

Fetal and Infant Mortality Review (FIMR): A Strategy for Enhancing Community Efforts to Improve Perinatal Health

The first Fetal and Infant Mortality Review programs were implemented more than a decade ago 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 federal Maternal and Child Health Bureau (MCHB) has been supporting and monitoring the proliferation of FIMR programs nationwide since that time. In 1996, MCHB awarded funds to the Women's and Children's Health Policy Center (WCHPC) at Johns Hopkins University to conduct a nationwide evaluation examining the impact of FIMR on perinatal health care systems.

The evaluation had two major objectives; first, to determine the unique contributions FIMR programs may make to their communities' perinatal health care systems, and second, to identify the key factors in the implementation of FIMR programs that influence their effectiveness. This brief summarizes the information related to these two objectives, illuminating the value of FIMR and aspects of implementation that are important to its success.

This brief is intended to provide information to both existing FIMR programs and communities that are in the process of establishing new FIMRs. Members of existing FIMR programs can share the evidence of FIMR's nationwide success contained in this document with current and future funding agencies, partner organizations, and community members. State and local health departments and perinatal initiatives seeking to establish FIMR programs can use this brief to draw upon the experiences of FIMR programs around the nation and pursue the strategies with greatest promise of success.

Study Methods

The design of the FIMR evaluation was a cross-sectional observational study in which geographic units were sampled across the nation based on the presence or absence of a FIMR or other Perinatal systems Initiative (PI). This design permitted us to compare the implementation of public health functions in communities that did and did not have a FIMR, along with communities in which there were other perinatal health systems initiatives. Data were collected in the first part of the FIMR evaluation from telephone interviews with 193 respondents responsible for or knowledgeable about maternal and child health (MCH) programs, practices and policy in local health departments. In the second part, 74 FIMR program directors and 62 directors of perinatal systems initiatives were interviewed about the characteristics of their program and their impact on public health activities and perinatal services and systems. The interviews focused on three populations: pregnant women, infants, and women of childbearing age in general. The study team also conducted ten case studies to augment the structured telephone interviews with more qualitative data, providing a more thorough understanding of FIMR programs within their community context. Data collected for the study covered the time period from June, 1996 to December, 1999. Preliminary results of this evaluation are presented in a separate document, *The Evaluation of FIMR Programs Nationwide: Early Findings*.

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Key Contributions of FIMR Programs

Bolstering Community Efforts for Perinatal Health

As part of the nationwide evaluation, data were collected from local health department officials responsible for maternal and child health (MCH) activities in their communities. Those communities were sampled on the basis of whether or not there was a FIMR present as well as other perinatal systems initiatives. The results presented here are based on comparisons of MCH activities in FIMR compared to non-FIMR communities.

The study results show that FIMR programs contribute significantly to improvements in systems of health care for pregnant women and infants through enhanced public health activities in communities. Given FIMR's goals and objectives, the evaluation employed a broad framework in which to examine the "value added" of FIMR programs. In particular, a focus was placed on assessing 8 of the 10 public health (MCH) functions (Grason and Guyer, 1995) and the development of recommendations for systems changes in perinatal health. **There were six areas in which health departments in communities with a FIMR were more likely to report public health activity as compared to health departments in communities without a FIMR:** 1) data assessment and analysis; 2) client services and access; 3) quality improvement for systems of care; 4) partnerships and collaboration; 5) population advocacy and policy development; and 6) enhancement of the health workforce.

Data assessment and analysis.

- Health agencies in communities with a FIMR were 2 to 3¹ times more likely to undertake a number of data collection and analysis activities as compared to those in communities without a FIMR. While these activities predominately related to pregnant women and infants, local health agencies in FIMR communities also were about 2 times more likely to report using a client database specific to nonpregnant women of reproductive age.

Client services and access.

- Health departments in communities with a FIMR program were more likely to be engaged in activities involving provision of client services and access to appropriate care, specifically with respect to use of common risk assessment instruments for pregnant women. These communities also were more than twice as likely as communities without a FIMR to have tracking systems to follow up on high-risk infants.
- In communities with a FIMR, health departments were 2 to 3 times more likely to support or offer outreach activities for prenatal care, such as information and referral services, home visits, and public awareness and media campaigns. Grief support was another type of service receiving significant attention in public health departments in communities with FIMRs.

Quality improvement for systems of care.

- Public health agencies in FIMR communities were more than twice as likely as those with no FIMR to report initiating or advancing changes in existing local or state regulations and policies promoting the health of pregnant women.
- Similarly, these agencies were more than 2 times as likely to lead or participate in the development of population-based standards of care for pregnant women and infants, and were even more likely to be involved in certification and quality improvement activities specific to facilities or providers of care to women and infants.

Partnerships and collaboration.

- Compared to those without a FIMR program, local health departments (LHDs) in FIMR communities were more than twice as likely to

¹ The results described here are based on odds ratio estimates of the comparison of FIMR communities with those without a FIMR. For ease of understanding, we describe the results in terms of likelihoods rather than odds.

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participate in a coalition of local agencies or citizens to advocate for the health or health needs of pregnant women.

- In FIMR communities, LHDs also were nearly 3 times as likely as those in communities without a FIMR to work with the local ACOG section to advocate for all 3 populations we studied-- pregnant women, infants, and nonpregnant women of reproductive age.

Policy.

- Where FIMR programs existed, health departments were more than 3 times as likely as those without a FIMR to report participating in or collaborating with initiatives or programs undertaken by other community groups, and providing them expertise specific to perinatal health concerns.
- LHDs in communities with a FIMR also were more than twice as likely to produce or disseminate reports about progress in meeting local goals and objectives related to perinatal health, as well as to produce a plan to system-

atically address priority health problems of pregnant women.

Workforce enhancements.

- LHDs in FIMR communities were twice as likely to undertake or participate in activities to advance the education of providers about health care for pregnant women and infants.
- LHDs in communities with a FIMR were two to three times more likely to convene meetings of local medical and family service providers to enhance the identification of high-risk pregnant women and high-risk infants.

The Development and Implementation of Recommendations

The identification of factors contributing to individual cases of fetal and infant death within a community, and the subsequent development and implementation of effective strategies for improving perinatal health care systems are integral components of the FIMR process. In order to determine the extent to which FIMR programs address certain perinatal

Table 1. The Discussion of Selected Perinatal Health Issues by FIMR Programs and the Subsequent Development and Implementation of Related Recommendations (N=69)

Topic	Discussion of Selected Topic % (N)	Developed Related Recommendations ^a % (N)	Implemented Recommendations ^b % (N)
Prenatal Care	98.6 (68)	83.8 (57)	82.5 (47)
Substance Abuse	94.2 (65)	81.5 (53)	75.5 (40)
SIDS	92.8 (64)	89.1 (57)	86.0 (49)
Smoking	92.8 (64)	78.1 (50)	72.0 (36)
Infections During Pregnancy	87.0 (60)	73.3 (44)	72.7 (32)
Domestic Violence	81.2 (56)	78.6 (44)	77.3 (34)
Family Planning	79.7 (55)	89.1 (49)	69.4 (34)
Very Low Birth Weight	79.7 (55)	78.2 (43)	83.7 (36)
Maternal Complications	79.7 (55)	76.4 (42)	66.7 (28)
Multiple Pregnancies	76.8 (53)	52.8 (28)	64.3 (18)

^a Percentage is of those respondents reporting that topic was discussed

^b Percentage is of those respondents reporting that recommendations were developed concerning topic

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health issues, FIMR directors were asked about their programs' discussion of several specific perinatal health topics (Table 1), as well as their efforts to development and implement related recommendations.

Each of the specified perinatal health topics was discussed by over 75% of programs interviewed, with over 90% of FIMR directors reporting that their program discussed issues such as prenatal care, substance abuse, sudden infant death syndrome (SIDS), and smoking. With the exception of multiple pregnancies, a high percentage of those reporting that a specified perinatal health issue was discussed also reported the development of related recommendations. In particular, over 80% of the FIMR directors reporting that their program discussed issues related to family planning, SIDS, prenatal care, and substance abuse also reported that their program developed recommendations to address these issues. Although the number of FIMR programs that implemented recommendations to address certain specified perinatal health issues was low in relation to the number of programs surveyed, in general FIMR programs appeared to be effective in implementing strategies to address those issues for which recommendations were developed. In terms of the perinatal health concerns for which FIMR programs were most effective in their attempts to facilitate improvements within perinatal health systems, over 80% of the programs that developed recommendations related to SIDS, very low birth weight, and prenatal care successfully implemented such recommendations.

Systems Changes Evolving from FIMR

Given its goal of improving systems of care, understanding the specific aspects of FIMR that contribute in this regard was considered key to the analysis. Defining a system as “a set or group of interconnected, interdependent, yet autonomous, components that form a complex whole addressing specified goal(s)” (Levey and Loomba, 1973), the evaluation considered how FIMRs affected each of

the elements of the system – the goals, components, and communication mechanisms.

Focus on systems goal. Information collected in all components of the evaluation points to FIMR's important role in bringing community members together to focus on issues related to fetal and infant deaths. The subject of infant deaths inspires concern and a call to action in the entire community – medical care providers, public health professionals, policymakers, consumers, and other activists alike – in ways that many other topics of public health concern have not. Moreover, the FIMR structure and process combines the specialized expertise of many professionals such as medical care providers, social welfare professionals, and medical examiners along with policy leaders in positions to act on its recommendations. It also 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 practices and programs occur; “things get fixed” and participants are motivated to take further action.

Enhance system components. In our sample, FIMR recommendations focused largely on practices and programs. FIMR case review findings often result in recommendations to improve the quality of specific components of the system (practices, services), and to fill gaps in the array of interventions implemented locally to address perinatal health. Community capacity was frequently bolstered as a result of the FIMR process. The evaluation case studies provided several examples of system component enhancements that were initiated or facilitated by the FIMR. For example, a review of SIDS deaths in one FIMR revealed that African American families did not perceive that Back to Sleep messages were directed to them. As a result, a Community Voices program was created to foster peer education about Back to Sleep within the African American population. Thus, the FIMR program enhanced cultural competence within the system of care.

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Enhance communication among system components. Without question, study findings point to the important contributions of FIMR programs in enhancing communication among system components at the agency/organizational level, at the public policy level and among service providers, particularly among team members representing the various perinatal health constituencies. Study participants noted improved communication among the full spectrum of providers. In FIMR programs, clinical, public health, social welfare, and law enforcement professionals (to name a few) work together around a common cause. FIMR participants uniformly reported the value of having professionals with different viewpoints at the same table to brainstorm and problem-solve together. Moreover, the FIMR process gave participants an opportunity to see the number and range of professionals and organizations involved with families, and to understand different perspectives about their families' experiences.

Many of the physicians interviewed in the case studies noted that if it were not for their involvement with FIMR, they would not interface regularly with colleagues from other specialties or hospitals, nor with professionals from social services, law enforcement or other community agencies. In communities where there was competition between hospitals, the FIMR program was cited as a place where allegiances can be set aside, providing a unique opportunity for physicians affiliated with competing facilities to work together.

FIMR is also an arena where private sector clinicians learn about public health roles and activities and public health professionals learn about concerns and challenges of medical practices. FIMR is a forum for new insights for the private medical community into the public health system and its resources, and for public health to learn how they can better collaborate with the private sector.

Case study findings indicate that when a community is positively inclined toward collaboration, the FIMR program can provide the information/data needed to take action. FIMR case review information provides credence to recommended strategies, making arguments for change more convincing to policymakers as well as to clinical providers. For example, in one case study site, the loss of a preterm infant was found to be related to the lack of clinical records available to the physician on call about a mother being admitted to labor and delivery. This information gleaned from the FIMR review was used to promote an earlier transfer of prenatal records to the delivery hospital among all obstetric providers in the community.

Factors Contributing to the Success of Individual FIMR Programs

The second objective of the evaluation was to identify the key factors contributing to the effectiveness of FIMR programs in improving community resources and service systems. This objective was first addressed by assessing the structural and operational features of FIMR programs. Of particular interest was

FIMR Teams

Although FIMR programs share a common goal, the structure of the review process may vary between individual programs. In general, FIMR programs are composed of one or both of the following types of teams:

- **Case Review Team (CRT)** – group responsible for identifying the factors associated with individual cases of fetal and infant death within a community, as well as the development of appropriate recommendations for addressing deficiencies within the community and perinatal health care system that contribute to such deaths.
- **Community Action Team (CAT)** – group responsible for implementing strategies to improve the systems of care available to women, infants, and families as outlined in recommendations resulting from the case review process.

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the question of how FIMRs organize themselves with respect to the roles of case review and development and implementation of recommendations. Both survey data (74 FIMRs) and case study interview data (10 of the 74 FIMRs) informed our analysis in this regard. In the case studies FIMRs also were examined in the context of the communities in which they operate. Particular attention was given to investigating the strength and variety of the connections forged with other perinatal health providers and organizations, and to determining how these connections affect FIMR's success.

Team organization. Three general team structures were identified among the 74 FIMRs surveyed: 17 had a Case Review Team (CRT) only, 16 had a combined/joint CRT and Community Action Team (CAT), and 36 had separate CRTs and CATs². In order to determine how these different team structures related to the success of the FIMR programs, two measures of the extent of successful implementation were compared by team structure. The first was the number of roles FIMRs played in supporting perinatal health, such as conducting perinatal needs assessments, advocacy for perinatal populations, and development of protocols for high-risk patients. The second measure of "success" was the variety of attributes – such as a focus on the social and behavioral aspects of perinatal health, or the promotion of a broad-based constituency to improve perinatal health – the FIMR exhibited. The study findings revealed that FIMRs with a separate CRT and CAT played a greater number of roles in perinatal health and also reflected a greater variety of attributes than those with a CRT only or joint teams.

Team structure appears to also have an impact on the implementation of FIMR recommendations. As previously discussed, FIMR directors were asked about their program's efforts to implement recommendations to address 10 specific perinatal health issues (Table 1). **In addition to addressing a higher**

² Five FIMRs indicated they had "other" team structures.

number of issues, FIMR programs with a separate CRT and CAT implemented a higher mean percentage of reported recommendations (88%) compared to FIMR programs with either a joint/combined CRT and CAT (42%) or a CRT only (71%).

Strong leadership. As is the case for most community initiatives, having a knowledgeable, credible, visible leader or champion for FIMR was seen as important by most all those we interviewed in the ten case study communities. Where such a leader was consistently identified in our interviews, a broader and larger group of community members were aware of the FIMR and the results of the FIMR process. **Such leadership was observed to be important for 1) recruiting "the right" people to participate on FIMR teams, 2) facilitating access to information needed for case reviews (e.g., provider records), 3) keeping the FIMR team members motivated and engaged, 4) disseminating FIMR-related information broadly throughout the community, and 5) making progress on moving from recommendations to action.**

Training for FIMR directors, staff, and team members. Significant efforts in training have been made by the National FIMR Program (NFIMR) (partnership between the Maternal and Child Health Bureau and the American College of Obstetricians and Gynecologists) as well as by State MCH programs. Seventy-four FIMR directors were queried about whether they, their staff, or their CRT and/or CAT members received training in a) perinatal health; b) how to use information generated from the case reviews; and c) strategies for implementing objectives or "action agendas." Over half of the FIMR directors reported having received training in all three areas. Training for program staff in all three areas was reported by 41 percent of FIMR directors, and training of FIMR team members in all areas was reported by 37 percent. **A significant association was found between receipt of training by FIMR participants and embracing a broader scope of attributes and roles related to improving perinatal health systems and status. Training specifically in "action agendas" was associated with over a 3-fold increased frequency of reported roles related to: 1) serving as a forum for**

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community concerns about perinatal health, 2) assessing perinatal health needs or status, 3) educating communities about perinatal health concerns, and 4) perinatal health care system policy implementation. We were unable to determine, however, whether FIMRs with more roles and attributes were more likely to pursue training of participants or whether the training itself led to the increases in roles and attributes.

State level support. The role of state MCH programs in the ten FIMRs we visited varied considerably. Most often the program provided some or all of the FIMR funding, as well as guidance and support in the specific procedures of FIMR activity (e.g., data abstraction, home interviews, etc.). **For several of the FIMRs in the case study sample, the state agency facilitated resolution of problems related to data access and confidentiality and worked to secure legislation or regulations allowing for FIMR use of data.** Where the state public health agency was less committed to promoting FIMR as a community-directed initiative, however, FIMR effectiveness overall appeared to be compromised.

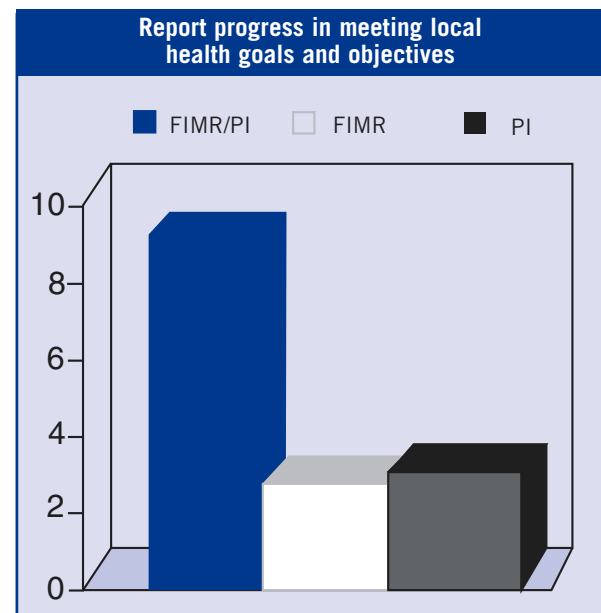
Disseminating information. **A key FIMR contribution is the provision of information to galvanize policymakers and the perinatal health system into action. Substantial efforts in this area were observed in several of the 10 FIMRs studied in depth.** We also found, nevertheless, that dissemination of information generated by the FIMR often did not appear to reach very far beyond individuals who interacted routinely with the FIMR (e.g., members of the FIMR team(s), and/or local health departments). Few individuals we interviewed who were not members of a FIMR team recalled having received reports or publications of the FIMR. In most sites, individuals interviewed from community organizations, clinicians in private practice, or elected officials, did not perceive that specific actions were generated by the FIMR process. In some cases, changes in perinatal services/the system had indeed been prompted by the FIMR process, but the FIMR's role was not known to those interviewed. This situation may reflect the informal nature of action taken within a hospital or across clinical practices, or could be the result of a specific strategy to give

others credit in order to promote further community "ownership" or engagement.

Synergy with other perinatal initiatives. As noted above, the presence of a FIMR has a number of positive effects on the level of perinatal health activity in its community's LHD. In addition to studying FIMRs, we also collected data from directors of other Perinatal systems Initiatives (PI). Analysis of our quantitative survey data suggests that **while having a FIMR or a perinatal initiative (PI) alone may have a beneficial effect, having both a FIMR and a PI operating concurrently in a community is of even greater advantage.** For instance, although LHDs were over 2 times more likely to report their progress in meeting community health goals and objectives for pregnant women when either a FIMR or a PI was present alone, they were 9 times more likely to generate such reports in localities with both a FIMR and a PI (see graph below, y-axis shows odds that LHD reported progress).

Similar synergistic effects were found in the areas of:

- collection of data on infants;
- needs assessment related to perinatal populations;



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- presenting information to local political leaders;
- collaborating with other community initiatives to address perinatal health problems; and
- collaborating and providing expertise on the health needs of pregnant women.

One reason for the synergy resulting from the presence of both a FIMR and a PI is that they frequently work together, and both are often located in health departments or work collaboratively with them. Case study findings illuminate this point. In one case study site, the PI initially funded and staffed the FIMR. In another community visited, data gathered by the Case Review Team were used to make the case for federal funding to initiate a Healthy Start project. This PI now serves as the vehicle for implementing a number of the FIMR recommendations. In some communities, the activities of the FIMRs and PIs were so intertwined that it was difficult to tease apart their separate impacts. Ultimately, the ongoing operation of the FIMR processes appears to be more stable and sustainable where the FIMR is either integrated into other perinatal systems initiatives, or where there are strong linkages with these efforts.

Concluding Observations

The findings from the Evaluation of Fetal and Infant Mortality Review Programs Nationwide indicate that FIMRs can play an important role in improving services and systems of perinatal health care. The presence of FIMR appears to significantly improve a community's public health functions and enhance the existing perinatal care system's goals, components, and communication mechanisms. FIMRs can be seen as a tool or strategy, used alone or in conjunction with other perinatal health improvement efforts, to promote positive change in communities' or states' ongoing stewardship of the health of women, infants, and their families. The effectiveness of FIMRs appears to be strengthened when combined with other perinatal systems initiatives in the community.

To maximize their effects, FIMR programs must be implemented with emphasis on certain structural and

organizational characteristics. Specific attention needs to be given to training, dissemination, outreach to policymakers, engaging and nurturing community participation, and the cultivation of strong program leadership. FIMRs must also establish a broad range of connections with its community's perinatal care providers and consumers. The state public health agency also needs to provide a supportive role to FIMRs in the state. Once these linkages are established, the resulting cooperation within the community is an effective means to address the ultimate goal of improving infant mortality rates and the overall health of pregnant women, infants, and non-pregnant women of reproductive age.

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<http://www.med.jhu.edu/wchpc>.



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