDR, MMR, etc.). (1, 5)

In addition, experts have suggested that local review processes and related programs might consider some of the following joint activities and strategies to improve coordination: (1–4, 17, 18)

- Identify one or two members who are common to two or more teams to provide continuity and share aggregate, de-identified recommendations back and forth. A city or county public health official may be a frequent crossover representative

- Include a SIDS program representative (if reviewing infant deaths) or another community bereavement professional on review teams
- Conduct joint training around common functions or issues, e.g., effects of loss and need for bereavement support and counseling services in the community; effective mechanisms for conducting team meetings
- Maximize use of complementary aspects of other programs, e.g., CDR's findings about infant injury prevention, SIDS programs bereavement counseling
- Establish contact with and obtain reports from state level programs (e.g., MMR) to keep informed of relevant findings and recommendations
- Hold a joint meeting annually to share aggregate findings, identify any mutual recommendations and discuss ways to collaborate on moving those recommendations to action
- Consider the feasibility of issuing joint, comprehensive reports at the local level. If joint reports are not possible, relevant information gathered during both processes might be incorporated in each other's annual reports
- Circulate local review reports with recommendations and findings to the state Title V director, so that findings from the local reviews can inform state Title V needs assessments

In summary, all of the programs described in this chapter collectively aim to improve the health and well-being of women, children (including infants) and their families. FIMR programs should identify which of these various processes are in place at the local, regional or state level. There may be opportunities to strengthen the FIMR program by coordinating with these other reviews or related programs that will ultimately benefit FIMR and the community.



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Appendix A–B



Appendix A

Standard Definitions for Reporting Selected Perinatal Health Statistics



Birth Weight—The weight of a neonate determined immediately after delivery or as soon thereafter as is feasible. It should be expressed to the nearest gram.

Fetal Death—Death before the 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 such expulsion or extraction, 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. Heartbeats are to be distinguished from fleeting respiratory efforts or gasps. This definition excludes induced terminations of pregnancies.

Infant Death—Any death at any time from birth up to, but not including, one year of age (364 days, 23 hours, 59 minutes from the moment of birth).

Live Birth—The complete expulsion or extraction from the mother of a product of human conception, irrespective of the duration of pregnancy, which, after such expulsion or extraction, breathes or shows any other evidence of life, such as such as 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. Heartbeats are to be distinguished from transient cardiac contractions; respirations are to be distinguished from fleeting respiratory efforts or gasps.

Low Birth Weight—Any neonate, regardless of gestational age, whose weight at birth is less than 2500 grams.

Neonatal Death—Death of a live-born neonate before the neonate becomes 28 days old (up to and including 27 days, 23 hours, 59 minutes from the moment of birth). Alpha-fetoprotein (AFP): A protein produced by a growing fetus, it is present in amniotic fluid and, in smaller amounts, in the mother's blood.

Appendix B

Glossary of Terms, Diagnoses and Procedures



This appendix contains basic information to assist non-medical members of the case review team to understand common terms, diagnoses and procedures that they might encounter in review of individual cases. (It may also be of use to the community action team members.) Local programs should feel free to add or delete items, as needed.

Please do not feel that these terms need to be memorized. Use this document as a dictionary and refer to it as needed. Experience tells us that after a year or so of reviewing cases, all team members will naturally come to an understanding of these terms, as well as others, without making any special effort.

Definitions in Appendix B are adopted from: American College of Obstetricians and Gynecologists. Your pregnancy and birth. 4th Ed. Washington, DC: ACOG; 2005 pp 353–361.

Amniocentesis: A procedure in which a small amount of amniotic fluid and cells are taken from the sac surrounding the fetus and tested.

Amniotic Fluid: Water in the sac surrounding the fetus in the mother's uterus.

Analgesics: A type of drug that relieves pain without loss of muscle function.

Anemia: Abnormally low levels of blood or red blood cells in the bloodstream.

Anencephaly: A type of neural tube defect that occurs when the fetus's head and brain do not develop normally.

Anesthetics: A type of drug that relieves pain by causing a loss of sensation.

Antibodies: Proteins in the blood produced in reaction to foreign substances, an antigen.

Antigen: A substance, such as an organism causing infection or a protein found on the surface of blood cells, that can induce an immune response.

Apgar Score: A measurement of a baby's response to birth and life on its own, taken two and five minutes after birth.

Autopsy: An exam performed on a deceased person in an attempt to find the cause of death.

Bacterial Vaginosis: A type of vaginal infection caused by the overgrowth of a number of organisms that are normally found in the vagina.

Bilirubin: A reddish-yellow pigment that occurs especially in bile and blood and may cause jaundice.

Biophysical Profile: An assessment by ultrasound of fetal breathing, fetal body movements, fetal muscle tone and the amount of amniotic fluid. May include fetal heart rate.

Braxton Hicks Contractions: False labor pains.

Breech: A situation in which a fetus' buttocks or feet would be born first.

Carrier: A person who shows no signs of a particular trait or disorder but has the gene and could pass the gene on to his or her children.

Cephalopelvic Disproportion: A condition in which a baby is too large to pass safely through the mother's pelvis during delivery.

Cerclage: A procedure to sew the cervix shut.

Cervix: The lower, narrow end of the uterus, which protrudes into the vagina.



Cesarean Delivery: Birth of a baby through an incision made in the mother's abdomen and uterus.

Chlamydia: A sexually transmitted disease that can lead to pelvic inflammatory disease, infertility and problems during pregnancy.

Chorioamnionitis: Inflammation or infection of the membrane surrounding the fetus.

Chorionic Villus Sampling (CVS): A procedure in which a small sample of cells is taken from the placenta and tested.

Cleft Palate: A congenital defect in which a gap or space occurs in the roof of the mouth.

Clubfoot: A misshaped foot twisted out of position from birth.

Congenital Disorder: A condition that is present in a baby when it is born.

Contraction Stress Test: A test in which mild contractions of the mother's uterus are induced and the fetus's heart rate in response to the contractions is recorded using an electronic fetal monitor.

Corticosteroids: Hormones given to mature fetal lungs, for arthritis or other medical conditions.

Crowning: The appearance of the baby's head at the vaginal opening during labor.

Cytomegalovirus (CMV): A virus in the herpes virus family that can be passed on to a baby during pregnancy, birth or breastfeeding and can cause problems with the liver, hearing, vision and mental functioning.

Diabetes: A condition in which the levels of sugar in the blood are too high.

Diastolic Blood Pressure: The force of the blood in the arteries when the heart is relaxed; the lower blood pressure reading.

Doppler: A form of ultrasound that reflects motion—such as the fetal heartbeat—in the form of audible signals.

Down Syndrome: A genetic disorder in which mental retardation, abnormal features of the face and medical problems such as heart defects occur.

Ectopic Pregnancy: A pregnancy in which the fertilized egg begins to grow in a place other than inside the uterus, usually in the fallopian tubes.

Edema: Swelling caused by fluid retention.

Effacement: Thinning of the cervix during the beginning stages of labor.

Electrode: A small wire that is attached to the scalp of the fetus to monitor the heart rate.

Electronic Fetal Monitor: An electronic instrument used to record the heartbeat of the fetus and contractions of the mother's uterus.

Embryo: The developing fertilized egg of early pregnancy.

Epidural Block: Anesthetic that numbs the lower half of the body.

Episiotomy: A surgical incision made into the perineum (the region between the vagina and the anus) to widen the vaginal opening for delivery.

Fetal Alcohol Syndrome: A pattern of physical, mental and behavioral problems in the baby that are thought to be due to alcohol abuse by the mother during pregnancy.



Fetal Monitoring: A procedure in which instruments are used to record the heartbeat of the fetus and contractions of the mother's uterus during labor.

Fetus: A baby growing in the woman's uterus.

Fibronectin: A type of protein made by the fetus that can be measured in secretions from the cervix.

Forceps: Special instruments placed around the baby's head to help guide it out of the birth canal during delivery.

Fragile X Syndrome: A genetic disease, inherited through the X-chromosome, that is the most common inherited cause of mental retardation.

Fraternal Twins: Twins, developed from two fertilized eggs, who are not genetically identical.

General Anesthesia: The use of drugs that produce a sleep-like state to prevent pain during pregnancy.

Gestational Diabetes: Diabetes that arises during pregnancy.

Gestational Hypertension: High blood pressure that occurs during the second half of pregnancy and disappears soon after the baby is born.

Glucose: A sugar that is present in the blood and is the body's main source of fuel.

Gonorrhea: A sexually transmitted disease that can lead to pelvic inflammatory disease, infertility and arthritis.

Hepatitis B Immune Globulin: A substance given to provide temporary protection against infection with hepatitis B virus.

Hepatitis B Virus: A virus that attacks and damages the liver, causing inflammation.

Human Chorionic Gonadotropin (hCG): A hormone produced during pregnancy; its detection is the basis for most pregnancy tests.

Human Immunodeficiency Virus (HIV): A virus that attacks certain cells of the body's immune system and causes acquired immunodeficiency syndrome (AIDS).

Human Papillomavirus (HPV): The common name for a group of related viruses, some of which cause genital warts and are linked to cervical changes and cervical cancer.

Hydramnios: A condition in which there is an excess amount of amniotic fluid in the sac surrounding the fetus.

Hyperemesis Gravidarum: Severe nausea and vomiting during pregnancy that can lead to loss of weight and body fluids.

Identical Twins: Twins, developed from a single fertilized egg, who usually are genetically identical.

Jaundice: A buildup of bilirubin that causes a yellowish appearance.

Kick Counts: Records kept during late pregnancy of the number of times a fetus moves over a certain period.

Labor Induction: Using medical or surgical methods to stimulate contractions of the uterus.

Local Anesthesia: The use of drugs that prevent pain in a part of the body.

Macrosomia: A condition in which a fetus grows very large.



Meconium: A greenish substance that builds up in the bowels of a growing fetus.

Miscarriage: Early pregnancy loss.

Multiple Pregnancy: A pregnancy in which there are two or more fetuses.

Neural Tube Defects: Birth defects that result from incomplete development of the brain, spinal cord or their coverings.

Nonstress Test: A test in which changes in the fetal heart rate are recorded, using an electronic fetal monitor.

Nuchal Translucency Screening: A special ultrasound test of the fetus to screen for the risk of Down syndrome and other birth defects.

Oxytocin: A hormone used to help bring on contractions of the uterus.

Perineum: The area between the vagina and the rectum.

Pica: The urge to eat nonfood items.

Placenta: Tissues that provides nourishment to and takes away waste from the fetus.

Placenta Previa: A condition in which the placenta lies very low in the uterus, so that the opening of the uterus is partially or completely covered.

Placental Abruption: A condition in which the placenta has begun to separate from the inner wall of the uterus before the baby is born.

Polydactyly: The condition of having more than the normal number of fingers or toes.

Postpartum Blues: Feelings of sadness, fear, anger or anxiety occurring about three days after childbirth and usually going away (ending) within 1-2 weeks.

Postpartum Depression: Intense feelings of sadness, anxiety or despair after childbirth that interfere with a new mother's ability to function and that do not go away after two weeks.

Pre-eclampsia: A condition of pregnancy in which there is high blood pressure and protein in the urine.

Premature Rupture of Membranes: A condition in which the membranes that hold the amniotic fluid rupture before labor.

Preterm: Born before 37 weeks of pregnancy.

Pyelonephritis: An infection of the kidney.

Respiratory Distress Syndrome: A condition causing breathing difficulties in some babies in whom the lungs are not mature.

Rh Factor: A kind of protein in some types of blood that causes responses in the immune system.

Rh Immunoglobulin (Rhlg): A substance given to prevent an Rh-negative person's antibody response to Rh-positive blood cells.

Rupture of Membranes: The breaking of the amniotic sac that surrounds the fetus.

Spina Bifida: A neural tube defect that results from incomplete closure of the fetal spine.

Spinal Block: A form of anesthesia that numbs the lower half of the body.

Stillbirth: Delivery of a baby that shows no sign of life.

Sudden Infant Death Syndrome (SIDS): The unexpected death of an infant in which the cause is unknown.

Surfactant: A substance, coating the air sacs in the lungs, that helps the lungs expand.



Syphilis: A sexually transmitted disease that is caused by an organism called *Treponema pallidum*; it may cause major health problems or death in its later stages.

Systemic Analgesics: Drugs that provide pain relief over the entire body without causing loss of consciousness.

Systolic Blood Pressure: The force of the blood in the arteries when the heart is contracting; the higher blood pressure reading.

Teratogens: Agents that can cause birth defects when a woman is exposed to them during pregnancy.

Tocolytics: Medications used to delay preterm labor.

Toxoplasmosis: An infection caused by *Toxoplasma gondii*, an organism that may be found in raw and rare meat, garden soil and cat feces and that can be harmful to the fetus.

Transducer: A device that emits sound waves and translates the echoes into electrical signals.

Trichomoniasis: A type of vaginal infection caused by a one-celled organism that usually is transmitted through sex.

Trimesters: The three-month periods into which pregnancy is divided.

Ultrasound: A test in which sound waves are used to examine internal structures; during pregnancy, it can be used to examine the fetus.

Umbilical Cord: A cord-like structure containing blood vessels that connects the fetus to the placenta.

Vacuum Extraction: The use of a special instrument attached to the baby's head to help guide it out of the birth canal during delivery.

Vertex Presentation: A normal position of a fetus in which the head is positioned down, ready to come through the vagina first.

Vibroacoustic Stimulation: The use of sound and vibration to wake the fetus during a non-stress test.

FIMR is an Action-Oriented Community Process

“...Americans are a peculiar people. If, in a local community, a citizen becomes aware of a need that is not met he thereupon discusses the situation with his neighbors. Suddenly a committee comes into existence. The committee thereupon begins to operate on behalf of the need, and a new community function is established. It is like watching a miracle.”

—Alexis de Tocqueville, 1840



To learn more about the fetal and infant mortality review process, please write, fax or call:

The National Fetal and Infant Mortality Review Program
The American College of Obstetricians and Gynecologists
Mailing Address: PO Box 96920, Washington, DC 20090-6920

Fax: 202-484-3917 • Phone: 202-863-2587

E-mail address: nfmr@acog.org

Web Site: www.nfmr.org