

State Mortality Reviews

State Title V Role in Maternal and Child Mortality Reviews

Earlier this year the **Association of Maternal and Child Health Programs (AMCHP)**, in partnership with the **National Fetal and Infant Mortality Review Program (NFIMR)** and the federal **Maternal and Child Health Bureau (MCHB)**, surveyed all Title V directors. The purpose of this survey was to identify types of maternal and child health mortality reviews occurring in each state, the purpose and characteristics of each type of review, relationships between the different review processes, and the role of the state Title V agency vis-a-vis each type of review.

Highlights of the Survey

Each of the 49 Title V programs responding to the survey reported having a role in at least one type of mortality review:

- fetal and infant mortality (FIMR)
- child fatality (CFR)
- SIDS
- maternal mortality (MMR).

Title V roles included providing technical assistance and funding, receiving mortality review reports, and using data from the reviews to complement or expand their assessment. Fifteen of the responding states coordinate mortality reviews at the state level, usually FIMR and MMR. Coordination examples include assigning the same coordinator to manage reviews, blending funding, combining information from reviews into one report.

Coordination of mortality reviews is more frequent at the local level than at the state level. Activities identified most frequently include cross representation of review panel, sponsorship by the same agency and sharing management staff.

Conclusions about the type and extent of Title V MCH program involvement

1. The State Title V Program was and continues to be a critical partner in the development, implementation and/or funding of comprehensive infant, child and maternal mortality review activities.
2. The States recognize the importance of both identifying and responding to issues raised by the death of an infant, child, or woman.
3. Formal and informal interagency coordination enhances information sharing among mortality review teams.
4. Many local communities have successfully consolidated and blended mortality review processes.
5. The states are at an earlier stage in consolidating and coordinating mortality review processes. Initial state efforts focus on cross representation, regional or statewide mortality reports and joint meetings.

FIMR PROJECTS

The Fetal and Infant Mortality Review process brings together key member of the community to review information from individual cases of fetal and infant death. The purpose of this type of review is to identify general community, social, economic, cultural and health systems factors highlighted by those deaths; to determine if they represent service delivery system or resource problems that require change; to develop

recommendations and assist in the implementation and monitoring of the changes. Case reviews are anonymous and confidential. Source: National Fetal and Infant Mortality Review Program.

Fetal and Infant Mortality Review (FIMR) projects have been conducted since 1988 but the majority of existing FIMRs started during 1990 to 1993. Over one third (35%) of the states reported their FIMR project began as a state Title V initiative, 29% began as a Title V partnership with another organization, and an additional 20% began as a federal initiative like Healthy Start.

Funding Sources Identified for FIMR Projects

Sources for on-going funding vary and FIMR projects often have multiple funding sources. State Title V was the funding source identified most frequently. Nearly one third of the FIMR projects receive some funding from non governmental sources such as business, hospitals, nonprofit agencies, foundations and medical associations.

Funding Sources Identified

124 responses from 27 reporting states

- 29% State Title V
- 21% Other
- 16% Federal Healthy Start
- 10% County/City Health Department
- 10% Other Federal Agency
- 6% Private Foundation
- 5% Local Non-Profit Agency

Leadership of Local FIMR Projects

Local health departments, in addition to contributing funding, play a major role in leadership of FIMR initiatives. Agencies including tertiary care hospitals, regional perinatal councils and community coalitions also play a significant role in leadership.

Primary Purpose of FIMR Projects

Title V program directors identify improving service delivery systems as one of the primary purposes for establishing FIMR (24 of 27 responses).

Other purposes identified include:

identifying the circumstances causing a death (22 of 27)

improving community resources (21 of 27)

developing policy (19 of 27)

CFR PROJECTS

Child Fatality Review teams are formed to review systemic responses to individual cases of child fatality, ages 0 to 18. Purposes of the review are to clearly establish cause of death; to review investigative procedures of all involved agencies; to determine the involvement of the community with the family prior to and following the death; to identify patterns in the family, the agency or community at large that may have contributed to death; and to ameliorate the conditions contributing to preventable child deaths. Identities of cases are known and review are not confidential. Source: American Bar Association.

Child Fatality Review (CFR) projects have been conducted since 1986 but the majority of existing CFRs started during 1993 to 1997. Sixteen of the 41 of the responding states reported their CFR was a state legislative mandate; ten began as a taskforce or special initiative; and an additional seven began as a formal state inter-agency collaborative agreement.

Funding Sources Identified for CFR Projects

Sources for on-going funding vary and some CFR projects have multiple funding sources. State agencies like child welfare or social/human services were the most frequently identified funding sources (17 of 41 responses), followed closely by Title V programs (15 of 41). Other funding sources (16 of 41 total responses) identified included Commission of Child and Youth, criminal justice systems, general state funds, Preventive Health and Health Services Block Grants. Private funding sources (3 of 41 responses) were insignificant.

Funding Sources for Local CFR Programs 65 responses from 41 reporting states

- 26% State agency (not Title V)
- 25% Other (justice, general funds, block grants)
- 23% State Title V
- 6% Other Federal Agency
- 5% Other County Agency
- 3% County/City Health Department
- 3% Local Non-Profit Agency
- 2% Private Foundation
- 2% Federal Healthy Start

Leadership of Local CFR Projects

Local health departments play a major role in leadership of CFR initiatives. Child welfare, social service, law enforcement and other agencies also play a significant role in leadership.

Primary Purpose of CFR Projects

Title V program directors identify improving service delivery systems as one of the primary purposes of CFR (37 of 41 responses).

Other purposes identified include:
identifying the circumstances causing a death (36 of 41)
developing policy (33 of 41)
improving community resources (26 of 41).

SIDS INVESTIGATIONS

Sudden Infant Death Syndrome Death Investigations are within the medical/legal system for any sudden unexpected infant death. The purpose of this investigation is to determine the cause of death. Local jurisdictions dictate the information required to ascertain the cause of death. Protocols generally include an autopsy, death scene investigation and medical history. SIDS investigation cases may be subsequently reviewed with FIMR and/or CFR processes. Source: Association of SIDS and Infant Mortality Programs.

Sudden Infant Death Syndrome (SIDS) investigation projects are conducted in 34 states. Five of these states have integrated the SIDS investigation into their CFR process.

Funding Sources Identified for SIDS Investigations

SIDS investigation projects have multiple funding sources and a more diverse base than either FIMR or CFR. Title V was the most frequently identified funding source (27 of 34 reporting states). Other (identified as medical examiner's office, legislative appropriations, hospitals, and volunteers) provided funding for 10 of the 34 reporting states. Private foundations ranked third (5 of 34). Local health departments (4 of 34) and state agencies (4 of 34) ranked fourth as funding sources.

Funding Sources for local SIDS Investigation Programs 136 responses from 34 reporting states

- 48% Title V
- 18% Other (medical examiner, legislative appropriations, hospitals, etc.)
- 9% Private foundations
- 7% County/City Health Department
- 7% State agency (not Title V)
- 5% Other county agency
- 4% Local non-profit agency
- 2% Other Federal agency

Leadership of Local SIDS Investigation Projects

Local health departments also play a major role in leadership of SIDS initiatives. Leadership roles are nearly evenly distributed among law enforcement, state professional groups, and other agencies (including medical examiner/coroner, emergency medical services, hospitals, medical schools, private foundations).

MATERNAL MORTALITY REVIEW

Maternal Mortality Reviews are periodic formal reviews to determine the factors involved in maternal deaths. Source: Centers for Disease Control and Prevention.

Maternal Mortality Review (MMR) projects are conducted in 32 states. The need to identify the circumstances associated with the cause of death (25 of 32 responding states) and improving service delivery systems (19 of 32) were the most frequently specified purposes for conducting an MMR.

Purpose for Conducting an MMR 78 responses from 32 reporting states

- 32% Identify circumstances that caused death
- 24% Improve service systems
- 18% Peer review process
- 14% Policy development
- 12% Improvement in community resources
- 8% Agency quality assurance
- 8% Other

- 3% Support for bereaved families

Title V Role in MMR Projects

The major roles assumed by state Title V programs are technical assistance (23 of 32 reporting states), receive reports on deaths (17 of 32), use project outcomes to complement state needs assessment (15 of 32) and provide summary reports to legislative or other administrative bodies (14 of 32).

Coordination Of Local Mortality Reviews

At the local level slightly over half of the states (25 of 41) report some degree of coordination exists among mortality reviews. The type of coordination and type of review vary significantly. Separate teams with cross representation is the function identified most often. FIMR/CFR review coordination is occurs most frequently.

SIDS investigation members participate as members of the FIMR and CFR review team in 19 of the 28 reporting states. SIDS professionals and medical examiner/coroner participate most often on FIMR teams. The medical examiner/coroner and police participate most often on CFR teams.

Coordination of State Level Mortality Reviews

The majority (29 of 48) of reporting states do not coordinate mortality reviews at the state level. The state Title V directors that do coordinate reviews at the state level report coordination between FIMR and MMR most often. Appointment of the same program coordinator to manage different reviews is the coordinating function Title V directors identify most frequently.

ROLE OF THE TITLE V PROGRAM

Title V programs play a variety of roles in their interactions with mortality reviews. These roles can be classified as **process roles** that assist local programs in carrying out the reviews and **outcome roles** that use the information garnered from the reviews for analysis. The most frequently identified process roles are funding and technical assistance. Using information from the reviews to complement and/or expand the state Title V needs assessment is the outcome role cited most often.