

Transferring Components of the Fetal and Infant Mortality Review Methodology to Maternal Mortality Review and Child Fatality Review

EXECUTIVE SUMMARY

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A fetal, infant, child or maternal death should be viewed as a sentinel event that indicates a community's social and economic well-being, as well as its health. These deaths also reflect the organization and abilities of the community's health and human services system as well as its array of other community resources.

A comprehensive review of these deaths serves as a springboard to organize community-level or statewide quality assurance or continuous quality improvement efforts to meet the needs of women, infants, children, and families. Fetal, infant, child and maternal death reviews also lay the cornerstone for the public health functions of assessment, assurance and policy development. To accomplish these goals, such reviews should ideally be conducted by a multidisciplinary team, which includes advocates and consumers as well as professionals. The focus of reviews is broad-based - considering both the health care needs of women and infants, as well as a host of relevant economic, social, cultural, environmental and safety factors that influence family health.

In 1984, the federal Maternal and Child Health Bureau (MCHB) first proposed a new broad-based, multi-disciplinary death review, *fetal and infant mortality review* (FIMR), as a strategy to improve service systems and

resources for women, infants and families. (1) In 2001, researchers at the Johns Hopkins Bloomberg School of Public Health completed a national evaluation of the FIMR process. According to the researchers' preliminary report:

"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 FIMR program] 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 practice and programs occur; 'things get fixed' and participants are inspired to take further action." (2)

In addition, the researchers found that:

- ▶ FIMR case review findings often result in recommendations that improve the quality of specific components of the system (such as practices and services) and fill gaps in the array of interventions implemented locally to address perinatal health
- ▶ The FIMR process frequently bolsters community capacity



- ▶ FIMR programs frequently enhance communication among system components at the agency/organizational level and among service providers, particularly among FIMR team members
- ▶ FIMR participants uniformly report the value of having professionals with different viewpoints at the same table to brainstorm and problem solve together
- ▶ FIMR case review information provides credence to recommended strategies, making arguments for change more convincing to policy makers and clinical providers (3)

Finally, Johns Hopkins also documents the specific usefulness of FIMR for enhancing local public health department efforts. They found that public health departments with a FIMR program (as opposed to those without a FIMR) are **2 to 3 times more likely** to:

- ▶ Undertake maternal and child health data collection and analysis activities
- ▶ Support or offer outreach activities for prenatal care
- ▶ Lead in the development of standards of prenatal care
- ▶ Participate in a coalition of local agencies or citizens to advocate for the health of pregnant women
- ▶ Collaborate with initiatives undertaken by other community groups and provide them expertise specific to perinatal health concerns (3)

In November 1997, MCHB brought together experts on child fatality review (CFR) and FIMR to

discuss the need to examine the uniqueness and commonalities of these two review processes. MCHB charged the invited group with developing recommendations to improve the effectiveness and efficiency of these processes. The group concluded that communities need to examine how they can integrate certain functions of the review processes and that all reviews should lead to community improvement efforts (4).

In 1998, MCHB initiated the State Mortality/Morbidity Review Support Program with grants to three states (Virginia, Montana, and Colorado) for a three-year period (1998-2001). Progress reports from these state grants have reinforced MCHB's position that adapting certain aspects of the FIMR process to other types of MCH-related mortality/morbidity review is a valuable and effective effort toward improving health services and systems for women and children at the local and state level.

This bulletin summarizes a plenary session panel presentation from the National Fetal and Infant Mortality Review Program Fourth National Conference held August 2-4, 2001 in Washington, D.C. The bulletin describes both local and state efforts to incorporate some of the principles of FIMR into maternal mortality review (MMR) and CFR programs in Florida, Michigan and New Jersey.

Components of the FIMR process can be relevant in developing other types of reviews. Two MCH review processes that can benefit from an action-oriented, quality-improvement approach are MMR and CFR. An informative side-by-side

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comparison of FIMR, CFR and MMR developed by Florida State Department of Health is included in Appendix A. Definitions of FIMR, CFR and MMR are included in Appendix B. Specific FIMR principles being adapted to these CFR and MMR reviews are the following:

- ▶ De-identifying case reviews so that names of families, providers, and institutions are **confidential and anonymous**. The FIMR focus is on improving systems, not assigning blame. This FIMR focus is consistent with principles of continuous quality improvement.
- ▶ Ensuring a community perspective by conducting **home interviews** with the mother who has experienced a loss. Her story is conveyed to the FIMR team members.
- ▶ Convening broad-based, multidisciplinary teams to study cases and make recommendations. FIMR promotes **broad community participation**. FIMR teams grow to be a community coalitions that represents all ethnic and cultural community views and become a model of respect and understanding.
- ▶ Moving from recommendations to **community action**. FIMR is action oriented and reviews lead to multiple creative community actions to improve resources and service systems for women, infants and families.

CFR and MMR programs, which have adapted some or all of these FIMR principles, have been able to expand the breadth and scope of their reviews and enrich the findings and recommendations that they generate. Some MMR and CFR programs choose a de-identified public health/continuous quality improvement approach—raising standards of care for all service providers, improving inter- and intra-departmental systems of care and enhancing community resources.

CFR programs, which include home interviews, are able to understand local families in the broader context of their culture and environment. All three programs are focused on public health issues with an

emphasis on prevention. Once adapted, these FIMR principles also firmly lead these CFR and MMR programs to an action agenda, moving from case review to community action.

A synopsis of the Florida, Michigan, New Jersey programs follows:

Florida's Palm Beach County CFR program uses a FIMR model, with home interviews, to examine deaths of all children from 0 through age 18. All reviews are de-identified and anonymous. Three broad-based multidisciplinary teams review child deaths in the age groups of fetal deaths and 0-1, 1-10, and 11-18, respectively. The Palm Beach County CFR team is developing community actions to prevent future tragedies. The team believes one child's death that is preventable is one too many and any preventable child's death is predictable and unacceptable.

Michigan has focused its emphasis for CFR on public health prevention, rather than solely on criminal investigation. Teams still need to ascertain whether any investigation is needed. However, in implementing a FIMR-type model of improving services, Michigan CFR teams also ask: *Are there services that we should have provided for the family, members of the family, or others in the community? Are changes needed in agency practice or policies after a death? What recommendations should be brought forth to prevent deaths?*

After seven years of FIMR implementation, the New Jersey Department of Health and Senior Services decided to expand its process of MMR using several principles of FIMR. (6) Now representatives from the Department of Health presents de-identified, anonymous findings and recommendations from broad based, multidisciplinary state reviews to each of New Jersey's seven regional Maternal and Child Health Consortia. The Maternal and Child Health Consortia in New Jersey coordinate child health services at the local level. Consortia will work with coalitions, such as Healthy Mothers-Healthy Babies, to take that information and implement community-specific action within their regions.

REFERENCES

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COORDINATING FIMR AND CFR

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The mission of the Palm Beach County Health Department is to become the healthiest community in the nation. Objectives leading to that goal include the following:

- ▶ Protecting and promoting a healthy community by assessing public health issues and developing public health policy initiatives.
- ▶ Assuring access to essential health services and assuring a healthy environment.
- ▶ Protecting the county's youngest citizens.

The Palm Beach CFR mission is to reduce child deaths in Palm Beach County, including fetal and infant deaths as well as those of all children through age 18. Through this process, the community takes responsibility for the death of each child. Toward that goal, the CFR Project has the following objectives:

- ▶ Conduct a comprehensive review of individual child deaths;
- ▶ Design and coordinate the implementation of prevention efforts;
- ▶ Evaluate prevention efforts and resource allocation; and

- ▶ Recommend policy changes.

The CFR Project also formally added the word *prevention* to the original name. Prevention is a major part of the mission. The definition of *preventable* in terms of a child's death comes directly from the Arizona State Child Fatality Review Program:

"A child's death is considered preventable if an individual or the community could have reasonably done something that would have changed the circumstances that led to the child's death." (1)

The Palm Beach County CFR team believes one child's death that is preventable is one too many and any child's death that is preventable is predictable and unacceptable.

History and Process

The Healthy Start Coalition in Palm Beach County originally developed a FIMR program in 1993 with support from the Florida State Title V agency. After several years, the community decided to expand the number and type of reviews to include all child deaths. At the same time, steps were taken to preserve the de-identified, quality-improvement approach of the FIMR method in the expanded

process. Participants felt that combining the qualitative information from the family interview and any available interviews with friends of teens who died with medical, social, and educational records would provide the most valuable blend of information.

As a first step, the coalition turned the sponsorship of the FIMR and CFR over to Palm Beach County Health Department. Thus, the state law that protects the Health Department from liability now also could protect CFR staff and community committee members. Three separate teams review fetal/infant deaths; child deaths, ages 1 through 9; and preteen and teen deaths, ages 10 through 18.

The Health Department's CFR staff have also developed medical data abstraction forms and a parent interview appropriate for death review of older children. The Health Department coordinates team meetings and maintains strict confidentiality. The department also takes care to offer culturally sensitive support for grieving families.

The issues addressed in the reviews include education, medical history, family history, substance-abuse history, payment for services, mental stress, mental illness, sexual activity issues, violence, and neglect. The effects of culture, environment, pediatric care, community services and family social support are also reviewed.

CFR staff conduct a home interview for each case, if the parents agree. The home interviewer asks parents and other caretakers who agree to participate to sign a consent form. This form includes a statement that informs the parents that the CFR interviewer must report information about child abuse or neglect to the Department of Children and Families. Parents who are being investigated or tried by the criminal justice system are not contacted for an interview until after their cases have been closed. This procedure prevents CFR from interfering with the judicial process. Also, the procedure prevents the community from confusing CFR with the investigative process.

A community task force of 40 community agencies provides project oversight and forms the springboard for community actions. The task force works with the community to move from recommendations to actions. These actions aim to benefit the community by improving services and resources for

women, infants, children, and families. The actions also target strategies to prevent unintentional injury to children.

The Health Department CDR project does not investigate cases to determine culpability in the death of children. The Florida State Department of Children and Families has mandated a separate rapid law enforcement review team, composed of law enforcement, the medical examiner, local prosecutors and others, to determine if abuse or neglect are evident in the death. These reviews are separate from the CFR. The rapid law enforcement review team is called up to investigate any sudden, unexpected child death. Within 48 hours, they must make a determination about the cause of death.

Palm Beach County in Action

One of the first issues the reviews identified was the high incidence of SIDS. From interviews of bereaved parents, the team also determined that many individuals and families at highest risk for SIDS did not know about risk-reduction messages.

To correct this problem, the Palm Beach County CFR/FIMR worked closely with the medical examiner's office and the Maternal Child Family Health Alliance on Safe Infant Sleeping Programs, beginning in September 1999 and continuing today. This coalition identified the most important messages about safe sleeping environments and co-sleeping and culturally appropriate strategies to reach those individuals and populations.

A public education media campaign, spearheaded by the chief medical examiner, carried the message to the general public, parents, and grandparents. The medical examiner warned: "The survival of your child will depend more on where and how he or she sleeps during the first year of life than on any other action or care issue during childhood!"

Team members targeted health-care providers and organizations with information tailored to their needs. The CFR/FIMR project helped staff the medical examiner's "Safe Infant Sleeping" exhibit at the South Florida Fair and staffed CFR/FIMR exhibits at two conferences for child-care workers sponsored by the Palm Beach County Child Care Resources and Referral agency. To complement existing risk-reduction brochures, the program pro-

duced and distributed a Safe Infant Sleeping Checklist to be used as a constant reminder of how to create a safe sleep environment.

To evaluate the impact and effectiveness of these efforts, the medical examiner's office compared Palm Beach County's average monthly incidence of unexpected sleeping infant deaths with an adjacent, but larger, county. At the start of the campaign, both counties had virtually the same incidence of deaths. Palm Beach County's incidence decreased significantly after the nine-month educational campaign; but the other county had no decrease and, in fact, experienced an increase.

During the 1999 Safe Infant Sleeping campaign launch, the number of unexpected sleeping infant deaths also decreased significantly. However, after the initial media coverage waned, deaths began to increase. Building on this experience, Palm Beach's coalition has developed a multifaceted strategy to institutionalize safe infant sleeping education for child-care workers, hospital staff, physicians and their office staff, prenatal- and postnatal-care coordination agencies, parents, and family members.

Program and Process: Lessons Learned

The importance of group process and respect. Initially, when reviewing cases, some team members became verbally abusive about perceived gaps in services related to agencies represented by other team members. This behavior violated the FIMR policy of not assigning blame. To address this issue, the CFR program has now added code of conduct language to its pledge of confidentiality. The pledge is reviewed and signed by each attendee at every CRT meeting. The code of conduct language reads as follows:

"I agree to work cooperatively and constructively with others members of the Child Fatality Review and Prevention Project to identify opportunities for improvement."

As team members began to know and respect each other, the CFR meetings and other activities have become more coordinated and more efficient. Because of participation in the Florida State Child Abuse Death Review and the County Domestic Violence Death Review, the project has actually brought in new community members and profession-

als as partners in community action and advocacy.

The value of FIMR interviews. At first, some team members were concerned about the family interviews being too intrusive, disruptive, or duplicative. Over time, as they experienced the quality and the quantity of valuable information gleaned through the interviews, and saw referrals made to bereavement counseling and other services during the interview, team members became strong advocates for the interview. Now team members feel that they are missing an integral component of the case review when no interview is present.

Joint reporting. The CFR Project has found that there is power in joint reporting and in joint media work that benefits all partners. The CFR and the FIMR component have some separate reports and media exposure, but at least annually, they present a major report combining the findings and recommendations. While the CFR and FIMR findings and recommendations may be somewhat different in focus, they share prevention as the common theme.

Coordinating CFR and FIMR in Palm Beach County has many benefits:

- ▶ The strength of shared staff—including professional expertise and bilingual capability.
- ▶ Increased funding from community agencies when they understand they are funding the full continuum of cases, from fetal and infant through age 18—FIMR and CFR are not competing.
- ▶ The opportunity to address concerns related to morbidity as well as mortality.
- ▶ Community pride for the Child Fatality Review and Prevention Project because it is based on the FIMR process and the national and state recognition and support that FIMR enjoys.

Finally, remember this one thought from Margaret Meade, the world-famous anthropologist who died in 1978:

"Never doubt that a small group of thoughtful committed citizens can change the world. In fact, it is the only thing that ever has."

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USING THE FIMR METHODOLOGY TO EXPAND THE FOCUS OF CFR

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Michigan Institute of Public Health

With about 8 deaths per 1,000 live births, Michigan continues to report infant mortality at a rate well above the U.S. infant mortality rate. The even bigger problem is the overwhelming disparity between black and white infant deaths. Because of these infant health problems, Michigan has invested in both FIMR and child death review (CDR) programs. The FIMR program in Michigan has been instrumental in shaping the process and outcomes of the CDR program. This section details the contributions that the Michigan FIMR has made.

History of Michigan FIMR

FIMR reviews began in Saginaw in 1991 and continue to the present in 9 counties. These 9 communities represent 60 percent of the infant mortality in Michigan. These action-oriented community programs are using the two-tiered MCHB model to move from recommendations to action. The state supported the development of FIMR programs in those cities and counties with the highest infant death rates. Gradually, the cities of Detroit and Pontiac, and the counties of Genesee, Kent, Kalamazoo, Calhoun, Branch, Tuscola, and Lapeer came online. Most FIMR programs review all infant deaths and selected fetal deaths. Larger projects review a representative sample of cases.

The funding for FIMR comes from a variety of sources including state general funds, local funds, in-kind contributions, the federal Healthy Start program, and the MCHB Morbidity/Mortality Collaboration grant. Saginaw received start-up funds from the National Fetal and Infant Mortality Review (NFIMR) program in 1991 and was one of the first FIMR demonstration programs in the country.

History of Michigan CFR

The Michigan CDR program titled Keeping Kids Alive started in the mid-1990s. In 1994, the Missouri Symposium on Child Death Review sparked state interest in the CDR process. In 1995, the Michigan Governor's Task Force on Children's Justice provided funding for 17 projects. Michigan made the strategic decision to base the CDR program at the Michigan Health Institute (MPHI) and to focus on the review of all types of deaths using a public health model with an emphasis on preven-

tion. The Department of Social Services also provides funding for training and technical assistance. Currently, all 83 Michigan counties participate in CDR.

The FIMR Program and Process: CDR Lessons Learned

Prevention Focus. Because of lessons learned about the FIMR process, Michigan has focused the emphasis for CDR on public health prevention, rather than solely on criminal investigation. Teams still need to ascertain whether any investigation is needed. However, in implementing a public health prevention model, Michigan CDR teams also ask:

- ▶ *Are there services that we should have provided for the family, members of the family, or others in the community?*
- ▶ *Are changes needed in agency practices or policies after a death?*
- ▶ *What recommendations should be brought forth to prevent deaths in the future?*

Team composition. Another FIMR component that was translated to CDR was team composition. CDR has been traditionally made up of law enforcement officers, prosecutors, social services representatives, and medical examiners. Pediatric and obstetric medical input was often lacking. CDR teams now include the expertise of obstetricians, pediatricians, pathologists, representatives of emergency departments, and family practice. Further there has been a benefit to FIMR, as well, because some Michigan FIMR programs have also added at least one member from the CDR team to their team—the law enforcement officer.

Prior to using the FIMR model in our CDR, teams tended to avoid perinatal death reviews because these deaths were considered to be medically complicated or not preventable. The FIMR process taught CDR is to examine some deaths considered not preventable because these cases may shed light on systems issues or need for changes in practice.

Michigan in Action

Finally, as with FIMR, child death review in Michigan is expected to lead to community action and improvement in service systems. Here are some examples of CDR actions:

- ▶ Two teenage girls died in a fatal automobile crash on homecoming night. They were returning from a post-homecoming party and were hit by another teen who was driving under the influence. The community needed much support after this event; 6,000 people visited the funeral home. The community's need for healing and for closure generated team action at prom time. The team developed educational materials and gave school sessions about the issues of drunk driving and safe partying and appointing designated drivers.
- ▶ Two streets in a community had a similar name—Adams Boulevard and Adams Avenue. Because an ambulance reported to the wrong street, a child died. After that incident, the 911 system was revamped and the street names were changed.
- ▶ In several communities, teams reviewed cases in which babies who had been abandoned in trash cans or alleys died. Now Michigan has recently passed the Safe Newborn Abandonment Act. Now, within 72 hours of the delivery, a woman can give up her infant with no legal consequences as long as she surrenders the infant to a "safe haven," such as a hospital, the police department, or the fire department.

Peter Vasilenko, PhD, a professor at Michigan State University in the College of Human Medicine

and a longtime FIMR team member and Terri Covington, Program Director for Child and Adolescent Health at MPHI have developed a conceptual model for triaging an infant death so that FIMR and CDR reviews are not duplicated. The two processes are kept separate. After the infant death has been identified, the FIMR and CDR coordinators review information from birth certificates and death certificates, and make a joint decision to forward the case for either FIMR or CDR review.

For example, a child homicide will be referred to CDR because of some of the issues regarding prosecution. In the Michigan CDR reviews, the infant's name and date of death are sent out and all the agencies involved bring their records to the table. CDR reviews are confidential but not anonymous. On the other hand, perinatal cases involving multiple service system issues or opportunities for public health prevention are forwarded to FIMR. The Michigan FIMR follows the MCHB model with the maternal interview, case preparation, case summaries, two-tiered team review, and a process leading from recommendations to action. FIMR cases are confidential and de-identified. Names of families, providers, and institutions are removed.

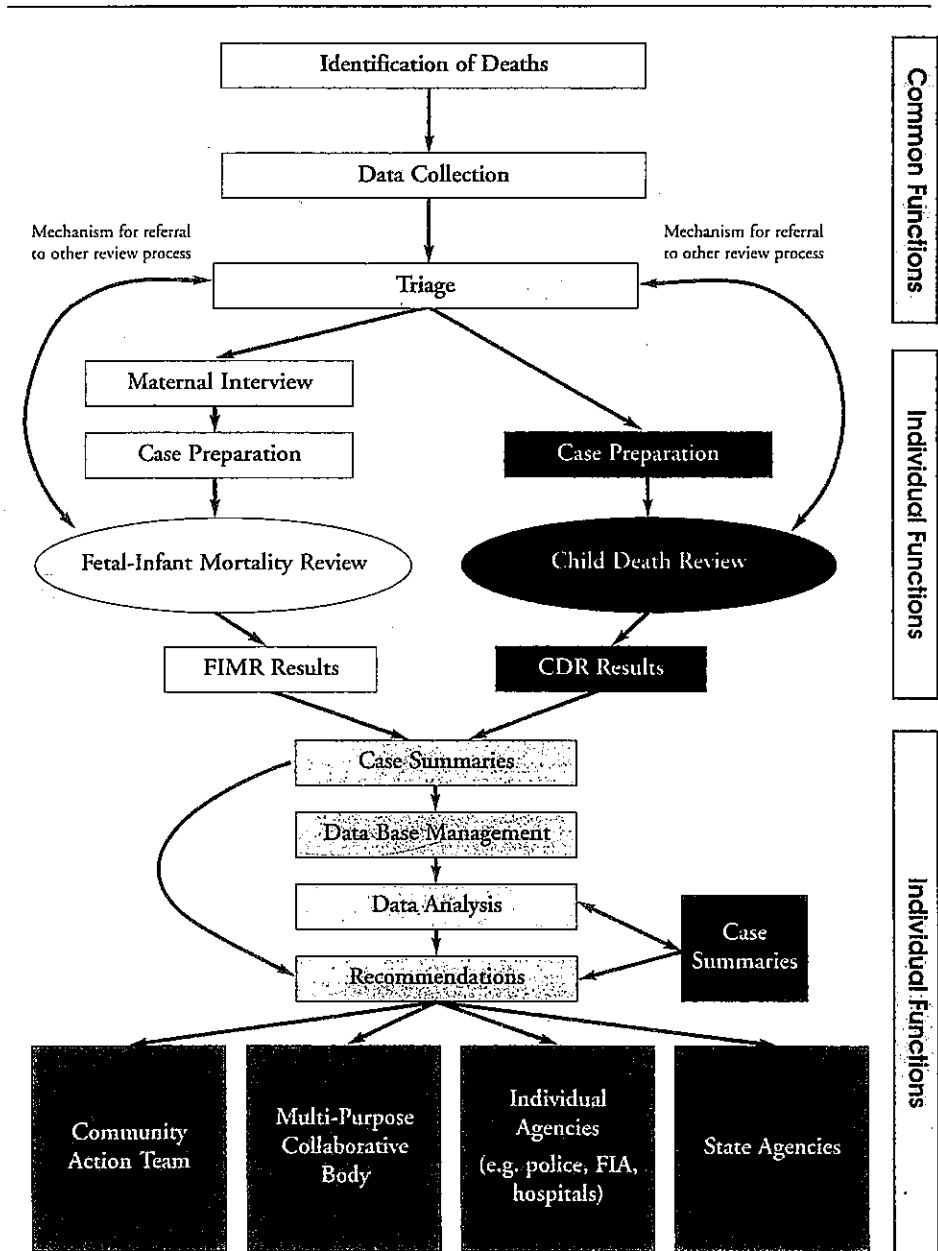
Currently CDR team findings and recommendations for the state of Michigan are published in an annual report. FIMR recommendations have historically been used locally and may be forwarded to the Community Action Team (CAT), multi-purpose collaborative body, individual local agencies, or state agencies. Reports go to those entities that have the ability to create meaningful change.

Communities in Michigan are recognizing the power in joint FIMR/CDR reports. There is movement toward publishing a joint annual report in Michigan using both FIMR and CDR review—not just on a local level, but to build state Title V capacity through needs assessment, policy development, and the continuous quality improvement. Last year, the annual CDR report caught the attention of Michigan lawmakers. A joint report would

only strengthen our ability to raise awareness among our state and local officials as well as the citizens of Michigan on how we can prevent infants and children from dying. In conclusion, the

Michigan goal for FIMR/CDR reviews has been and remains that they expand their potential to prevent deaths and to improve the lives of Michigan's women, infants, children, and families.

COORDINATING FETAL-INFANT MORTALITY AND CHILD DEATH REVIEW IN A COMMUNITY



EXPANDING MATERNAL MORTALITY REVIEW

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After seven years of FIMR implementation, the New Jersey Department of Health and Senior Services decided to expand its process of MMR using several FIMR principles. This presentation discusses the history of maternal mortality in the state, discusses the process of expanding the maternal mortality review, and describes the outcomes.

History

New Jersey has been reviewing maternal deaths since 1931. At that time, the Medical Society of New Jersey had the lead role for maternal mortality review. The Department of Health and Senior Services provided technical assistance by forwarding death certificates for case identification and facilitating access to medical records in the hospitals and medical examiners' offices. To ensure the strictest confidentiality, the Medical Society held an annual

meeting closed to all but team members in the society building. The Medical Society defined maternal death as any death that occurred within 90 days of the pregnancy-related event. To avoid discovery or subpoena, the Medical Society did not keep records of its meeting, input case data, or produce reports. It did use the findings from case reviews to target continuing education to physicians in New Jersey. The Medical Society continued reviewing cases in this way for 40 years. In 1974, the New Jersey Department of Health became involved in the process. They continued reviewing records together until 1997.

In 1996, the New Jersey assistant commissioner of health attended the joint Centers for Disease Control (CDC)-American College of Obstetricians and Gynecologists (ACOG) session on maternal mortality that is held at ACOG's annual clinical meeting. The participants discussed the benefits of

The Florida MMR Model

In Florida's pregnancy-associated mortality review (PAMR) program, not only terminal event records, but also medical, social, and psychological information from prenatal care, labor and delivery, postpartum records, social service records, and care coordination/home visiting, are abstracted. Once all this information has been gathered, identifiers are removed, and a case summary is written. Confidentiality is key. No provider, institution, or family identifiers are included. All review team members sign a pledge of confidentiality before each review. The team members are protected and held harmless based on Florida statutes sections 395.3025 (4), 405.01, and 405.03. The review aims to foster improvements in systems of care by identifying gaps in care, systemic service-delivery problems, and areas in which linkages between community resources can be improved; the review makes recommendations for improvements.

The Florida PAMR team is a multidisciplinary committee; it includes representatives from the Florida Obstetrical and Gynecological Society; Midwife Resource Center; Association of Women's Health; Obstetric and Neonatal Nurses; Regional Perinatal Care Centers; Florida Medical Society; National Association of Social Workers; Florida Association of Healthy Start Coalitions; Florida Nurses Association; Alcohol, Drug, Abuse and Mental Health; Domestic Violence; Florida State University Center for Prevention and Early Intervention; Florida Department of Health; Florida Public Health Association; Florida Pediatric Society; Florida Perinatal Association; Medical Examiner's Commission; Vital Statistics; Florida Association of Nurse-Midwives; and county health departments. Team members volunteer their time and travel costs. The review team meets quarterly to review de-identified cases. They examine trends and formulate strategies to address issues identified (Adapted from the Florida PAMR Data Report, 1997-1999).

matching death and birth certificates to ascertain the true number of deaths. The Florida state Title V director described the Florida pregnancy-associated mortality review (PAMR) model in detail. The CDC presented its expanded definition of maternal mortality:

“the death of a woman, from any cause, while she is pregnant or within one year of termination of pregnancy, regardless of duration and site of pregnancy.”⁽¹⁾

In light of the recommendations of that meeting, the Department assessed New Jersey’s maternal mortality review process and realized that the process had some limitations, including the following:

- ▶ The New Jersey model was a traditional medical review. Social, cultural, and health systems factors were not assessed.
- ▶ The case identification method left some deaths undetected.
- ▶ There was no standardized data collection or analysis.
- ▶ There was very limited use of the review findings and recommendations to develop state policy or programs.
- ▶ The reviews did not take a public health approach or result in enhanced public health in the state.

The Department decided to increase the scope of the reviews to become an action-oriented, public health MMR process. Taking a lesson from FIMR and Florida’s PAMR, the department also wanted to make the reviews less vulnerable to discovery by using de-identified case summaries rather than the actual medical records. The Commissioner of Health explained the rationale for an expansion to the Medical Society. After discussion, the Medical Society agreed to pilot the new process.

Pilot of New Maternal Mortality Review

From 1999 through 2001, the New Jersey Department of Health and Senior Services assumed the responsibility for the revisions and the pilot process. After consultation with attorneys from the Health Department, the new review deliberations

were deemed to be not discoverable and the team members not subject to subpoena under New Jersey laws (NJSA 26: 1A-37, 37.2, 37.3, NJAC 8:33-1.5).

The Department contracted with one of the maternal child health regional consortia in New Jersey to help it develop the process. The state wanted to accomplish several goals:

- ▶ Improve reporting of maternal deaths by 1) expanding the definition of the pregnancy-associated mortality to one year; 2) identifying cases by matching death certificates with birth certificates; and 3) analyzing hospital discharge data to identify maternal deaths.
- ▶ Expand the multidisciplinary membership of the case review team (CRT).
- ▶ Standardize the data abstraction method.

At the onset, the ability to identify the maternal deaths improved significantly. Using matched birth death files and hospital discharge data, case ascertainment increased by 50 percent.

To provide continuity, the chairperson of the former Medical Society Review Team continued as the new committee chair. The team increased its membership to 20 members. Ten were physicians, and the other members included nurses, nurse-midwives, social workers, public health personnel, a minority advocate; a substance abuse provider, an obstetrics anesthesiologist, a risk manager and an emergency medical service representative. They continued to review the medical issues, but members also examined the social, economic, cultural, and health systems factors associated with each case. The information that the team found as part of the review, as well as its recommendations, was captured on a standardized summary form, which is again very similar to the Florida FIMR. The team completed those forms after each review and summarized a wealth of information. Their recommendations and findings will now be used to conduct needs assessment and develop local and state programs and policy.

During the pilot, the case review team members completed a written satisfaction survey about their participation in the reviews to ascertain the value of the process for the members and to learn if the members used the findings. The overwhelming

majority commented that they had found this process to be very beneficial to them. Even the physicians who were involved in the old process remarked that these expanded reviews have raised their awareness of the other factors involved in maternal deaths.

Finally, the Department standardized a maternal mortality database using the maternal mortality data abstraction forms developed by the Florida Department of Health. Using forms already developed and tested saved a significant amount of time and expense, an approach the team members say they would recommend to any other states wishing to expand their maternal mortality reviews. With this ability to analyze consistent data elements, the Department will be able to study trends in maternal deaths over time.

During the 2-year pilot, a nurse, using the standardized forms, abstracted information from each case on site. The nurse who abstracted the data wrote up a de-identified case summary similar to the Florida's PAMR. And this case summary was presented to the CRT when it met.

Outcomes

In 2001, the Medical Society and the Department of Health and Senior Services completed the pilot program and agreed that it was a resounding success. The expanded maternal mortality reviews are now ongoing and institutionalized within the Department of Health and Senior Services.

One of the most surprising outcomes is that the process has garnered increased visibility and positive feedback across the state. After three-quarters of a century, the review process is still confidential and de-identified but no longer secret. Providers and consumers alike now understand the need for maternal mortality review. They are proud of the new

comprehensive program and eager to read about the findings and recommendations.

On the state level, the CRT functions as a community action team (CAT). That is, the team members are the ones who have made recommendations for state initiatives. These members were deliberately chosen because they are state change agents and could help the department implement systemic improvements, when needed.

At the local level, the findings and recommendations from the reviews will be presented to each of New Jersey's seven Maternal Child Health Consortia. The Maternal Child Health Consortia in New Jersey coordinate maternal and child health services at the local level. They will work with coalitions, such as Healthy Mothers-Healthy Babies, to take that information and implement community-specific improvements within their regions.

Plans

New Jersey applied for and has been awarded a new mortality and morbidity review grant from the federal Maternal and Child Health Bureau. The goal of the grant is to coordinate death reviews. New Jersey plans to coordinate maternal mortality review with FIMR and CFR by sharing recommendations between the teams.

Finally, the state is exploring the possibility of developing one very comprehensive data abstraction tool, which will allow data collection across the whole maternal-child health spectrum. Such a tool would enhance the state's ability to standardize analysis, make recommendations, and decrease duplication of efforts. Combining these efforts will ensure improved services and resources to mothers, children, and families in New Jersey.

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1. Centers for Disease Control and Prevention. Strategies to reduce pregnancy related deaths. Atlanta, GA, 2001 p 5

CONCLUSION

The FIMR process is an action-oriented, community process that uses an anonymous review of cases as a springboard to improve a wide array of local service systems and resources for women, infants and families. The FIMR process is a proven public health/continuous quality improvement paradigm. The FIMR process includes several principles that have enhanced the efficacy of CFR and MMR programs in Florida, Michigan and New Jersey. These principles include the following:

- ▶ De-identifying case reviews so that names of families, providers and institutions are confidential and anonymous.
- ▶ Ensuring a community perspective by conducting home interviews with families who have experienced a loss.
- ▶ Convening broad-based, multidisciplinary teams to study cases and make recommendations.
- ▶ Making recommendations to improve service systems and community resources, rather than pointing a finger of blame.

- ▶ Moving from recommendations to community action to improve service systems and resources for women, infants, children, and families.

This transference of FIMR components to other review processes has expanded the breadth and scope of their reviews and enriched the findings and recommendations that they generate. The MMR program in New Jersey and the CFR program in Florida de-identified their reviews and are operating as positive continuous quality improvement programs—raising standards of care for all providers, improving inter- and intra-departmental systems of care and enhancing community resources. The comprehensive CFR review in Florida, which includes home interviews, provides a better understanding of families in the broader context of their culture and environment.

All three programs are focused on public health issues with an emphasis on prevention. Once adapted, FIMR principles also firmly led all of three of these CFR and MMR programs to an action agenda, moving from case review to multiple community actions.

APPENDIX A

Comparison of Fetal Infant Mortality Review, Pregnancy-Associated Mortality Review and Child-Abuse Fatality Review

Adapted from: Florida Department of Health, July 2000

COMPARISON POINTS	Fetal and Infant Mortality Review (FIMR)	Pregnancy Associated Mortality Review (PAMR)
AGE	Ages for review—20 weeks of gestation to 1 year, and in some projects to age 3. Some projects include low birth weight.	The death of any woman pregnant within 1 year of death is included in surveillance data.
TYPE OF CASES REVIEWED	De-identified case reviews.	De-identified case reviews.
CONFIDENTIALITY	Case reviews are confidential—only aggregated information and recommendations are made public; discussion is limited to the abstracted case information and summary of interviews (no direct input from participants if they feel they know the case).	Case reviews are confidential—only aggregated information and recommendations are made public; discussion is limited to the abstracted case information and summary of interviews (no direct input from participants if they feel they know the case).
TEAM MEMBER PROTECTION	Laws that govern immunity, confidentiality, and discovery protect members of the project. In some areas this means formulation under the auspices of a specially designated sponsor (such as a medical board or health department).	Laws that govern immunity, confidentiality, and discovery protect members of the project. In some areas this means formulation under the auspices of a specially designated sponsor (such as a medical board or a health department).
COMPOSITION OF CASE REVIEW TEAM (CRT)	CRTs are multidisciplinary to represent the system of care for prenatal women, infants, and the preconception period—further, the teams are ongoing, representative of the diversity of the community, and voluntary.	CRTs are multidisciplinary to represent the system of care for prenatal women, infants, and the preconception period—further, the teams are ongoing, representative of the diversity of the state, and voluntary.

Child Abuse Fatality Review

Opportunities for Collaboration/Sharing

Birth to age 18.

Establishes a seamless approach to death reviews.

Cases are individually reviewed with all identifying information available—name of child, providers, facilities, etc., and limited to abuse cases with prior involvement by child protection agency.

Findings may verify perceptions from one team to another.

Case reviews are confidential. Open and complete information sharing regarding the cases is encouraged and may be required.

Support each other in ensuring that confidentiality is maintained—helps to keep review credible, which encourages cooperation from providers.

Law may specifically elate to child fatality review (CFR) and protect team members. Responsibility for formulation of the review is usually legally defined, as well.

Use this information to encourage participation on the teams.

Review teams are multidisciplinary with ongoing membership in law enforcement officials, social services staff, and child advocates; when involved in the case, health-care providers or other agency representatives participate.

Some core team members may cross over.

Enhance awareness of professions that interact with the MCH population.

APPENDIX A (CONTINUED)

COMPARISON POINTS	Fetal and Infant Mortality Review (FIMR)	Pregnancy Associated Mortality Review (PAMR)
IMPLEMENTATION OF TEAM RECOMMENDATIONS	<p>Recommendations of the team are implemented in a variety of ways. The range is from a formal community action committee to individual team member response to ideas generated in the case reviews. Actions may involve a variety of strategies ranging from improved collaboration to education of specific target groups (from providers to consumers). The goal of the recommendations is to improve the system of care with a focus on the processes and people involved at all levels. Sometimes the recommendations and actions are meant to maintain the quality that has been recognized in the review process as well as to add or change specific system components.</p>	<p>Recommendations of the team are implemented in a variety of ways. The range is from a formal community action committee to individual team member response to ideas generated in the case reviews. Actions may involve a variety of strategies ranging from improved collaboration to education of specific target groups (from providers to consumers). The goal of the recommendations is to improve the system of care with a focus on the processes and people involved at all levels. Sometimes the recommendations and actions are meant to maintain the quality that has been recognized in the review process as well as to add or change specific system components.</p>
PROCESS LEVEL	<p>The process is initiated at the community level. Some projects have been developed as a response to recommendations by funding sources (such as federal Healthy Start projects), and others have been developed as part of state initiatives to improve infant mortality. Some projects receive funding particularly earmarked for the process, and others may receive a variety of funds or be required to document community-matching funds.</p> <p>Most teams are constituted at the local level.</p>	<p>The process is initiated at the state level in order to develop a systematic approach to examining maternal deaths, thereby enhancing public health efforts to reduce and prevent maternal mortality. Accurately identifying the occurrence of pregnancy-related deaths is necessary for interpreting trends, identifying high-risk groups, and developing effective interventions.</p> <p>The team is constituted at the state level.</p>
PURPOSE OF PROCESS	<p>The process is used in an effort to broaden the understanding of the community and bring together a variety of experts from the community who then can help to ensure that the lessons learned are incorporated into local planning processes in a proactive manner rather than in a reactive response to each individual case.</p>	<p>The process is used in an effort to broaden understanding and bring together a variety of experts from the state who then can help to ensure that the lessons learned are incorporated in a proactive manner rather than in a reactive response to each individual case.</p>
COSTS	<p>Costs are approximately \$400 to \$600 per case. Team members contribute their time, while abstractors, interviewers, and some project staff are compensated for their work.</p>	<p>Costs per case are not yet available. Team members contribute their time and are compensated for travel. Project staff are compensated for their work.</p>

Child Abuse Fatality Review

Team findings are used in a variety of ways. In some, rule, law, or protocols are changed. In some, litigation may ensue. In some, there may be recommendations for community system change.

A variety of mechanisms to move toward implementation exist—some places have formal processes and referral mechanisms in place; others may take only individual action on the case at hand.

Reviews are initiated as a response to child abuse concerns and may focus on individual preventability of the death.

The process is a requirement of state statutes. Publicly funded for the organizing and responsible agent, team members, while voluntary, are usually covered for participation through their work relationships.

May review cases as they are prepared to be moved forward for litigation; may recommend litigation.

Teams will be at the state and local level.

The review process seeks to answer specific questions related to the performance of agencies, providers, and caregivers involved with the care or actions taken in the case and in the future will provide broader input to community planning.

Costs per case are not yet available. Team members contribute their time and are compensated for travel. Project staff are compensated for their work.

Opportunities for Collaboration/Sharing

Joint research and analysis of each team's data can establish correlation, linkages, and gaps in systems and services.

Findings can be used for planning and service delivery.

Common findings can be linked in order to strengthen recommendations for change.

Answer questions regarding status of surviving children and siblings.

Linkage allows projects to share with each other effective methods and tools in order to reduce duplication of effort.

Linkage between projects facilitates dissemination of information at state and national levels.

Linkage of the child abuse death review with PAMR and FIMR ensures the broader public health system perspective remains a part of the process.

Enhances systems of care and service delivery for pregnant women and children.

To maximize funding and training, one effective approach is to share abstractors, project staff, and grant funding.

APPENDIX B

Definitions of MCH Death Reviews¹

Child Fatality Review

The purpose of a child fatality review team is to prevent deaths. The review is generally achieved through some or all of the following activities: review or investigation into individual child deaths, service planning and provision, system study, data collection, and identification and implementation of changes to prevent deaths. Teams may be either state or local, and some states may have local as well as state teams. A caveat: In "investigating" child deaths, teams do not take over the responsibilities of the police, the medical examiner/coroner, or even child-protective services. Those agencies have and continue to have responsibility for the investigation into the cause of death. What the child fatality review team does is examine the facts and circumstances surrounding the death. That may include using the team meeting as an opportunity to provide information needed by the investigators and reviewing the investigators' activities. Many states have legislation mandating child fatality review teams. These laws often specify team membership, authority, purposes, and reporting requirements.

Fetal and Infant Mortality Review

Fetal and infant mortality review (FIMR) is a community-based action process aimed at guiding communities in identifying and solving local problems contributing to poor reproductive outcomes and infant health, with the ultimate goal of improving assessment capacity, policy development, and quality. Specifically, by using infant death as a sentinel event, FIMR is a systematic examination of factors that play a role in death, integrating information about the health of individuals with information descriptive of medical care, community resources, and health and social/welfare systems. Information from these reviews is then used to focus planning and policy development and to enhance efforts to develop and maintain community resources and quality programs for women and children. The FIMR process helps state and local health departments operate the core public health

functions of assessment, policy development, and assurance. Several types of agencies have sponsored local FIMR programs, including health departments, regional perinatal consortia, and community-based coalitions.

Maternal Mortality Reviews

Maternal mortality reviews are periodic formal reviews used to determine the factors involved in maternal deaths. Maternal mortality reviews can be conducted at the community, regional, or state level. While some are still individual institutional reviews, the Centers for Disease Control and Prevention now recommends a broad-based review of systems of care for women of childbearing age, which includes a diverse professional and community review team membership.

MCH Morbidity Reviews

MCH morbidity reviews are community reviews of sentinel events (e.g., injuries, children with special health-care needs, maternal and infant transport, or surviving low-birth-weight infants) that may result in significant morbidity. These reviews seek to improve the overall services and resources for women, children, and families in the community being reviewed as well as to improve specific services for those families most affected by the adverse outcome or event. Typically, the method or process for conducting these reviews is patterned after the FIMR method, and the reviews are confidential and anonymous.

SIDS Programs

By definition, SIDS is the death of an infant between the ages of one month and 1 year without expectation or explanation. Establishing SIDS as the cause of death involves ruling out anything that might explain the death—it is a diagnosis of exclusion. One activity that SIDS programs undertake is to define how a diagnosis is made. While each local jurisdiction sets out the information required to determine the cause of death in a sudden, unexpected infant death, protocols usually include an autopsy, a death scene investigation, and a medical history, collectively known as a SIDS investigation.

¹ These descriptions are taken from federal MCHB's request for proposal (RFP) for Coordinating Mortality Reviews 2000.

