Invitational Meeting on CFR, FIMR and SIDS

Executive Summary of the Invitational Meeting on CFR, FIMR, and SIDS convened by HRSA's Maternal and Child Health Bureau on November 20-21, 1997 in Washington, DC.

Statement of Purpose
To focus discussion, the group decided to develop a statement of the common, overall purpose of CFRs and FIMRs. Participants proposed and refined the following statement to reflect not only this purpose but also the methods and orientation of the CFR and FIMR processes:

A collaborative process to understand how and why children die, to improve systems, prevent child fatalities, and promote well-being through systematic, comprehensive, multidisciplinary, multiagency, community-oriented case review.

Preliminary Recommendations
Participants unanimously agreed that although there are unique distinctions between CFRs and FIMRs that need to be preserved, valuable collaboration between components of CFRs, FIMRs, and SIDS programs is possible and should be encouraged at the local, state, and Federal levels. Examining 11 identified components of CFRs and FIMRs, participants developed preliminary recommendations with the focus of fostering collaboration, coordination, and/or integration between processes.

SIDS programs were not considered a separate, third process because they are service programs and reviews of SIDS deaths usually occur as part of a FIMR or a CFR. However, it was agreed that SIDS programs offer specific strengths, particularly at the community level, and their service components need to be linked with the two review processes. Additionally, people serving in SIDS programs should be included in CFR and FIMR case reviews.

Participants did not make recommendations about whether communities should have both CFRs and FIMRs. It was acknowledged that there are many models of infant and child mortality review that can be parallel or integrated, and all models that achieve the stated goals should be allowed to flourish. Rather than have mandated review processes, communities should be encouraged to conduct a needs assessment to determine which programs are appropriate. The establishment of CFRs and/or FIMRs in communities that demonstrate a readiness for these programs should be fostered and funded.

1. Legal Authority
The type and extent of legal authority varies among states. Some review teams have implicit authority (e.g., implied by the authority of agencies participating on the review team) rather than explicit legal authority (i.e., granted specifically to the review team). The lack of legal authority for requiring autopsies and death scene investigations for cases of infant death can be a barrier to the success of the infant and child fatality review process.

-Although explicit legislated state authority for review teams is not always needed, it can facilitate visibility and access to resources. Some type of legislative support for accessing and sharing records is critical.
-Teams may find sufficient legal authority in separate pieces of existing state legislation rather than in a single law. However, teams should identify the types of authority needed to conduct their work and examine existing statutes to determine whether they contain such authority. Information about existing legislation should be clearly communicated from the state to the local level. It was reported that the American Bar Association has cataloged existing legislation for CFRs.

-When legal authority for review teams is lacking and appears to be needed, teams may need to work together for the passage of relevant legislation. A single piece of enabling legislation is preferable to authorization contained in several statutes.

-Legislation should be inclusive and flexible to enable all infant and child death review processes and notification. Legislation should empower and support reviews without confining or dictating the processes. Federal legislation should not dictate how reviews should be conducted at the state and local levels but should support state efforts.

-Models of good legislation should be shared among review processes. When using such models, review teams should consider their own objectives, membership, methodology, resources, and needs.

-An updated national review of the types of legislation that states require for FIMRs and CFRs should be conducted to develop a model template for legislation that would work for both processes.

-Technical assistance at the national level should continue to be made available to facilitate review teams' startup activities, including reviews of legislative issues.

-Teams should examine confidentiality guidelines contained in the latest CAPTA legislation, which allow for the sharing of CPS information with "child fatality review panels."

2. Funding

Funding for review teams may come from multiple sources and, in the case of many CFRs, may not be explicit funding. SIDS programs in some areas have successfully sought grants and may engage in fundraising. Collaboration in this area has the potential to save money for all three programs.

-Funding streams should provide flexibility to allow for funding from multiple sources and the development of collaborative models that pool funding in some way.

-Collaborative funding should be flexible and support not only CFR and FIMR teams but also activities that are necessary for a comprehensive and appropriate community response to child deaths, including autopsies, death scene investigations, and family services. Review teams should not be responsible for ensuring funding for all identified needs but should
advocate for adjunctive funding to ensure appropriate community response at all levels.

-Federal funding should be continued for technical assistance to local CFR and FIMR teams. Community programs should collaborate on the development of state plans, which will address how technical assistance funds are dispersed.

-Federal requests for proposals could include stronger language or guidelines to states on encouraging coordination and collaboration between CFRs, FIMRs, and SIDS programs.

-Funding mechanisms should require review teams to include an evaluation plan with specific outcome measures.

-Collaboration should be encouraged between Federal, state, and local funding streams.

-Federal agencies should collaborate on funding for CFRs, FIMRs, and SIDS programs through interagency agreements.

-A structure for stronger Federal collaboration and coordination should be established (e.g., an interagency task force or work group that addresses all three programs). MCHB, CDC, and NCCAN should be involved in such an effort. Alternatively, NCCAN's interagency working group should be reinvigorated. However, shared leadership and neutral placement of this interagency structure should be considered.

-MCHB should take a more active role in encouraging Title V programs to coordinate, participate in, and promote a prevention focus for CFRs.

-MCHB should use funding and in-kind services (e.g., technical support and training) to encourage review teams to include as members culturally diverse representatives of hard-to-reach populations and address issues related to these populations.

3. Case Finding
Despite local variability, the process of identifying deaths and cases to review is an area where review processes could benefit from coordination and/or integration. Many counties now use a single contact as case finder for CFRs, FIMRs, and SIDS support services.

-CFRs, FIMRs, and SIDS programs that collaborate on case finding at the local level should jointly develop a standard case finding protocol and clearly define the purpose of and criteria for their respective case reviews.

-Whether using single or multiple contact points, CFRs, FIMRs, and SIDS programs should integrate case finding efforts to the greatest extent possible. However, this integration should not preempt prompt intervention to bereaved families.

-Collaborating review teams should acknowledge each other's timetables for conducting reviews. Case finding should be done early enough to accommodate the time frame required for all appropriate referrals.

-The sharing of vital records between states should be encouraged. A Federal review should be conducted to determine the current status of protocols for sharing records across state lines.

-Training should be provided to ensure the accuracy of autopsies, death scene investigations, and death certificates. Consideration of electronic death certificates should be encouraged.

4. Information Gathering
Review processes vary in their methods of collecting and protecting information and in the timing of their information gathering and should remain distinct.

-Although the information-gathering methods of CFR and FIMR review teams are and should remain distinct, all three programs should explore ways to move beyond their historical practices to identify what information can be shared legally and ethically without compromising their respective purposes.

-Review teams should assess the purpose of the information they are gathering. They should use appropriate tools for collecting the type of information that will provide feedback on how to focus risk reduction activities.

-The development of standard protocols for gathering information and developing minimum data sets should be encouraged.

5. Membership
The membership of review teams varies enormously, but great potential exists for some shared membership between CFRs and FIMRs.

-Despite the variations in CFR and FIMR team membership, some common members could be shared between teams to provide continuity, share information and perspectives, and reduce work overloads. A representative of the SIDS community should serve on both review teams.

-Both CFR and FIMR review teams should include members who reflect the community's diversity, including differences in culture, socioeconomic status, and urban or rural concerns.

-The multidisciplinary and multiagency aspect of review teams should be used to broaden the perspective of all members and to ensure that the team is deriving optimal benefit from all disciplines represented.

-Ideally, review teams should include a skilled facilitator who can ensure that input from all perspectives, approaches, and disciplines is included in discussions.

-CFR and FIMR trainings should consider coordinating to allow joint sessions as well as breakout sessions for team-specific topics.

-Review teams could consider adapting and using a model such as the CFR-based training curriculum being developed by the American Bar Association's Center on Children and the Law. The curriculum will be available December 31, 1997.

-Review team members could benefit from training by the SIDS community in areas such as bereavement, risk reduction, and prevention.

6. Review Meetings

Although both CFRs and FIMRs involve an expert technical review, FIMRs also use a second tier of review by community action teams whose purpose is to implement recommendations. CFRs could learn from the coalition-building experiences of FIMR teams and benefit from accessing a broader pool of community leaders who can help effect practice, resource, and policy change. Recommendation development is one stage at which CFRs and FIMRs can overcome confidentiality issues and work together.

-CFR and FIMR teams should consider designing mechanisms to coordinate community-based reviews of infant and child mortality cases. Both teams should share findings and recommendations with the appropriate community coalitions.

-During case review meetings, team members should identify officials, agencies, and organizations that can facilitate the implementation of team recommendations and tailor reports and recommendations to these target audiences.

-Both teams should collaborate with existing entities to facilitate the implementation of recommendations. These entities could include the Children's Justice Act Task Force, Children's Trust Fund, state legislatures, SIDS programs and advisory boards, and the HRSA-funded Maternal and Child Health (MCH) programs.

-Local CFR and FIMR teams should consider collaboratively developing and sharing recommendations with interested public and private agencies and organizations, including officials such as governors, mayors, state legislators, local health department officials, and representatives from advisory councils. The findings and recommendations of local SIDS programs also should be considered for these reports. It may be advantageous for reports and recommendations to be disseminated at the state level to interested organizations and agencies in the public and private sector, including law enforcement agencies, state public health agencies, and MCH programs.

-Local CFRs and FIMRs should develop standard protocols for running review meetings and establish a core, and, if possible, shared set of questions that will be asked during every case review. The development of a national set of standard questions for case review meetings could be the responsibility of the proposed Federal interagency task force.

7. Timing of Review Meetings
This component of infant and child mortality reviews involves the period of time after a death that a review is conducted. The timing of reviews is affected by different team purposes and decisions points regarding the death of a child. CFRs tend to meet sooner than FIMRs.

-CFR and FIMR teams should meet as soon as possible after an infant's or child's death, considering factors such as available resources, the need to respect other processes, the need to collect certain information (e.g., the FIMR maternal interview), and the need for immediate case management.

-Although differences between CFRs and FIMRs in the timing of review meetings can mitigate against integration of their respective reviews, both processes should try to share information whenever possible.

-States should develop systems to expedite early notification of SIDS programs about sudden, unexplained deaths of children.

8. Findings
System issues determine the type of information that CFRs and FIMRs can share. For example, FIMRs cannot disclose case decisions but can share aggregated information.

-Within legal and ethical limits, CFR and FIMR teams should consider sharing findings from their respective reviews. Collaborative followup reviews should be held to share information, identify constellations of events, and verify perceptions.

-CFR and FIMR teams should consider the feasibility of issuing joint, comprehensive reports at the state and local levels. Local CFRs and FIMRs could prepare reports and data that are as comprehensive as possible for dissemination to interested local groups and state MCH agencies. If joint reports are not possible, information gathered during both processes should
be incorporated in each team's report.

9. Use of Findings
The use of findings may depend on whether the primary focus of the team is recommendations for systems change or followup for specific cases. Review teams concerned with system change recommendations will seek to ensure that team aggregate findings will be forwarded to and considered by an implementation tier. Teams concerned with followup for specific cases may
seek to use findings to further case management or legal action.

-CFRs and FIMRs should develop a minimum circulation list of individuals, agencies, and organizations with whom they routinely share their reports of findings and recommendations. These recipients should be the same entities that will be responsible for implementing review team recommendations.

-Federal assistance should be provided to states and communities to help them identify not only effective interventions and recommendations to address identified problems but also strategies for implementing these interventions. Interventions, recommendations, and strategies should incorporate bottom-up as well as top-down input.

-The Federal and state governments should consider establishing focal points (e.g., World Wide Web sites, clearinghouses, annual conferences, electronic bulletin boards) for sharing practical information such as ideas and solutions, implementation and action plans, and published resources such as literature reviews. Web sites should include links to MCH
clearinghouses.

10. Outcomes
This component addresses the need to establish measurable outcomes that will indicate the extent to which infant and child mortality review processes are fulfilling their purpose. No standard measures

currently exist, and their development will be problematic.

-Technical assistance and training should be used to promote the development of methods for linking recommendations with components to follow and track the outcomes of recommendations.

-Lessons about the development of effective outcome measures learned by one review process should be shared with other processes.

-Review teams should focus on measurable, obtainable, and sustainable short-term effects as well as long-term systems change.

-Review teams should try to develop specific, measurable outcomes that are related to the purpose statement developed earlier in the meeting. The development of outcome measures also should seek to address emerging standards and the need to work toward forthcoming Healthy People 2010 goals.

-Review teams should consider initial evaluation measures that are focused on process goals. Process goals could include system changes (e.g., improved EMS response), appropriate responses to individual cases, increased cooperation among agencies represented on review teams, and the development of team members through training and other methods. However, participants cautioned that although outcomes such as improvements in child
health and safety may be appropriate for monitoring recommended system changes, they cannot be used to actually evaluate the review process itself.

11. Performance Evaluation
This component focuses on systems performance and process evaluation.

-Efforts should be made to develop strategies for evaluating increased communication and information sharing among review team members as performance evaluation measures.

-Performance evaluation measures should be considered early in the process of developing a review team.

Next Steps
In its review of the preliminary recommendations developed at the Invitation Meeting on CFR, FIMR, and SIDS, MCHB will incorporate comments by meeting participants on the summary document. It is anticipated that recommendations generated at the invitational meeting will help MCHB identify priorities for future funding and plan future activities involving infant and child mortality review at the Federal level. In addition, a second, more inclusive invitational meeting might be planned to review the recommendations and take further steps. MCHB also hopes to maintain an ongoing dialogue with meeting participants to continue the cross-fertilization of ideas.