

Perspectives on State Title V Programs' Involvement in FIMR Programs

Holly Grason, MA,^{1,3} Gillian B. Silver, MPH,¹ and State Title V Program Representatives²

Objectives: The aim of this paper is to explore the involvement of state Title V programs in fetal and infant mortality review (FIMR) programs. *Methods:* On the basis of information from four data sources, this article explores interactions among state Title V and FIMR programs, and considers recommendations regarding how these connections can be fostered for their mutual benefit. *Results:* A brief history of state Title V engagement with FIMR programs is reviewed. Examples of state Title V–FIMR interactions are provided as suggestions for consideration by other states. *Conclusions:* Fetal and infant mortality review programs are, by design, local interventions, but there are many instances in which state Title V agencies can play roles in individual local, regional, or statewide FIMRs.

KEY WORDS: Fetal and Infant Mortality Review Program; Title V; maternal and child health; essential public health services.

INTRODUCTION

Fetal and infant mortality review (FIMR) programs are by design local interventions. The goal of FIMR is to enhance the health and well-being of women, infants, and families by improving community health resources and service systems available to them (1). The FIMR approach involves discussion by interdisciplinary groups about fetal and infant death cases in the community and the identification of asso-

ciated health and related service and system problems. Recommended actions for addressing these problems follow from the case review process.

Beginning in the late 1980s, the federal Maternal and Child Health Bureau (MCHB),⁴ foundations and national organizations promoted FIMR through direct interaction with communities (1). Demonstrations and pilot programs were funded, program guidance developed, and the National FIMR Program (NFIMR) was established as a partnership of the MCHB and the American College of Obstetricians and Gynecologists (ACOG). A number of FIMR-related community-state relationships evolved naturally as local “experiments.”

Under Title V of the 1935 Social Security Act, state maternal and child health (MCH) programs are charged with improving and assuring the health of all mothers and children. The work of state Title V programs is focused on preventing death, disease,

¹Department of Population and Family Health Sciences, Women's and Children's Health Policy Center, Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland.

²The state Title V Program representatives are from the various states included in the case-study phase of the evaluation of FIMR programs nationwide—Annette Phelps (Florida), Joan Corder-Mabe (Virginia), Cheryl Fogarty (Minnesota), Christine Carson and Leona Shields (California), Richard Nugent (Arkansas), Maureen Edwards and Jeanne Brinkley (Maryland), Kathleen Swanson (South Carolina), Elizabeth Ferraro (New Jersey), and Pam Muth (Alaska).

³Correspondence should be addressed to Holly Grason, MA, Department of Population and Family Health Sciences, Women's and Children's Health Policy Center, Johns Hopkins Bloomberg School of Public Health, 615 N. Wolfe Street, Room E4140, Baltimore, Maryland 21205; e-mail: hgrason@jhsph.edu.

⁴From the mid-1980s until the present, the federal Maternal and Child Health program has existed under several organizational entities. For simplicity, throughout the article the program is referred to by its current organizational title, the Maternal and Child Health Bureau, located in the Health Resources and Services Administration, U. S. Department of Health and Human Services.

and disability, and assuring access to quality health care for the state's women and children. Two developments evolved in parallel, which have significant impact on state Title V programs' involvement with FIMR. First, starting as early as the 1970s and continuing today, state Title V programs assumed leadership roles in forming, maintaining, and monitoring regionalized perinatal services systems (2). Second, at the close of the twentieth century, state health departments began transitioning from the provision of direct services to broader implementation of the essential maternal and child health services, derived from the three core public health functions of assessment, policy development, and assurance (3). As a result, state Title V programs refocused their energies toward accountability for population health.

State Title V involvement in FIMRs was also fostered by MCHB's financial and technical support to further develop and encourage state roles with regard to FIMR and other similar case-based mortality reviews [e.g., child fatality reviews (CFR) and maternal mortality reviews (MMR)]. State MCH programs used federal grant funds to stimulate the development of new FIMRs in communities, support ongoing efforts, and capitalize on the outputs of the local programs. The MCHB initiated two sets of projects related to state involvement in FIMR programs in the mid- and late 1990s. The first involved competitive grants awarded to five states (Arkansas, California, Maryland, Michigan, and Mississippi) to help further promote the creation of new FIMRs and to strengthen ongoing FIMR efforts. The second set focused on coordination of FIMRs and other mortality or morbidity review programs (e.g., CFR, MMR, etc.) within states receiving grant awards (Colorado, Montana, and Virginia). Currently, MCHB is funding four states (District of Columbia, Connecticut, New Jersey, and Illinois) in a second round of the latter type of state mortality/morbidity grants; the grantee states have concluded their final year of funding, and are in the process of completing final reports.

In many instances, state Title V programs play a variety of roles in individual local, regional, or statewide FIMR programs. In this article we explore interactions among state Title V and FIMR programs by describing several different organizational structures or approaches to these relationships, and by providing examples of the roles of state Title V programs in and with local FIMR programs. We highlight the similarities between the FIMR and state Title V programs' goals, and identify specific FIMR–state Title V program interactions likely to benefit both.

METHODS

Four data sources were used to provide a cumulative set of results. First, we selected data based on responses from representatives of 88 FIMR programs to questions on funding sources, dissemination of technical case review findings, and on dissemination of policy recommendations fielded as part of the Johns Hopkins University evaluation of FIMR programs nationwide (4).

Second, we reviewed case study findings from 10 site visits to communities with FIMR programs conducted in the nationwide evaluation. The case study FIMRs include Alaska; Allegany county, Maryland; Bay, Gulf, and Franklin counties, Florida; Humboldt county, California; Vanderburgh, Indiana; Lynchburg, Virginia; Camden, New Jersey; Fayetteville, Arkansas; Florence, South Carolina; and Minneapolis-St. Paul, Minnesota. A diverse group of respondents was interviewed from each community, including individuals associated with FIMRs, local health departments, hospitals, community organizations, the medical society, elected officials, and, in 7 of the 10 sites, a representative of the state Title V program. The state Title V representatives were each asked about Title V's role in local FIMRs generally, and specifically with respect to training, technical assistance, funding and data; the state program's role in other FIMRs in the state; what prompted the state program to become involved with that particular FIMR program; and whether a mechanism was in place for communication between the FIMR program (or other FIMR programs in the state) and the state Title V program. Additionally, the directors of local perinatal initiatives, directors of the local health departments' MCH program, and FIMR directors were asked to comment on how they characterized the involvement of the state Title V program with the FIMR program. Moreover, directors of local health department MCH programs were asked about mechanisms in place for communicating FIMR findings or recommendations to the state Title V program.

A third source of information was the grant application guidance for the MCHB Special Programs of Regional and National Significance (SPRANS) competitions for the State FIMR Support Program and the State Mortality/Morbidity Review Support Program. We reviewed both guidances and abstracted final project reports to summarize the experiences of five grantee states—two state mortality/morbidity projects (Colorado and Virginia) and three states

funded under the State FIMR Support Program (Maryland, Michigan, and Mississippi).

Information from the three sources described above was compiled and shared with state Title V program leaders from case study states to glean their insights, experiences, and perspectives. The latter two data sources provided additional ideas and perspectives to the findings and recommendations presented herein: they were not used to corroborate findings obtained through review of the first two data sources. Using these data sources, we provide a more detailed explanation of the ways in which state Title V programs interact with FIMR programs.

RESULTS

Variation is observed with respect to whether and how community-based FIMR programs are organized within a state. There are statewide FIMR programs, exemplified by Alaska, where the structure evolved as a strategy to address low numbers of infant deaths and geographic challenges to convening local or regional teams. A variation on this approach is the state-level organization of FIMR programs existing in all localities in the state, as exemplified by Florida. Local FIMR programs in some states are organized regionally, as in Virginia where the FIMR programs operate at the local level but are organized regionally through the perinatal coordinating councils. Finally, some states have multicounty programs, as in both Florida and Maryland, in order to review fetal and infant deaths in rural areas where the annual numbers of fetal and infant deaths in individual counties are few.

There are many roles that the state Title V programs undertake in FIMR programs, varying by the state context. State Title V roles are observed to vary in emphasis and intensity, depending on state-specific “structural factors”: degree of centralization of the state health agency, the legal basis (or lack thereof) for establishing FIMR programs in the state, the mix of urban versus rural areas in the state, and traditional roles and relationships with other community-based perinatal organizations or initiatives (e.g., Healthy Start, perinatal consortia, etc.).

To describe the range of vehicles and activities through which state Title V programs interact with FIMR programs, we have drawn on the core public health functions as identified by the Institute of Medicine (1988)—assessment, policy development, and assurance (5). As further articulated by the Public Health Functions Steering Committee in 1994 (6), a

fourth category of function—management—is added to better enable understanding of state roles vis-à-vis locally administered programs, such as FIMR. Examples of state Title V roles and activities in relationship to FIMR presented in Table I are drawn from the four data sources described earlier.

Management

State Title V programs reported assisting FIMR programs with securing financial support by helping with applications for foundation funding, leveraging monies from community-based organizations such as Healthy Start, or directly funding the FIMR through the Title V block grant. According to the FIMR evaluation findings, 32% of FIMRs received funding from federal sources, 60% from state sources (including but not only Title V), 18% from local sources, 5% from foundations, and 4% from other sources. Information from a 1997 survey of state maternal and child health programs fielded by the Association of Maternal and Child Health Programs (AMCHP) is consistent with the findings of the FIMR evaluation. One third of states reported starting the FIMR as a Title V initiative. Twenty-nine percent of the respondents from the 27 states reporting to AMCHP indicated that their FIMR programs received funding from the Title V block grant (7).

State Title V programs also reported instrumental roles in legislative action, for example, to formalize the authority for FIMR and for other case review program operations, including assuring liability protections. To facilitate both the passage of such legislation and FIMR implementation overall, state Title V staff develop, participate in, and support partnerships and linkages with perinatal health-related professional groups, as well as key policy players.

State Title V programs provide a support network for those involved with the FIMR process; this can be especially important for FIMRs operating in more isolated communities. States reported providing FIMR programs with staffing resources, such as having a FIMR coordinator in the state office, or designating state staff to participate in case identification, abstraction, or review meetings. Other supportive activities include providing materials that inform review team members about their liability protections, and arranging for release of medical records for case review.

State Title V programs in some instances reported establishing basic program guidelines for local

Table I. Examples of State Title V Program Reported Roles and Activities in FIMR

Management	Policy
<ul style="list-style-type: none"> • Prepare legislation to formalize mortality reviews • Assist in garnering funds for FIMR • Administer/house FIMR operations • Participate in FIMR case review meetings • Assure a state FIMR coordinator role/position • Establish FIMR program guidelines • Fund translation of FIMR materials into other languages • Monitor operations (e.g., conduct site visits) • Support integration with other perinatal/review efforts 	<ul style="list-style-type: none"> • Develop, participate in, and support partnerships/linkages with <ul style="list-style-type: none"> – Key policy players (e.g., elected officials, community leaders, universities, businesses) – Perinatal health-related policy, advisory and professional groups – Out-of-state providers • Compile FIMR findings into reports and regularly disseminate to state health agency units, hospitals, professional societies, consumers, and advocacy groups • Disseminate FIMR information through multiple media (e.g., briefs, newsletters, MCH web sites) • Integrate FIMR into state Title V needs assessment, planning, performance measurement, and reporting • Encourage state and local public programs to implement FIMR recommendations • Use FIMR data to support legislation (e.g., gun trigger lock law)
Assessment <ul style="list-style-type: none"> • Obtain IRB approval for FIMR, address other IRB issues • Procure mandated release of records • Provide epidemiologic support to abstract, analyze, and report data • Determine minimum data set for FIMRs • Establish MCH data coordination council • Develop a statewide database of local FIMR findings • Analyze local FIMR data <ul style="list-style-type: none"> – Feedback to localities – Examine from a statewide perspective • Link FIMR data with other state data sets (e.g., CFR) 	Assurance <ul style="list-style-type: none"> • Assume responsibility for FIMR-recommended actions • Develop a mortality review manual • Provide information on national FIMR-relevant resources • Provide teleconferencing resources, convene regular technical assistance conference calls • Sponsor an annual statewide FIMR conference • Sponsor training for local review team members and/or staff (e.g., data collection; provider liability; bereavement issues; conducting home interviews; child death investigation)

FIMR team operations and also reported taking an active role in quality improvement. Some Title V programs also work with FIMRs to assure that the FIMR model is being appropriately implemented, that the FIMRs are well versed in all applicable laws, rules, and regulations, and that client confidentiality is maintained.

Assessment

State MCH programs reported assisting FIMRs in accessing needed data, developing standard systems for FIMR data collection (i.e., a minimum coordinated data set), and in linking FIMR data with other data sets (vital statistics or other mortality reviews) to enhance their utility. They facilitate local communities' access to hospital records, set standards for confidentiality, and/or advise on other legal issues specific to FIMR data. State Title V programs also are well positioned to secure Institutional Review Board (IRB) approval for the FIMR review process or to provide guidance on how to do so. Additionally, they reported facilitating data sharing among FIMRs within the state, and providing time of a staff epidemiologist, or other technical assistance to perform data

analysis. For example, one state Title V program established an MCH data coordination council to support FIMR efforts.

A number of state Title V programs report assisting FIMR programs with analysis of data collected locally and aggregating data from multiple FIMR programs. One state reported using the FIMR case-review method to systemically examine deaths of low birth weight babies, thereby addressing morbidity as well as mortality issues.

Policy

Given their governmental roles and organizational placement, state Title V programs are well positioned to communicate with key policy players such as staff in governors' offices and in the state legislatures, about FIMR findings and recommendations. State Title V programs serve as advocates for FIMR programs, working to garner authority, resources, and data for FIMRs, and promoting greater public or policymaker attention to the implementation of recommendations. State Title V programs further indicate that they collaborate with local FIMRs to compile, disseminate, and implement FIMR policy and

practice recommendations; some prepare newsletters or briefs with information on FIMR recommendations, or post FIMR information on health department or community organization web sites.

FIMR findings can inform new state policy or program strategies, and/or indicate areas for further investigation. States report showcasing recommendations, sponsoring statewide or regional conferences, and assisting with distribution of reports. Further, state Title V programs play an important role in determining whether and how other mortality and morbidity assessment processes [reviews of deaths attributed to Sudden Infant Death Syndrome (SIDS), Child Death Review/CFR, MMR, and Perinatal Periods of Risk (PPOR)] can and/or should be integrated with the FIMR (8).

FIMR findings are used to bolster a variety of state perinatal surveillance efforts. For example, some states systematically incorporate FIMR findings into institutionalized Title V activities such as the 5-year needs assessment and the annually reported performance measures. Since 1989, state Title V programs have been required to conduct comprehensive needs assessments for their maternal and child health populations every 5 years. The results of these assessments guide program development and budget plans. FIMR program findings are used to inform the needs assessment, contributing to more strategically designed programs aimed at improving perinatal health services systemwide. State Title V programs also are required to report annually on national and state-specific performance measures.⁵ In addition, six states are known to include a negotiated performance measure specific to FIMR (e.g., the percent of infant deaths reviewed/investigated by local teams, or the state Title V program has a coordinated program of maternal, fetal, infant, and child death review): Arkansas, Maryland, Montana, New Jersey, New Mexico, and Pennsylvania.

Assurance

State Title V programs connect and facilitate communication across FIMRs for support and col-

laboration. Such connections can contribute to programmatic and fiscal efficiencies. Some state Title V programs report activities related to providing technical assistance, including informing FIMR team members about current national MCH issues (e.g., the “Back to Sleep” Sudden Infant Death Syndrome prevention campaign). Efforts to enhance the capacity of the local FIMR teams (as well as other perinatal health professionals in the community) also include providing training on case data abstraction, home interview techniques, data analysis, and cultural competence. Some state Title V programs compile “lessons learned” from these efforts and share them with FIMR programs statewide. Other mechanisms are used to promote skills development, including sponsoring regular conference calls, meetings, or conferences, as well as facilitating FIMR staff participation in on- and off-site trainings.

CHALLENGES

While our findings indicate that state MCH program and FIMR collaboration can be and is frequently of mutual benefit, challenges exist as well. Tensions often generically noted in state-local governmental relations can also be found in specific regard to FIMRs; these frequently are related to divergent priorities, concerns about equity of funding distribution, and degree of control. As with all organizational relationships, communication and the mechanics of administration are often central issues.

State and local staffing changes pose formidable challenges, especially with government agency reorganizations occurring with increasing frequency nationwide. Frequent turnover of state-level decision makers can engender FIMR program confusion about broad directions, as well as about specific requirements or requests (e.g., data collection or reporting). Where state Title V programs have committed to providing resources and/or leadership and coordination for training and technical assistance, constant turnover of local FIMR staff and/or members means that states need to be continually attending to local-level administrative and training issues.

On occasion, a state MCH program will find some local programs resistant to state involvement. This can result from a FIMR not seeing the benefit of bringing local activities (FIMRs) together at the state level, or perceiving that demands exceed the resources states allocate to the FIMR. Equitable distribution of state funds to local FIMRs was reported as an issue in one

⁵Relevant measures include the percent of very low birth weight infants among all live births, percent of very low birth weight infants delivered at facilities for high-risk deliveries and neonates, percent of infants born to pregnant women receiving prenatal care beginning in the first trimester, the infant, neonatal, postneonatal, and perinatal mortality rates per 1000 live births, and the ratio of black to white infant mortality.

state. Smaller counties indicated to the state that they felt neglected, while some larger jurisdictions claimed entitlement to larger shares of available resources.

Some state programs are called upon to assist with challenges faced by FIMRs during start-up. In particular, community participants may resist certain components of the process, being uncomfortable with interviewing bereaved mothers, or being reluctant to conduct maternal interviews because of legal or procedural concerns. Some FIMRs are reported to, even when fully operational, prefer pursuing case management strategies (individually oriented intervention) to address problems identified through the FIMR process in lieu of taking on broader system change challenges that target needs of the population at large. A second start-up issue noted by state staff involves data system development. While there are national models and forms available for this purpose, some FIMRs find these forms unclear and systems cumbersome, thereby protracting the timeframe for start-up.

The challenges inherent in multicounty FIMRs also often lead FIMRs to involve their state MCH program in problem solving. A regional strategy is frequently used where few fetal or infant deaths occur annually in a single county; seeking resource and time efficiencies, multiple jurisdictions may join together so that the number of cases of fetal and infant deaths warrant the travel and meeting time of team members and provide sufficient material to generate recommendations. However, new difficulties are generated. Statistically, deaths may be more likely to occur in one of the counties, making the reviews and recommendations less relevant for the others. Moreover, maintaining complete anonymity during case review means each county's unique set of resources and challenges may not be able to be taken into account, limiting a FIMR team's ability to make appropriate recommendations. Committee members from one area might need to travel much longer distances than others, depending on the region, to attend meetings. Where this results in limited participation by some members, "buy-in" of those communities can be difficult to maintain.

Finally, starting or maintaining a FIMR program is often a "hard sell," since it doesn't provide a concrete, observable service, and because the benefits may be difficult to measure. FIMRs look to state Title V programs to assist with garnering resources. The findings from the evaluation of FIMRs nationwide have already been useful for some states and may provide helpful documentation for others. However, the current fiscal situation in many states is dire, and

additional empirical information and strategic arguments in support of resource allocation to FIMR may be needed.

RECOMMENDATIONS AND CONCLUSIONS

This paper provides multiple examples of the roles state Title V programs undertake in and with local FIMR programs. Many are applicable to other state Title V programs, and implementation should be considered where feasible. Moreover, reflecting on the challenges cited earlier, state Title V Programs might also, in concert with FIMRs in their state, give consideration to the following:

- Institutionalize state Title V–FIMR program relationships through Title V needs assessment and performance measurement requirements. A national performance measure on FIMR similar to those already developed by some states and applicable to all states may be warranted as FIMRs continue to proliferate nationwide.
- Facilitate the participation of FIMR team members located significant distances from FIMR meeting sites by supporting access to teleconference or telemeeting resources. States might also assist by reviewing findings from rural areas as a group or by working with localities to consider regional strategies to address common or shared infant mortality concerns.
- Fine-tune state Title V program involvement in FIMR programming such that micromanagement of FIMRs is avoided and the critical principle of community ownership is respected and nurtured.
- Devise and disseminate creative ways to leverage multiple funding sources and combine funding streams to sustain FIMR programs.
- Advocate for further study of FIMR that involves enhanced qualitative and process evaluation in order to more specifically elucidate the community process benefits of FIMR, and to help fine-tune FIMR models and methods.

State Title V and FIMR program interaction can be mutually beneficial. State Title V programs are directly carrying out the public MCH program functions under their purview—including data collection, system development and analysis, investigation of health problems, informing the public about MCH,

policy leadership, quality assurance and improvement, and developing workforce capacity—when they take an active role in their state’s local FIMR programs. Further, FIMR is an important public health tool that can provide qualitative information missing from vital statistics and other population data routinely collected by states. By supporting FIMR, states obtain data that can inform programs and policy efforts. FIMR programs receive state infrastructure support and buy-in, and state Title V programs obtain a closer link with their constituencies concerned with maternal and infant health.

While state and local government relationships vary widely, the experiences of the state Title V programs to date in interacting with their local FIMR programs have overall been positive, as the examples cited portray. Maintaining, strengthening, and further developing such relationships in all states could contribute to further improvements in perinatal health system organization and efficiency.

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