More First Birthdays
A Report on the Status of Fetal & Infant Mortality Review in the United States, 2018
June 2020
Grateful acknowledgement and thank you to the many local FIMR programs and state FIMR coordinators who contributed this information. Special gratitude is extended to the parents and families who have shared their stories and experiences with loss in order to prevent future fetal and infant deaths for other families. Their dedication and commitment to their communities improves the health of families.

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The National Center for Fatality Review and Prevention State Profile Database:
Reports from Fetal and Infant Mortality Review programs

Citation:
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Introduction

In the United States every year, about 23,000 liveborn babies do not survive to their first birthday. An almost equal number of babies are stillborn, without signs of life at delivery. While fetal and infant mortality in the United States has improved in the recent years, disparities persist between whites and persons of color, especially African Americans, Latinos and Native Americans.

Fetal and Infant Mortality Review (FIMR) is a community-based, action-oriented process to review fetal and infant deaths and make recommendations that spark systems-level changes and prevent future deaths. The National Center for Fatality Review and Prevention (National Center) is funded by the Maternal Child Health Bureau (MCHB) within the Health Resources and Services Administrations (HRSA) of the United States Department of Health and Human Services to provide technical assistance, training, and data support to FIMR programs across the country.

FIMR programs differ in their scope and composition of state and local teams, level of state support, placement of administrative leadership, supporting legislation, case selection methods, and reporting systems used. To better understand these similar but diverse programs, the National Center conducts a bi-annual survey of FIMR program leaders to collect additional team-specific profile data to assess the status of programs. The following report is a synopsis of 157 local and 17 state coordinator responses from 28 states in 2019 and describes programs in calendar year 2018. In 2018, there were 174 local FIMR programs operating in the United States, Puerto Rico, and the Commonwealth of the Northern Mariana Islands (CNMI). If a team’s response was received in a previous year’s survey, but not the survey for activities in 2018, the most recent response is reported.

The purpose of this report is to provide a summary of the status of FIMR programs across the United States: how they are situated within states and communities; what agencies participate and fund them; the legal bounds in which they function; how these
factors guide case selection within states and local jurisdictions; how data are collected and used; and how these teams work to decrease fetal and infant fatalities.

The National Center provides this report with hope that it informs review teams, their partners, their local, state, and federal governments, and other concerned parties about the breadth, diversity, and impact of the FIMR process. Policy makers can use this report to develop policy agendas and to help shape the debate around how to eliminate the disparities in maternal and infant mortality.

The information in the following report is not static, as sites often make changes to their programs, adopt new legislation to support FIMR, or build new and expand existing teams; but the following information provides a comprehensive snapshot of the status of FIMR in the United States. More complete information and links to individual programs can be found on the National Center website (URL: www.ncfrp.org).
Report Highlight Summary, 2018

Fetal and Infant Mortality Review (FIMR) is a multidisciplinary, community-based, action-oriented process where teams meet to discuss case information to better understand fetal and infant deaths.

There were 174 FIMR teams in 28 states, Washington, D.C., Puerto Rico, and the Commonwealth of the Mariana Islands.

82% of these teams are coordinated by state or local health departments. Others are led by hospitals, Federally Qualified Health Centers (FQHCs), and Healthy Start programs.

62% of FIMRs have an active Community Action Team to implement recommendations.

67% of FIMRs reviewed cases from within their own county of residence.

62% conducted parental interviews.
Most FIMR teams were enabled or mandated by statutes or administrative rules that support records access and case review.

- **Mandated, 30%**
- **Permitted, 38%**
- **Not addressed, 32%**

FIMR cases in the NFR-CRS. 211 Approved users of the National Fatality Review-Case Reporting System (NFR-CRS) by the end of 2018.

14 participating states.

Over **3200** FIMR cases in the NFR-CRS.

FIMR teams commonly collaborate with other review processes and public health programs, including:

- **Child Death Review**
- **Healthy Start**
- **Maternal Mortality Review**
- **Maternal Child Health programs**
Fetal and infant case reviews have great potential to stimulate, and subsequently reflect, community improvement. The process itself is considered continuous quality improvement (CQI) for systems that impact maternal and infant populations. To assess the case in the level of detail required to make meaningful case findings and recommendations, a significant amount of work must be done in preparation for the review itself, and special attention given to the de-identified nature of records and of the review.

The FIMR methodology strikes a balance between having a standardized process and enough flexibility to adapt to each local FIMR’s regulatory, funding, and public structure. Having guidance and protocols for the fatality review process leads to better data, which ultimately leads to more effective prevention and systems-improvement efforts. The number of states with statutes or regulations that cover protocols for FIMR review continues to stay steady, and they determine or require:

- Confidentiality and de-identification of cases
- Access to records
- Privacy of review meetings
- Protection of reviews from subpoenas/discovery and FOIA
- Program reports
- Designation of required state and local team members
- Required review protocols
Each of these provisions is important to the integrity of the FIMR process.

Partners

The unique, multidisciplinary nature of fatality review is what makes it most effective. In particular, the impact of teams’ prevention work is increased through strategic partnerships with maternal child health programs like home visiting, the federally funded Healthy Start programs, Title V maternal child health programs, and medical care providers.

In 2018, 66% of local teams reported formal coordination with their Title V Maternal Child Health Services Block Grant Program.

The Title V Maternal and Child Health Services Block Grant of the Social Security Act of 1935, United States Code 701-710, Subchapter V, Chapter 7, Title 42 (Title V), is to create federal/state partnerships that enable each state or jurisdiction to address the health services needs of its mothers, infants, and children, including children and youth with special healthcare needs and their families. Title V is a key source for promoting and improving the health of America’s mothers and children.

Coordination with other programs

Fetal and Infant Mortality Review programs effectively coordinate and collaborate with other types of fatality review processes and public health programs. Notably, there is an enhanced alignment with federally-funded Healthy Start programs, as both programs receive funding from the Division of Perinatal Services within the MCHB. Twenty-seven local teams indicated that there was a local Healthy Start in their community, and that the FIMR was coordinating with it in some way. For example, FIMR findings may spur a community to apply for Healthy Start funding. A Healthy Start Community Action Network may also serve as the FIMR Community Action Team. FIMR aligns with the four overarching Healthy Start Goals:

1. Reduce differences in access to and use of health services
2. Improve the quality of the local health care system
3. Empower women and their families
4. Increase consumer and community participation in health care decisions
It is common that a case that falls under the purview of FIMR may also be selected for review in a different fatality review process, such as Child Death Review (CDR). Coordination between FIMR and other fatality reviews is considered a best practice. Examples of different ways that FIMR teams report collaborating with CDR include:

- Assigning one agency to coordinate/administer CDR and FIMR
- Consolidating staff resources
- Partnering on grant applications
- Coordinating trainings
- Establishing a dedicated staff member who participates in both CDR and FIMR

Of the 17 state coordinators who responded, 11 reported coordinating with their local CDR. In addition to coordination with these programs, many FIMR programs benefit from specialized analyses by epidemiologists who support them in case selection, including through the perinatal periods of risk analysis (PPOR).
Teams

The FIMR process is a two-tiered model. A Case Review Team conducts an analytic function, and a Community Action Team performs an implementation function. While the majority of reviews occur at the local level, some programs are supported by state-level coordination or reviews.

Structure

Case Review Teams

Case reviews are conducted by a Case Review Team (CRT). Team participants are often frontline providers, bringing relevant content and procedural expertise to case review meetings, providing institutional and professional context to help create the full picture of how and why a baby died. Teams conduct root cause analyses to identify risk factors, protective factors, and systems gaps. This information is used to create recommendations that are then delivered to a Community Action Team (CAT) whose role is to implement these findings-based recommendations in the community.

There were 174 FIMR teams in 28 states and the District of Columbia, Puerto Rico, and the Commonwealth of the Northern Mariana Islands (CNMI) in 2018. Twelve jurisdictions have a single team; the remaining jurisdictions range from having 2 to 31 teams.

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Case Review Teams are made up of professionals who commonly deliver services to maternal and infant populations. They provide their expertise on how systems interact with families, maternal and infant medicine, social service programs, and other important perspectives to help teams get a clear picture of deaths and their contexts. Composition of these teams varies, but standard participating organizations for the case review process include:

- **Obstetrician/Gynecologists**
- **Pediatricians**
- **Maternal/Fetal Medicines**
- **Child Welfare**
- **Family Planning**
- **Women, Infant, & Children (WIC)**
- **Medical Examiners or Coroners**
- **Managed Care Plan Representatives**
- **Law Enforcement**
- **Maternal Child Health Professionals**
- **Mental Health Professionals**
- **Community Advocates**

More than half of FIMR teams included mental health professionals, pediatricians, child welfare representatives, and OB/GYNs. Two-thirds of teams had social workers. Another 43% had representation from family planning programs, and 28% included a Medicaid representative.

**Community Action Teams**

**Community Action Teams (CAT) are most effective when comprised of community decision makers.** This allows them to implement community improvements recommended by CRTs. These teams develop creative solutions to improve services and resources for families and work with the community to implement interventions to improve services and resources. Among responding local programs, 98 (62%) indicated they had a two-tiered system including a CAT in 2018.

**FIMR teams reported 98 local Community Action Teams.**

Successful CATs include two types of members: those who have political will and fiscal resources to implement larger-scale systems change, and those who can best define a community perspective on how to create the desired change in the community. Some FIMR
programs have integrated “consumers” into their CAT, individuals who live, work, worship, and play in the FIMR catchment area and use its services and resources. Examples of CAT membership may also include: members of the city council, CEOs of local hospitals, the director of the local medical society, those who sit on housing and redevelopment authorities, social services, schools, the CEO of the managed care organization, clergy, local March of Dimes chapter members, and representatives from the Chamber of Commerce.

State vs. local models

The majority of FIMR teams review cases in their local communities. Local teams commonly review deaths from within a specific county; occasionally they are from a more specific area of the community. Some states with multiple local FIMR teams have a state coordinator; fourteen of them responded to this survey. In states with several FIMR teams, case review data funnels up to a state program or agency, contributing to a larger, state-level dataset to support broader prevention efforts. Some state programs select certain cases to review for quality assurance, or to inform the state team and contextualize the data from local programs. States’ approaches vary based on a number of factors, including infant mortality rates and rates of disparities, state statues, geography, population size and density, funding, and program staffing.
Staffing

Programs have diverse levels of funding and staffing to support state FIMR activities. These are significantly impacted by state budgets and competing priorities. At the local level it is very common for FIMR staff to also hold other roles or responsibilities in their local communities. In addition to having a program or team coordinator, many communities also have a parental interviewer. In some communities, the coordinator serves in both roles. The reported median FTE for local programs was .5 in 2018.

The amount of staffing and financial support drives program capacity and, ultimately, success in obtaining parental interviews, caseloads, and case selection criteria. The most common source of funding that states allocate to support FIMR are Title V Block Grants—or Maternal Child Health (MCH) Block Grant funds.

Statues and rules that apply to FIMR

Some states have legislation or administrative rules that mandate FIMR. More commonly, FIMR is enabled or permitted by state statute or public health code, code that allows entities to share personal health information for the conduct of “public health surveillance, public health investigations, and public health interventions”.

These protections may make it easier for teams to access case records for review, create a reporting mechanism for teams to inform specific agencies, the governor, or legislature of their findings and recommendations, or require agencies to respond or act on FIMR recommendations. Permissive language generally facilitates a more responsive programmatic approach. In general, whether mandated language or

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1 HIPAA Section 164.512(b) Public Health Disclosures
permissive language, a higher level of specificity in legislative language can sometimes limit program flexibility.

**Lead Agency**

While most FIMR programs were coordinated by local health departments in 2018, others were coordinated by Healthy Start programs, other perinatal coalitions, or hospitals.

82% of state local FIMR teams were coordinated by health departments in 2018.

**Regions**

Fatality review is a unique function within states and communities, and coordinators often do not have local colleagues who can share lessons learned, provide input, or give advice from a place of in-depth programmatic understanding. **The National Center supports five regional**
collaboratives for local and state FIMR program participation, divided into West, Midwest, Southern, Central, and North Atlantic. Local and state coordinators and other FIMR personnel and team members participate in regional collaborative opportunities, including community of practice calls to:

- **Create a “virtual” learning collaborative around FIMR and infant mortality reduction issues**
- **Strengthen support available to local and state FIMR coordinators and team members**
- **Exchange Information**
- **Share successes**
- **Provide mutual problem solving**

Each region has a facilitator from one of the participating states who works closely with the National Center to plan and execute regional activities. The regional networks provide quarterly opportunities for state FIMR coordinators to interact with professional peers, share resources, learn from colleagues, and provide professional support on a regular basis. Regional networking calls provide opportunities for shared problem solving and mentorship between coordinators. Additional opportunities exist for the broader field of all coordinators.
Case Selection

The selection of cases to bring to case review also varies by program.

Most communities select cases for review based on risk and/or population factors such as vital statistics data.

They also consider information about the causes of infant mortality and how these statistics change over time. Many communities attempt to review all cases of fetal and infant death that occur in a calendar year to give them a better picture of the risk and protective factors in the community and its services and resources overall.

Of the FIMR program respondents, almost two-thirds (67%) report they review cases of fetal and infant death of residents from their county.

Some programs select cases from known high-risk areas such as a city or residents of certain zip codes. Especially in more rural settings, a FIMR program may include multiple counties for case selection and review, creating a regional team. Thirteen percent of teams reported using a regional approach.

Cachment area for case reviews is most commonly at the county level.
Case selection criteria are influenced by multiple factors in addition to geographic catchment area including:

- **Lead agency**
- **Public health priorities**
- **Program capacity**
- **Residency of mother**
- **Cause/manner of death**
- **Observed disparities in outcomes**
- **Fetal/infant age**

**This diversity of case selection criteria creates important context when examining FIMR data from the state level or aggregated at the national level.** While few communities are able to review 100% of their cases or review a completely representative sample of cases, limiting the use of FIMR data at the population level, the details and qualitative information provided through FIMR reviews provide context to and enrich examinations of population-level statistics in fetal and infant death cases.
Parental Interviews

As a community-level quality improvement effort, FIMR aims to identify the gap between institutional-policy intent and actual end-user experience; FIMR parental interviews are vital to fulfilling this aim. With stakeholders from multiple sectors providing case-specific information, FIMR teams are uniquely positioned to see the system at work: how many medical appointments the mother had, how well her baby was growing, whether she enrolled in WIC, if she received safe sleep education, and much more. With the sheer amount of administrative record information assembled in case summaries (medical, mental health, public health, social service records to name a few), teams can get the sense that they have a complete picture of what happened and why, based solely upon these records. However, without a parental interview, the picture is crippling incomplete.

No matter how well documented, case summaries that rely exclusively upon administrative records show only one side of the story, and that side is the institutional one: the side with the power and the resources. Without the family side, the side that is way too often alone and disenfranchised, this picture is incomplete. With an incomplete picture, teams will face significant challenges identifying true system gaps.

The value of parental interviews is well-recognized by FIMR teams, with 6 out of 10 FIMR respondents (62%) reporting they conduct them.

While not necessarily the primary goal of the interview, participation can help the families themselves in multiple ways: giving them an opportunity to tell their story, the knowledge that they are helping identify system problems that may save other families from such tragedy, facilitating their grief process, and linking them to bereavement or community resources.

Testifying to the challenges inherent in securing these interviews, FIMR respondents who conduct parental interviews report that, on average, just 28% of all possible interviews are
conducted. Most of these teams, in fact, report completing interviews for a quarter or less of their cases. Obstacles cited by both FIMR respondents who conduct parental interviews as well as those who do not are outlined below.

- **50% of local FIMR respondents:** Obtaining accurate contact information and finding the parent or other family member
- **18% of local FIMR respondents:** Lack of funding for staff to do parental interviews
- **11% of FIMR respondents:** Discomfort of staff with the interview process itself
- **9% of local FIMR respondents:** Inadequate or absence of staff training, and resulting discomfort with their ability to address parental grief

Teams have overcome these challenges in a variety of ways. They have partnered with evidenced-based home visitation programs for developing the interview process as well as conducting the interviews themselves. This can counter limitations in funding and staff capacity. Other teams have extended their abstractions to include contact data so that they have the most updated and comprehensive contact information possible. Trainings, materials, and technical assistance at the state and national level have proven invaluable for increasing FIMR staff skillsets and comfort levels. Clearly more is needed, however, to raise interview numbers and to empower FIMR staff so they have the time, the skill and the knowledge to reach parents and families.

*In sum, parental interviews are essential for effectively identifying gaps and informing potential solutions, the very essence of FIMR programming.*

The interviews can be a means for helping heal the very families suffering these terrible losses, and they have the potential to lift up the voices of people who have been silenced by racial or social discrimination.  

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The National Fatality Review-Case Reporting System

In 2005, the National Center initiated its web-based National Fatality Review Case Reporting System (NFR-CRS) and made it available at no cost to all local and state Child Death Review teams. **In April 2018, the system was expanded to include data collected by FIMR teams across the country.** Since that time, more and more teams have executed data use agreements with the National Center to join and use the NFR-CRS. By the conclusion of 2018, there were 211 approved FIMR users of the system from 14 states, with over 3200 FIMR cases entered.

_The nature of in-depth multidisciplinary case review through record sharing and deliberation provides more contextual data, family history data, data on underlying health disparities, risk and protective factors, and community systems to inform robust policy recommendations, service delivery improvements, and prevention and programmatic planning._
The system is designed to systematically collect, analyze and report comprehensive data on the deaths of each infant and child, including risk factors by cause of death, services needed, provided or referred and recommendations for, and actions taken, to prevent deaths.

The integration of FIMR into the system was an important step to facilitate standardized data collection and enhanced ability to analyze and use review findings to inform communities and the greater MCH field.

To make this rich data resource available for further analysis and study by maternal child health researchers, the National Center developed data dissemination policy and procedures through which researchers can apply to use the data. An external committee of scientists, fatality review coordinators, and federal partners review research applications. In the future, articles by researchers who used data from the NFR-CRS may be a powerful tool to help inform policy and practice, and to understand how and why babies die. Data from FIMR case reviews will be available for research requests in 2021.

By the end of 2018, there were 211 local FIMR users of the NFR-CRS from 14 states. Together they had entered over 3200 cases into the system.
Prevention

A hallmark of FIMR is the way teams and communities use their findings by translating them into meaningful actions. Teams are effective in seeking solutions to prevent the types of deaths they review and have a strong focus on primary and secondary prevention and systems-level improvements. They are encouraged not to focus on individual-level responsibility or blame-finding when reviewing cases, but rather to focus on broader issues that communities can improve and that impact the most people.

Examples

Baltimore, Maryland

In almost 60% of FIMR cases reviewed, mothers experienced their first birth as teens and, consistent with the literature, seemed to have poorer health in their 20s and 30s contributing to fetal and infant death. The FIMR CRT recommended that young people in Baltimore City needed more support to develop their own reproductive life plans and choose family planning methods that meet their needs. They worked with the Youth Advisory Council to launch the U Choose campaign, which includes video, a web site, print materials, and swag, and uses “guerilla marketing” tactics to reach youth with reproductive life planning messages. They have subsequently been awarded a grant to conduct comprehensive reproductive health education in Baltimore City Public Schools. Through training and technical assistance on billing, they have increased the number of clinics offering the full range of contraceptive methods including IUDs and implants.

San Francisco, California

The FIMR team found that a high percent of the infant deaths they reviewed were associated with chronic maternal health conditions, including hypertension, gestational diabetes, obesity, and mental health illness. More than half of the women with chronic conditions had a pregnancy that was unplanned and needed a medical home. The team recommended that more resources should be directed to preconception and interconception counseling for women so they can plan for optimal pregnancy outcomes. The team was able to secure funding to hire an additional 1.0 FTE Public Health Nurse to address young women’s pre- and interconception health, with emphasis on interviewing women with a recent pre-term birth.
**Inter-Tribal Council of Michigan**

Consistent case reviews found that American Indian/Alaska Native (AI/AN) women experience higher rates of commercial tobacco use before, during, and after pregnancy. The Inter-Tribal Council (ITC) FIMR team recommended that families have improved access to evidence-based and culturally appropriate commercial tobacco cessation services. In partnership with the Michigan Department of Health and Human Services, the ITC promoted the Michigan Tobacco Quitline and American Indian Commercial Tobacco Program within all tribal programs and communities. They also convened a network of trained Smoking Cessation and Reduction in Pregnancy Treatment (SCRIPT) providers in five tribal communities where they are actively serving families. To specifically address sudden unexpected infant deaths (SUIDs), the ITC developed an online course for new parents called The Power of Your Newborn (URL: www.itcmi.org/newborn), a culturally-grounded curriculum covering breastfeeding, breast health and healing, newborn reflexes, traditional practices, and infant safe sleep for AI/AN parents.

**Pinellas County, Florida**

Florida statute guarantees all pregnant women receive screening for Healthy Start services at their first OB appointment. Pinellas County FIMR case reviews revealed that over 92% of women were screened for services but more than 81% of women who had experienced a fetal or infant loss had not participated in Healthy Start services. It was recommended to increase participation and engagement by improving the way families were introduced to services and care coordination programs. Central Registration was transformed to the Coordinated Intake and Referral Program. This shift was rolled out statewide. This new program provides the best service for families by prioritizing their needs and preferences and minimizing duplication of services. The process begins with an interview to ensure effective use of local resources and to collectively track what happens to each family. Soon-to-be and new parents in Pinellas County have many care coordination options. Each program has its unique benefits for moms, dads, and other family members involved in the care of the newborn. Clients choose the desired program to participate in and are quickly connected with a care coordinator. This process has increased true interest in participation, ensuring more effective engagement.
Conclusion

The FIMR field was active and expanding in 2018. By the end of the year, there were data from over 200 approved FIMR users in the NFR-CRS, despite the system only serving FIMR teams for 8 months. Teams made actionable recommendations to prevent future fetal and infant deaths and collaborated across programs to achieve this goal. The diversity of various aspects of these programs reflects the diversity among the communities in which they operate. The information from the bi-annual state profile surveys provides an opportunity for FIMR programs to learn from the structure, methods, and experiences of other programs to support ongoing efforts to review fetal and infant fatality cases to inform prevention efforts, make communities safer for families, and ultimately save lives.

For more information about FIMR in the United States, please contact the National Center for Fatality Review and Prevention at info@ncfrp.org.