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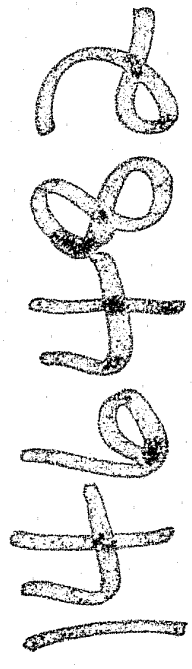
Recommendations of the Child Fatality Review Advisory Workgroup



MCHB
Maternal and Child Health Bureau

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Health Resources and Services Administration
Public Health Service
U.S. Department of Health and Human Services

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DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Maternal and Child Health Bureau

Health Resources and
Services Administration
Rockville MD 20857

JUL 20 1993

Dear Colleague:

In the United States large numbers of children continue to die as a result of abuse and neglect. It is therefore essential to constantly improve the identification of cases of fatal abuse and neglect, and insure appropriate law enforcement and legal action. Child fatality review systems have been identified as one of the major components of a comprehensive effort toward this end.

This document has been produced by the Maternal and Child Health Bureau to provide guidance in the development and implementation of child fatality review systems at the local, State and national level. It attempts to stimulate and coordinate action among those organizations and individuals concerned with child abuse and neglect, and to encourage a collaborative approach to systems development and program implementation. A number of important issues are identified, and specific recommendations and strategies are suggested to facilitate the development of a comprehensive approach.

These recommendations are a result of two meetings of an ad hoc Child Fatality Advisory Workshop convened by the Maternal and Child Health Bureau at the request of the Secretary of the Department of Health and Human Services. The Workgroup consisted of representatives from several Federal agencies, from advocacy groups, from State Maternal and Child Health programs, as well as several individuals directly involved with the implementation of fatality review systems at the State and local level. The final set of recommendations was reviewed by the U.S. Advisory Board on Child Abuse and Neglect and the Inter-Agency Task Force and selected comments are also included at the end of this document. The contributions of all members of the Workgroup are greatly appreciated.

The Maternal and Child Health Bureau encourages you to assist in disseminating this guide to appropriate organizations and individuals committed to preventing child maltreatment.

Sincerely yours,

Audrey H. Nora, M.D.

Audrey H. Nora, M.D., M.P.H.
Assistant Surgeon General
Director

TABLE OF CONTENTS

PREFACE vi

INTRODUCTION 1

BACKGROUND ON FEDERAL ROLE 2

RECOMMENDATIONS 4

COMMENTS ON THE RECOMMENDATIONS 23

CHILD FATALITY REVIEW ADVISORY WORKGROUP MEMBERS 26

PREFACE

This *ad hoc* advisory group on child fatality review was convened by the Maternal and Child Health Bureau at the request of Dr. Louis Sullivan, the United States Secretary of Health and Human Services. The Child Fatality Review Advisory Workgroup was created for the purpose of developing recommendations for a federal role in guiding the development and implementation of a consistent and systematic mechanism for child fatality review at the local, state, and national level. Members of the Workgroup included representatives from federal agencies, advocacy groups, and state Maternal and Child Health systems, as well as several individuals directly involved in organizing and implementing local and statewide fatality review systems.

The Workgroup met in Rockville, Maryland, in March and again in August 1992 for full-day working sessions. At the initial meeting the issues which would be addressed by the recommendations were identified, and responsibilities were assigned for preparing the various sections of the document. At the second meeting the draft recommendations were reviewed, and revisions and additions were suggested. Based on these discussions, an edited version of the recommendations was prepared and circulated to Workgroup members for additional review prior to preparation of the final document.

The Public Health Social Work Training Program in Maternal and Child Health at the University of Pittsburgh was responsible for organizing and coordinating the meetings, and for preparing the recommendations document. Individual members assisted in the preparation, review and revisions of the various sections of the document. The resulting set of recommendations represents the joint efforts of the Workgroup whose names are listed at the end of this report.

In November of 1992 the initial recommendations were presented to the United States Advisory Board on Child Abuse and Neglect and the Interagency Task Force for review. Several comments were received, and these have been summarized in this document as well.

Kenneth J. Jaros
Pittsburgh, Pennsylvania
January 4, 1993

INTRODUCTION

An unacceptably large number of children die each year in the United States as a result of abuse and neglect. Many of these fatalities, however, are wrongly classified as accidents or "unexplained," and no further action is taken. This tragic situation demands a response from those institutions responsible for the safety and welfare of our children.

Although many of the children who die or are severely injured are known to social service and health care providers, the existing maze of agencies not only makes recognition of the causes of child death difficult, but also significantly impedes our ability to learn from these incidents in order to better protect other children. Criminal justice, child protective services, social welfare, health, mental health and other organizations play varying and at times conflicting roles in dealing with families and children at risk for abuse. The lack of communication and information sharing between these agencies, jurisdictional boundaries and overzealous adherence to confidentiality policies often confound the problem.

In response to this situation, a growing number of counties and states have begun to take action to adopt strategies for comprehensively reviewing and managing cases of child fatality. The child fatality review process is seen as an essential addition to a system that is currently not as effective as it could be in identifying fatalities resulting from abuse and neglect, and in subsequently preventing future child deaths.

At the present time, twenty six states have state and/or local multi-agency teams and half of the remaining states are actively attempting to develop teams. It is estimated that some type of systematic fatality review will be in place in thirty states, covering over 50% of the nation's population, by the end of 1992.

Even though child fatality review systems are operational in a number of locations, the process is moving forward in a haphazard way with little coordination, planning and information dissemination between organizations or jurisdictions. There is no central responsibility for collecting and disseminating data on the activity of the existing fatality review systems. At the present time the system is being driven by the activity at the local and state level with little or no organized national leadership.

Although a number of national advocacy groups, such as the American Bar Association, the National Center for Prosecution of Child Abuse, and the American Academy of Pediatrics, have held conferences, prepared publications, conducted training and provided technical assistance on this topic, additional coordination and direction is required. The federal leadership role in this process must be further expanded and defined.

BACKGROUND ON FEDERAL ROLE

The federal government has begun to recognize the importance of child fatality review. In its 1990 report, the United States Advisory Board on Child Abuse and Neglect specifically recommended that the Secretary of Health and Human Services and the Attorney General (working through the U.S. Interagency Task Force on Child Abuse and Neglect) undertake joint efforts to address the issue of fatal child abuse and neglect caused by family members and other caregivers. The Board recommended the identification and vigorous dissemination to states and local governments of models for: (a) prevention of serious and fatal child abuse and neglect; (b) multidisciplinary child death case review; and (c) identification and response to child abuse and neglect fatalities by the social service, public health, and criminal justice systems.

Within Health and Human Services, Secretary Louis Sullivan's Initiative on Child Abuse and Neglect has included child death review as a strategy in its plan to improve coordination among federal agencies and collaborative efforts between the public and private sector. A major vehicle for promoting this effort at coordination and information exchange will be the Interagency Task Force on Child Abuse and Neglect, which has included in its mandate the promotion of child fatality review teams.

Congress has also emphasized the importance of child fatality review in its reauthorization (P.L. 102-295) of the Child Abuse Prevention and Treatment Act (CAPTA). The Advisory Board on Child Abuse and Neglect was given two years to produce a report to Congress outlining a national policy to reduce and prevent maltreatment-related deaths. The Board's report will include necessary changes in federal laws and programs, as well as specific improvements in national data collection.

The reauthorized CAPTA also requires the National Center on Child Abuse and Neglect to include information on the number of deaths due to child abuse and neglect in its national incidence study. Under the basic state grant program, the law now requires states to include in their program plans information on their child fatality review panels. In addition, the purpose of the Children's Justice Act program has been expanded to require state task forces to address the handling of fatality cases suspected of being caused by child abuse or neglect.

In March 1992 a multidisciplinary *ad hoc* Child Fatality Advisory Workgroup established by Dr. Sullivan met with the goal of preparing recommendations which would facilitate the systematic development and expansion of a child fatality review structure at the state and local level. The Workgroup was comprised of representatives from federal departments and agencies administering child abuse and neglect programs, representatives from national organizations concerned with child abuse and neglect, as well as a number of experts already involved in implementing fatality review teams at the state and local level (A list of the Workgroup members is included). This group is being sponsored and coordinated by the Maternal and Child Health Bureau, Health

Resources and Services Administration, U.S. Public Health Service. Following the March meeting, the members of the Workgroup collaborated to develop an initial set of recommendations. The emphasis of the recommendations was on developing and implementing review teams, model standards, protocols, training of fatality review team members, information sharing, cultural sensitivity considerations, model legislation, evaluation, financing, confidentiality, and the federal leadership role. The Workgroup convened again in August 1992 to achieve consensus on the draft recommendations, as prepared by individual members.

ISSUE # 1: NATIONAL CHILD FATALITY REVIEW TEAM

Recommendation

A national Child Fatality Review Team should be established at the federal level under the auspices of the Department of Health and Human Services and in joint collaboration with the Department of Justice. These two departments should expand the existing memorandum of understanding on child abuse and neglect to include an agreement to create this federal team.

Other federal departments with an involvement in, or responsibility for, prevention of child deaths, including child abuse and neglect, should also be invited to be a part of this effort.

Appropriate legislation and allocation of funding (in Justice and Health and Human Services) should be implemented to support the staffing and other functions of the Team.

Purpose, Structure, and Functions of the National Team

The National Child Death Review Team will provide leadership to facilitate the development and implementation of coordinated, high-quality systems for child fatality review nationwide. This role may take the form of promoting federal and state legislation to support the development and implementation of child fatality review; coordinating federal activities relating to child fatality review; collecting, synthesizing, and disseminating information on child deaths from crime, social service and health sources; providing consultation to emerging systems at the state and local level; promoting the implementation of model systems; identifying resources for state and local efforts; and encouraging appropriate education and information dissemination among organizations and jurisdictions pursuing the development of systems for fatality review. In addition, the Team would provide assistance to federal agencies that serve families directly, such as the Indian Health Service and the Department of Defense. (see A, Pg. 23 for comments)

The Team should consist of 10-15 members representing federal departments, and appropriate agencies and bureaus within those departments. The Team should be co-chaired by the Departments of Health and Human Services and Justice. It is recommended that the Secretaries of each participating federal department appoint representatives at the highest levels possible. These representatives should have responsibility for policy development and coordinating mandated program areas.

The Team should also include several non-governmental members who will serve in a strong advisory capacity. Organizations such as the American Bar Association, the National Center for the Prosecution of Child Abuse, the American Academy of Pediatrics, the American Humane Association, and the National Committee for Prevention of Child Abuse and Neglect, among others, should be considered. It would also be important to include experts from existing (and developing) child fatality review systems at the state and local level.

Meetings should be held at least quarterly.

Team functions should include:

- Advocating for federal and state legislation supporting child fatality review;
- Encouraging federal agencies to support research, data collection, training, and use of clearinghouse resources;
- Promoting the implementation of pilot projects, the establishment of appropriate system standards, and the implementation of model protocols;
- Issuing an annual report and preparing periodic reports on the child fatality review system in states and localities nationwide;
- Facilitating the exchange of information, training, and coalition-building by promoting national and regional conferences and workshops; and
- Facilitating the collection, analysis, and dissemination of data on child death from states and counties.

To carry out the proposed activities, the team should receive administrative support from appropriate staff in the various participating federal departments and agencies. In addition, it is critical that a specific appropriation be sought to insure that core staff support is directly available to the Team. Until funding is provided for staff support, personnel could be loaned on a full- or part-time basis to this effort. It is recommended that the Maternal and Child Health Bureau in Health and Human Services coordinate the establishment of the Team until the appropriate support and leadership functions are officially structured.

ISSUE #2: DEVELOPMENT OF PROFESSIONAL FATALITY REVIEW SYSTEM AT THE STATE AND LOCAL LEVEL

Recommendation A

All states should be encouraged to develop a statewide system of prompt and professional child fatality review by multidisciplinary teams at the local level. The overriding goal of this system should be prevention of future child fatalities in the target area. A state level team should be established which would be responsible for coordination and monitoring of the overall system functioning and progress.

Technical assistance and consultation should be provided from federal and state resources to local jurisdictions for the purpose of coordinating the development of local child fatality review systems, establishing review panels, obtaining public and professional support for the fatality review process, and delivering required training.

Federal responsibility in this effort should include publication of model guidelines, dissemination of exemplary approaches, and delivery of technical assistance and training through the federal regional office structure.

Rationale, Structure, and Function

Child fatality review teams based in local jurisdictions are generally better suited than state teams for effectively reviewing unexplained or unexpected deaths. Local teams are familiar with the organizations and structures in place in the community and are able to immediately examine evidence and gather information from individuals directly involved with the case. In certain circumstances where local teams do not exist, however, the state team should assume responsibility for the primary review of the case.

Although individual fatality review systems will vary depending on the existing organizational infrastructure and legal environment, there are a number of guidelines and basic structures that should be adhered to when establishing a new system. Newly emerging systems should give strong consideration to basing their systems on models, procedures and protocols which have been successfully implemented in other sites. The functions of a state team should be clearly delineated and should include at least the following:

- Advise the Governor, Legislature and public on changes in law, policy and practice which will reduce child deaths;

- Recommend new policies and strategies for local and state agencies which may assist them in being more effective in identifying and reviewing cases and ultimately preventing child deaths;
- Provide support and guidance for local teams to assist them in carrying out their duties;
- Develop appropriate protocols for the investigation and collection of data regarding child deaths; and
- Provide an annual report on the activity of the state team and the overall fatality review system statewide.

The functions of local teams also should be clearly defined and should include at least the following:

- Establish and implement protocols for their locality based on model state protocols;
- Investigate individual child deaths in accordance with mandated procedures;
- Plan the implementation of methods of improving coordination of services and investigations between member agencies and plan the implementation of changes within the member agencies which will reduce the incidence of preventable child deaths;
- Collect and maintain data as required by the state team; and
- Advise the state team on changes to law, policy, or practice which will prevent child deaths.

The emergence of a successful fatality review system depends on an appropriate and effective strategy for mobilizing organizational and community involvement in the process and for actually organizing the multidisciplinary child fatality review teams. This can be a complex and demanding task. In many cases, the agencies and individuals being asked to become involved may lack understanding of the need for such a fatality review process, and actual implementation of the system may be perceived as unnecessary or even disruptive. Well-developed systems of communication and information sharing may not exist between the agencies which are the key participants. Unless these issues are addressed, the effective and efficient functioning of the review team (and related data collection and information sharing) may be compromised.

A related issue is the need for understanding and support of the fatality review process by the local health/social service professionals, the political leadership, and, to some degree, by the community in general. The operation of the review team, and any subsequent investigations, should be enhanced by the cooperation and support of community-based professionals.

States and the federal government should provide adequate technical assistance, consultation and other resource support to those responsible for team development at the local level. This should involve formal dissemination of model strategies for local system development. A handbook or guide suggesting the various steps to be taken in the process would be helpful. Ideas for mobilizing coalitions, generating community support and conducting professional education could be provided through such vehicles as on-site technical assistance and regional organizational development workshops.

Although training is discussed in greater detail later in this document, it is important to emphasize the need for using well-developed and comprehensive models for training review panel members. In addition to required technical information and protocols, training should be required to include cultural sensitivity issues. Use of cross-disciplinary training and creative strategies (such as mock case review) should be employed whenever possible.

Recommendation B

States should require the development of professional forensic medical examining systems statewide and in local jurisdictions. These systems are necessary to insure comprehensive forensic medical examinations of child deaths. (see B, Pg. 23 for comments)

Rationale

Professional medical examining systems do not exist in many jurisdictions throughout the United States. Well qualified and appropriately trained personnel may not be available to conduct adequate autopsies (particularly of young children), and consistent and quality procedures for determining cause of death may not be in place. As a result, fatalities resulting from abuse or neglect may not be appropriately identified.

ISSUE #3: SUGGESTED ESSENTIAL ELEMENTS OF STATE & LOCAL SYSTEMS

Recommendation A (Statement of Purpose)

A mission statement including a clear statement of purpose should be developed by state and local child fatality review systems. The primary purpose of the total system should be prevention, but also may include investigation, data collection, development of policy and legislation, education, and services to families.

Rationale

It should be made clear that the review system does not replace existing programs responsible for these various functions. While child death review systems can be established for a number of purposes (e.g., as an aid to criminal investigations or in improving the accuracy of reporting on child deaths), the most significant purpose is the prevention of further unwarranted deaths. The goal of the system is not to find fault with participating agencies, but to create a process for converting the lessons from particular cases into policy and administrative changes.

Recommendation B (Legislation)

Although it may not be necessary in all situations, states should give serious consideration to the development of new or the expansion of existing legislation to define and support the child fatality review process.

Rationale

State legislation mandating a child death review system is not necessary in all cases. The elements of a quality system can be supported and implemented under various auspices. For example, a comprehensive and effective system could be established by an executive order of the Governor or through a formal cooperative agreement among agencies. Whatever the process used to establish the system, it is strongly recommended that it be based on the principles and elements suggested in subsequent sections of this document.

State legislation should also be considered in the area of confidentiality and immunity. Regardless of whether legislation is considered necessary to establish and maintain a review system, a state may need legislation to protect the participants and the process.

Each state and locality needs to determine the best mechanism for establishing child death review teams for that jurisdiction. In a number of circumstances, legislation may be required to push the

process forward and to assure compliance by state and local agencies. When legislation is deemed necessary, jurisdictions should adapt (as much as is feasible) the language of existing, tested models of legislation. This should help avoid the creation of confusing and inappropriate laws regarding child fatality review structures and procedures.

States considering child death review systems should consider the examples of states that have already implemented models. Also, model legislation prepared by the American Bar Association's Center on Children and the Law is recommended.[1] Present state experience with legislation in support of interagency child death review of suspicious deaths is varied. Only eight states have legislation specifically addressing the establishment of, or support for, interagency child death review teams. In other states, teams exist under other auspices. It is clear that states do not have to have enacted legislation to put into practice a system of death review teams. In fact, teams exist in some localities without any state leadership or involvement. In other places, teams exist only at the state level.

Recommendation C (Scope of Cases to be Reviewed)

State and local review teams should seek to implement the most expansive and comprehensive approach for identifying cases for review. Every fatality (birth to age 19) should be eligible for consideration at some level. (see C, Pg. 24 for comment)

The National Team should examine existing models for screening and prioritizing cases for review, and should summarize and disseminate those most appropriate for general use.

Rationale, Structure, and Function

In some localities it may be possible for all child fatalities to be reviewed. In others, a protocol for screening or prioritizing cases may be necessary. The inclusiveness of the review process will of course depend to a great degree on the volume of fatalities and the resources and capabilities of the local or state system. For example, a state may choose to focus its reviews on deaths under age 5, which may include most deaths resulting from child abuse and neglect. Not reviewing older children's deaths however, will fail to address issues related to child suicide and many homicides. Whenever possible, existing models for prioritizing fatalities for review should be adapted for use.

In any case, the optimal goal should be to review all "unexplained or unexpected" child deaths. This does not mean, however, that all cases will require in-depth investigation.

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[1] Sarah R. Kaplan, Child Fatality Legislation: Sample Legislation and Commentary, Washington, D.C.: Child Maltreatment Fatalities Project, American Bar Association, Center on Children and the Law, 1991.

Recommendation D (Data Collection)

Child fatality review systems should implement uniform data collection systems relying on an accepted and consistent minimum data set.

Rationale

Such a system should be capable of linking birth and death certificates on every case. The system should allow the tracking of individual cases as well as providing aggregate information about the scope, nature and disposition of child fatality cases in the target state. As much as is feasible, the system should interface with existing data collection and record keeping systems (e.g., vital statistics, Medicaid, coroner's data, criminal justice, and child abuse and neglect data bases).

Recommendation E (State Team Composition)

Membership of the review team at the state level should be clearly specified and choices should be made with appropriate consideration for existing leadership, agency structures and responsibilities, and legal and political factors.

Structure

Teams might include representation from the Attorney General's Office, Chief Medical Examiner or related official, the department of social services (child protective services), the state public health system, the education department, state police or other appropriate law enforcement agency, state office with authority for vital statistics, state drug abuse agency, state mental health agency, and the agency with responsibility for SIDS. Other individuals with particular expertise (e.g., forensic pathology or injury prevention) should be considered. If circumstances warrant, other experts may be included on an *ad hoc* basis. It will also be essential to have representation from advocacy or citizens' groups on the team, or at least in an advisory capacity.

Recommendation F (Local Team Composition)

Permanent core members of the team should be formally designated and should reflect the local agency infrastructure dealing with child fatalities (including child abuse and neglect) as well as reflecting the sociocultural characteristics of the area.

Structure

Members might include the District Attorney, the county medical examiner or coroner, the health officer, a physician with experience in diagnosing and treating child abuse and neglect, child protective services, a forensic pathologist (if the medical examiner/coroner is not a forensic pathologist), and representatives from the school system, law enforcement and juvenile justice, emergency services/fire department, local drug abuse program, local mental health program, and county SIDS program. The above types of individuals and agencies are important for local interagency review teams. As with the state teams, other disciplines and organizations may be included, and *ad hoc* participants should be added to reflect the specialized nature of particular cases.

Recommendation G (Timeliness)

The team review process should activate as soon after the child death as possible based on the objectives, functions, and guidelines of the individual state or local child fatality review system.

Rationale

Beginning the review process as soon as possible after the death occurs will insure the collection of the most useful type of evidence for decision making. This is particularly relevant for local teams that have investigatory functions and which need to potentially consider protection of other family members. The longer the interval for reconstructing evidence, the less likely it is that the fresh details, that are often the most revealing, will be obtained.

ISSUE #4: COMMUNICATIONS BETWEEN FEDERAL, STATE, AND LOCAL SYSTEMS

Recommendation

A national communication system should be developed to: (1) facilitate communication between existing and prospective local, state, and national child death review teams and the legal, social and health care systems available to support them; and (2) reach out to states and communities that have not developed such teams to encourage them in this effort by providing models, expertise, and an understanding of how death review teams will contribute to their respective state efforts to improve the health and welfare of their children. This would be facilitated through the following specific activities.

The federal government should (1) support the development of an annotated directory with listings of contacts in agencies and associations, as well as state and local contacts, and (2) support the creation of a newsletter dedicated to fatality review (or coordinate the use of existing newsletters).

Background, Rationale, and Implementation

Even though each state faces unique issues in the development of a fatality review system, they can learn from and be motivated by the experience of others. States and communities in the process of developing and/or improving their systems need to be able to tap into the numerous resources and expertise that are available. For those states not having contemplated the development of child fatality review teams, there should be available educational and informational resources to support the development of their systems.

The directory should include members of the federal/national team, contact persons in relevant federal agencies and programs, national organizations (e.g., American Bar Association, American Academy of Pediatrics, American Academy of Family Physicians, National Center for Prosecution of Child Abuse, National Association of Public Welfare Directors, National Association of Medical Examiners, American Public Health Association, Association of Maternal and Child Health Programs, Association of State and Territorial Health Officers, etc.), state and major local teams, and additional information resources (e.g., National Clearinghouse on Child Abuse and Neglect, National Center for Missing and Exploited Children, etc.). Compiling, disseminating and updating of the directory might be contracted by a federal agency to a private organization with experience in this field.

This single, national directory would be augmented by state and local directories, professional directories, clearinghouse lists of publications, and calendars of training opportunities and conferences.

A newsletter or a coordinated effort to utilize existing newsletters would be necessary to: (1) keep states, communities, and the legal, social, and health communities updated on the activity of others, new information and resources, and model programs; and (2) to educate and recruit new communities (on the state and local level) in the effort to establish a nationwide system of child fatality review teams. The newsletter would be central to the larger effort by the national team to engage communities in this process.

If a dedicated newsletter is used, it should be distributed nationally. Although the major means of distribution would be by mail, such a system could be augmented by E-Mail systems and an electronic Bulletin Board (such as those maintained by the National Committee for Prevention of Child Abuse and the California Consortium for the Prevention of Child Abuse). There are numerous existing professional and organizational newsletters and a coordinated effort to utilize these could insure that current and relevant information reached the appropriate audience.

As in the case of the directory, the federal government could contract with experienced organizations to carry out these functions.

ISSUE # 5: TRAINING AND EDUCATION

Recommendation

Models and standards for education and training should be disseminated to states and local jurisdictions for use in establishing, developing and maintaining child fatality review teams. Mechanisms should be established for identifying the training needs at the local and state levels, and this information should be used by the federal system to develop additional educational strategies and training models as needed.

Rationale and Implementation

Education and training will focus primarily on members of local and state fatality review teams. In addition, some emphasis should also be on educating and training professionals (e.g., police, EMS and emergency room personnel, physicians, social workers) in a position to identify deaths and injuries which may have resulted from abuse or neglect.

Training specific to fatality review team members should be multidisciplinary and provide individuals with the technical knowledge and skills necessary to analyze information and make judgements about individual child death cases. Team members may also require a knowledge of the existing service and legal infrastructure addressing child deaths, as well as abuse and neglect. Specifics of the training may include methodologies for distinguishing child abuse and neglect from other causes of child death; case management and referral procedures; overview of pertinent laws, regulations, and investigative protocols; review of autopsy procedures; and clarifications of roles and responsibilities of agencies.

Training should also emphasize a macro approach (e.g., system development/community organization strategies) to facilitate team development and public support at the state and local level. This component of the training may not be required by team members but by those individuals responsible for the development and implementation of the fatality review system.

Based on the success of existing models (e.g., California, Colorado, Georgia, Missouri, Oregon, Cook Co., Illinois) and the emerging training needs, the federal team should take the lead in encouraging the development of standardized training manuals and/or training videos which would support a basic educational curriculum, and could easily be disseminated, tailored to the individual jurisdictions, and implemented in various sites. They should also take the lead in locating resources to support the educational and training activities.

There should also be a federal role in coordinating regional training activities. The federal government (primarily through DHHS or Justice) might allocate funds to support contracts for regional education and training.

ISSUE #6: CONFIDENTIALITY

Recommendation A

All state and local fatality review systems should address the issue of confidentiality in a manner consistent with local statutes and organizational policies, but should not interpret these regulations as a mechanism to restrain the appropriate sharing of information. The national team should not only encourage the implementation of appropriate and systematic procedures for information sharing at the state and local level, but should also examine existing federal statutes and regulations in an attempt to minimize the impediments to necessary sharing of information between organizations.

Rationale

Confidentiality and privacy issues are major considerations in any child fatality review system that necessitates maximum organizational cooperation and information sharing. It is extremely important for the confidentiality of each participating organization to be recognized and respected, however, this must be appropriately balanced against the need for information to make the review system operate successfully. Essentially there are two information sharing issues, the teams' access to information from other organizations, and the public access to the records of the teams' proceedings. In a number of states these issues have been addressed in the legislation. For example, teams may be guaranteed access to information (health, mental health, child welfare, etc.) that might otherwise have been confidential, and teams may be exempted from full disclosure under freedom of information statutes, subpoena, etc. As the existing child fatality review systems continue to gain experience, and as new systems emerge throughout the United States, it will be necessary to maintain a focus on the issue of confidentiality to assure that the appropriate balance is developed and maintained.

Recommendation B

The system should have in place legal protection pertaining to confidentiality. There should be clear legal authority permitting the sharing of information among child death review team members, and there should be protection against subpoena of information that results from team reviews.

Rationale

Issues of confidentiality are crucial to the success of child death review teams. Although information sharing can usually be arranged through interagency agreements, it can be helpful to have statutory authority that clarifies the permissibility of sharing information for fatality review purposes. Statutory authority may also be necessary to protect the confidentiality of deliberations of the team from subpoenas by defendants in legal proceedings.

ISSUE #7: EVALUATION, DATA COLLECTION, AND REPORTING

Recommendation

State and local child fatality review systems should develop appropriate data collection and monitoring systems to enable evaluation of their overall systems. The national fatality review team should encourage and support, at the state and local level, the development of systematic evaluation and monitoring capability including collection of standardized data elements. The national team should support a mechanism for compiling data from multiple jurisdictions, preparing reports, and disseminating information.

Rationale and Structure

Evaluation strategies should include both a process and outcome focus. The ultimate objective of the child fatality review process is the reduction in child deaths (from abuse and neglect), and this long-term outcome should be tracked over time. It is anticipated, however, that these rates might actually increase in the short run as greater numbers of unexplained deaths are accurately classified as resulting from abuse, neglect, or homicide. The ability of the system to correctly identify cause of death is an important intermediate outcome.

Process evaluation in the form of analytic case studies should document the implementation of the child review systems and examine their ability to reach projected objectives. Also addressed should be issues of the teams' functioning, ability to obtain necessary information, developing appropriate protocols, projected interagency cooperation, effectiveness of training, and roles of team participants, among other relevant factors.

A minimum data set from local and state fatality review systems should be centrally compiled and analyzed to facilitate the monitoring and evaluation of the existing framework of systems from a national perspective. This task could be assumed by the Centers for Disease Control or contracted by DHHS to universities or other institutions with appropriate data management and analysis expertise.

ISSUE #8: PROTOCOLS FOR CHILD FATALITY REVIEW

Recommendation

State and local fatality review systems should adopt written protocols to specify activities and timetables for the review process. The U.S. Department of Health and Human Services and the Department of Justice should support the development and dissemination of model protocols to enhance the consistency and reliability of the child fatality review process.

Rationale and Implementation

A number of protocols have been developed and these are currently being used by various child death review teams. There is, however, a need for a uniform approach which will present significant advantages in the following areas: quality of outcome of reviews, consistency of the review process, reliability of data collection, and an increased likelihood that research initiatives directed at understanding and preventing fatal child maltreatment will be successful.

The unique circumstances, both political and administrative, which exist in each jurisdiction present the most serious challenge to the development of a uniform protocol, thus this protocol must be broad enough to allow the flexibility of adjustment to these realities; at the same time it must be specific enough to fulfill its objectives.

The system should develop guidelines and seek agreement about procedures governing the responses of each participating agency to an unexpected or unexplained death.

Guidelines, protocols, and interagency agreements help insure that appropriate information is collected, investigations are handled properly with minimum stress to the families, and that agency staff clearly understand their responsibilities.

The protocol should address three levels:

- Intraagency specific subprotocols (medical examiner, hospitals, protective services and law enforcement);
- Interagency communication (information flow as defined through interagency agreements); and
- Review team activities.

The review team carries out its mandate by implementing a protocol which may vary according to the unique needs of the jurisdiction. The protocol should address:

- Administrative and logistic structure of the system, including responsibilities of the Chair, delegation of responsibilities, frequency and location of meetings, administrative support, format and agenda, etc.;
- Determination of cases to be reviewed based on a predetermined list of criteria;
- Data collecting methods and mechanisms for requesting information;
- Procedures for review and synthesis of information by the team;
- Communication of final disposition of cases (purpose, and scope of distribution);
- Interaction of review team components (local vs. state level);
- Communications strategies with media and community; and
- Publication and distribution of reports.

Some agency-specific protocols are already in existence (e.g., in California, Illinois and New Mexico). The American Bar Association has also developed a relevant sample protocol. These and other resources can serve as examples for organizations implementing new systems.

ISSUE #9: CULTURAL SENSITIVITY CONSIDERATIONS

Recommendation

Child Fatality review systems should be developed and implemented with appropriate attention to and involvement of the socioeconomically and culturally diverse groups in the service area.

These factors should be taken into consideration during the planning and system development process, in defining the composition of the review teams, in making decisions regarding system policies, and in the choice of procedures for selecting and managing cases for review.

Rationale and Implementation

Addressing cultural, ethnic, and socioeconomic considerations at all levels is important in the child fatality review process, particularly since attitudes can easily affect the way the system is implemented, how information is interpreted, and how the rules and protocols are applied. It is essential to insure adherence to mechanisms and strategies which will guarantee the elimination of a biased approach.

Insuring culturally diverse and culturally competent approaches can be done in several ways. For example, community meetings, focus groups and meaningful advisory committees can be employed during the planning and system development phase. Special attention should be paid to insuring that the fatality review team is culturally representative of the community, and that all team members receive formal "cultural sensitivity" training. The review process, including the process of case selection, should be examined to avoid possible bias or insensitivity in the process. State teams which serve in a review and advisory capacity to local teams should insure that these criteria are met at the local level.

ISSUE #10: FINANCING CHILD FATALITY REVIEW SYSTEMS

Recommendation

Key functions of state and local child fatality review systems should be supported through designated and stable funding allocations.

States and local jurisdictions should explore strategies to expand the funding potential from federal and private sources for various components of their fatality review systems. This may involve use of Medicaid funds, CAPTA, MCH Block Grant, Social Services Block Grant, and also approaching private foundations for partial support.

Rationale and Implementation

The cost of implementing child fatality review varies depending on the scope of the system. In addition to the salaries of the required support staff, costs will include coordination, data collection and processing, training, technical assistance, information sharing, and reporting. It is possible to minimize certain costs by involving participating agencies in sharing the burden of operating the system. Support staff may be contributed, and participation as a member of the actual review team should be contributed by each member, or by their agency. Participation on the review team should be considered part of the basic responsibility of the member organizations. The work of the team does not supplant the work of any agency, but enhances its ability to carry out its mandated responsibilities. Therefore, to the extent possible, agencies should fund the staff support from existing resources.

Cost areas will include those associated with performing quality autopsies, conducting death scene investigations, and maintaining laboratory evidence, as well as for training. It is in these areas that creative funding strategies and the allocations of new monies will most likely be required. Reallocation of existing state and local funds, use of Medicaid and other federal resources (e.g., CAPTA, MCH Block Grant, Criminal Justice, etc.), application for new federal grants, and private foundation resources should be aggressively pursued.

A major part of the information sharing between organizations should focus on funding options being used by different state and local systems.

COMMENTS ON THE RECOMMENDATIONS OF THE CHILD FATALITY REVIEW ADVISORY WORKGROUP

In early November the Recommendations of the *ad hoc* Child Fatality Review Advisory Workgroup were distributed to members of the U.S. Advisory Board on Child Abuse and Neglect and to the Interagency Task Force for review and comment. The responses received from members of these groups were favorable and consistent with the intent of the Workgroup's recommendations. In general, the comments suggested mechanisms or strategies for strengthening the recommendations and for facilitating their implementation. Several of the comments addressed specific recommendations and others were more general in nature. The comments are summarized below.

A. National Child Review Team

Issue #1 addressed the idea of a national child fatality review team. Although it was recommended that the national team "...provide assistance to federal agencies that serve families directly, such as the Indian Health Service and the Department of Defense," one respondent commented that the national team should go beyond simply providing assistance to "actively facilitate the development of review teams" in these federal jurisdictions.

B. Professional Forensic Medical Examiner Systems

A number of comments were made regarding the recommendation for professional forensic medical examiner systems in state and local jurisdictions (#2, B). Suggestions included national legislation to require the establishment of these systems, with states providing quality control oversight of the surveillance mechanisms and the forensic pathology investigations. It was suggested that systems should be required to meet minimum standards for procedures, protocols, forensic medical expertise, and for data acquisition. It was also suggested that funds be appropriated to support these systems because they are labor intensive, and because even where medical examiner systems are already in place, they may not presently have adequate resources to meet the minimal requirements for child fatality review.

To address the shortage of trained forensic pathologists (particularly with skills in examining infants and children), one respondent suggested federal training programs, fellowships and other incentives be offered as a mechanism for encouraging physicians to pursue this specialty.

C. Scope of Cases to be Reviewed

The Recommendations stated that "every fatality (birth to age 19) should be eligible for consideration" (#3, C). A comment was made that it might be useful to give an example of prioritizing, or establishing a primary focus for the review process, (e.g., pre-school age children beyond the neonatal period). Such an example would not preclude review of all cases, but would allow for targeting of efforts to those children at greatest risk for child abuse and neglect.

(Note: The Workgroup considered addressing the issue of prioritizing in this manner. The Workgroup did recognize that many systems would choose to set priorities or target their systems. It was decided, however, that by presenting this option in an example, it could detract from the desirability of trying to make these systems as comprehensive and all-encompassing as possible.)

D. Data Collection and Reporting

Comments supported the development of a national surveillance system. It was noted however, that if a standardized minimum data set is to be developed for use at all levels, this must be done carefully. Considerable thought should be given to selecting and defining the data elements, and to determining how these data will be collected from and shared with state and local jurisdictions. A mechanism must be developed to allow state and local input into this process to insure compliance with the surveillance and reporting system.

E. Interface With Other Systems

Several suggestions were made along these lines. It was suggested that standards and protocols for child fatality review be "compatible with those set by perinatal and infant mortality review systems" (and by abuse/neglect review systems) which are in place or presently being developed. These systems could be formally linked or integrated, but must in any case be collaborating in a meaningful way.

F. Other General Comments

One comment asked whether there were data available documenting the effectiveness of fatality review systems in reducing the incidence of child abuse. The concern was raised that the lack of this data might make it difficult to promote a national fatality review system which is of undetermined effectiveness.

(Note: The Workgroup did consider this issue. Data regarding the impact of these systems on child abuse reduction is not yet available. The primary short-term objective of these systems, however, is improving the identification of cases of fatal abuse and neglect, and insuring appropriate law enforcement and legal actions. In this respect they have been clearly demonstrated to be effective.)

Other miscellaneous comments included: a reminder of the Manual for Fetal and Infant Mortality Review prepared by the American College of Obstetricians and Gynecologists as a resource for guidance in developing local and state review systems; and a suggestion that the National Institute of Child Health and Human Development (NICHD) be included on any National Fatality Review Team that is developed.

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