A PROGRAM MANUAL *for* CHILD DEATH REVIEW

Strategies to Better
Understand Why Children Die
and Taking Action to
Prevent Child Deaths

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Dedicated to the more than 53,000 children who die
in the United States every year. We honor their memories by
working to ensure the health and safety of America's children.

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Tools for Teams

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Chapter 1
Introduction & How to Use this Manual

Children are not supposed to die. The death of a child is a great loss to family, friends and community and often represents unjust sufferings and unfulfilled promises. Understanding the circumstances causing a child's death is one way to make sense of the tragedy and may help to prevent other deaths of children. A child's death is a sentinel event and can be a marker in a community of the health and safety of children. Efforts to understand the entire spectrum of factors that lead to a death may help prevent other deaths, poor health outcomes, injury or disability in other children.

Child Death Review (CDR) is a process that works to understand child deaths in order to prevent harm to other children. It is a collaborative process that brings people together at a state or local level, from multiple disciplines, to share and discuss comprehensive information on the circumstances leading to the death of a child and the response to that death. These reviews can lead to action to prevent other deaths locally, at a state level and nationally.

In the past decade, CDR programs have sprung up across the United States. There has been a great variance in how and why these programs evolved. Many programs began as an effort to better identify fatal maltreatment. The majority of programs today have expanded to include a focus on understanding and responding to many other preventable deaths of children.

Review programs and teams across the country go by different names. This manual uses the term Child *Death* Review. This is interchangeable with child *fatality* review, child *mortality* review, etc.

Review teams can be convened at a state, regional, county or city level. In this manual, we will use the term "community" or "jurisdiction" to refer to any level of

team. When the distinction is important, we will use the terms local review or state review to refer to these specific levels of reviews.

This manual describes strategies for developing and managing a state or local CDR program. Suggestions are offered for conducting effective reviews and making recommendations that translate the understanding of how a child died into action to prevent other deaths.

This manual was written to provide you with the information and tools needed to establish, manage and evaluate effective review teams and team meetings. It is meant to serve as a foundation for you. We hope that you will adapt the information presented here to fit your own community context.

Each chapter contains information on a specific aspect of the review process. The final chapter, *Chapter 18, Tools for Teams,* includes sample documents to make the process of establishing a team and conducting reviews easier for you. You can tear them out and adapt them to meet the needs of your own state or community. *Chapter 18* also includes *Guides to Effective Child Death Reviews.* These guides are one-page descriptions organized by cause of death. They can be useful to you in identifying the information you need to bring to a review, help guide the discussion at a review and help move your reviews to prevention.

An electronic copy of this manual, as a PDF file, is available at the Center's website: www.childdeathreview.org. You may also contact the Center to obtain an electronic file on a compact disk that can be edited and customized for your own state or community.

Throughout the manual, a red star ★ will indicate a best practice for child death review. These best practices are based on the experiences of the authors of this manual in implementing CDR in their states.

The National Center for Child Death Review is an additional resource for you. Staff can provide you with additional information, consultation, linkages to other CDR programs and training.

This manual is and will continue to be a work in progress. We welcome your feedback and will continue to make improvements based on your experiences using the manual.

This manual is dedicated to the more than 53,000 children who die in the United States every year. We honor their memories by working to ensure the health and safety of our children.

Use the Manual to Help

- Administrators better understand the purpose and functions of child death review teams.
- State or community organizations establish a review team or review program.
- CDR team coordinators effectively coordinate review teams or programs.
- Individual team members understand their roles in order to actively participate in reviews.
- Team members identify prevention strategies and take action to prevent other deaths.

Chapter 2
CDR Principles, Purpose & Objectives

There is much consistency among Child Death Review (CDR) programs in their purpose and objectives. The following can be adapted for your state or local program.

The Operating Principles of Child Death Review

- The death of a child is a community responsibility.
- A child's death is a sentinel event that should urge communities to identify other children at risk for illness or injury.
- A death review requires multidisciplinary participation from the community.
- A review of case information should be comprehensive and broad.
- A review should lead to an understanding of risk factors.
- A review should focus on prevention and should lead to effective recommendations and actions to prevent deaths and to keep children healthy, safe and protected.

The Purpose

Through a comprehensive and multidisciplinary review of child deaths, we will better understand how and why children die and use our findings to take action to prevent other deaths and improve the health and safety of our children.

The Objectives

The objectives of the CDR process are multi-faceted and will meet the needs of many different agencies, ranging from the investigation of deaths to their prevention.

1. **Ensure the accurate identification and uniform, consistent reporting of the cause and manner of every child death.**
   - Reviews ensure team members are informed of all deaths and thus they are more likely to take actions for investigation, services and prevention.
   - More complete information may help to identify cause and manner.
   - Reviews can lead to modifications of death certificates.

2. **Improve communication and linkages among local and state agencies and enhance coordination of efforts.**
   - Meeting regularly can improve interagency cooperation and coordination.
   - The benefits of sharing information and clearly understanding agency responsibilities can make the CDR process worthwhile in and of itself.
   - Reviews facilitate valuable cross-discipline learning and strategizing.
   - Reviews improve interagency coordination beyond the review meetings.

3. **Improve agency responses in the investigation of child deaths.**
   - Reviews promote early and more efficient notification of child deaths, facilitating more timely investigations.
   - Sharing information on the type of investigation conducted leads to improved investigation standards.
   - Reviews can identify ways to better conduct and coordinate investigations and resources.
   - Many teams report that new policies and procedures for death investigation have resulted from reviews.

4. **Improve agency response to protect siblings and other children in the homes of deceased children.**
   - Reviews can often alert other agencies, such as social services, that other children may be at risk of harm; and they identify gaps in policies that may have prevented the earlier notification to these agencies.

5. **Improve criminal investigations and the prosecution of child homicides.**
   - Reviews can provide new case information to aid in better identifying intentional acts of violence against children.
   - Reviews may bring a multi-disciplinary approach to assist in building a case for adjudication.
   - Reviews can provide a forum for professional education on current findings and trends related to child homicides.

6. **Improve delivery of services to children, families, providers and community members.**
   - Reviews can identify the need for delivery of services to families and others in a community following a child death.
   - Reviews can facilitate interagency referral protocols to ensure service delivery.

7. **Identify specific barriers and system issues involved in the deaths of children.**
   - Team members can help agencies identify improvements to policies and practices that may better protect children from harm.

8. **Identify significant risk factors and trends in child deaths.**
   - Reviews bring a broad ecological perspective to the deaths, thus medical, social, behavioral and environmental risks are identified and more easily addressed.

9. Identify and advocate for needed changes in legislation, policy and practices and expanded efforts in child health and safety to prevent child deaths.

1. Every review should conclude with a discussion of how to prevent a similar death in the future.
2. Reviews are intended to be a catalyst for community action.
3. Teams are not expected to always take the lead, but should identify where and to whom to direct recommendations, then follow-up to ensure they are being implemented. Solutions can be short-term or long-term.

10. Increase public awareness and advocacy for the issues that affect the health and safety of children.

- When review findings on the risks involved in the deaths of children are presented to the public, opportunities can be identified for education and advocacy.

The Objectives of Child Death Review

1. Ensure the accurate identification and uniform, consistent reporting of the cause and manner of every child death.
2. Improve communication and linkages among local and state agencies and enhance coordination of efforts.
3. Improve agency responses in the investigation of child deaths.
4. Improve agency responses to protect siblings and other children in the homes of deceased children.
5. Improve criminal investigations and the prosecution of child homicides.
6. Improve delivery of services to children, families, providers and community members.
7. Identify specific barriers and system issues involved in the deaths of children.
8. Identify significant risk factors and trends in child deaths.
9. Identify and advocate for needed changes in legislation, policy and practices and expanded efforts in child health and safety to prevent child deaths.
10. Increase public awareness and advocacy for the issues that affect the health and safety of children.

Worksheet for Your Team: Principles, Purpose & Objectives

Our Guiding Principles:

Our Purpose or Mission:

Our Objectives:

1.

2.

3.

4.

5.

6.

7.

8.

Chapter 3
Core Functions, Models & Authority for CDR

Three Core Functions of CDR Programs

Although the purpose and objectives of Child Death Review are consistent across the United States, there are variations on how the process is implemented by states and communities. A review program can include any or all of the following three core functions:

1. **The case review team that conducts individual case reviews of deaths.**

- Share comprehensive information from multiple agencies on the circumstances of child deaths.
- Identify and review system problems.
- Improve communications among agencies.
- Improve coordination among agencies, especially concerning child death investigations and child protection strategies.
-
- Examine local trends and issues, especially with regard to child death investigations.
- Improve investigation protocols.
- Develop interagency agreements to improve reporting and review procedures.
- Provide access to available information to improve child death investigations and ensure accurate reporting.
- Ensure that those responsible for a child's death are held accountable.
- Review deaths in a timely manner.
- Provide community education, promote awareness and/or implement prevention strategies.

2. The advisory team that assesses the case review findings and child mortality trends and makes recommendations or takes action.

- Examine the data from the case reviews, child mortality statistics, trends and issues.
- Identify and review system problems.
- Identify best practices that promote child health and safety.
- Make recommendations to develop or improve policies, practices or prevention programs.
- Advocate for prevention programs.
- Promote better communication within and between state and local agencies.
- Advocate for enhancement of the review process.

3. The program administration that manages and/or supports the case review teams.

- Promote development of local review teams.
- Provide training and technical assistance to review teams.
- Facilitate identification of deaths for team reviews.
- Collect case review reports and child mortality data and prepare annual reports.
- Link review teams to prevention resources.
- Staff the advisory team.
- Promote multi-agency participation.

Models of CDR Programs

Your program most typically will fit one of four different models. The models vary by what core functions they perform, by whether reviews are conducted at the state or local level, by the types of deaths they review and by where their authority lies.

In 2005, all but one state in the United States had a designated person in a state agency that served as the state lead for child death review. However, this does not mean that every state has a state-level review program or that the support included all three of the core functions listed above.

Local reviews may take place in a number of different jurisdictions. Most local teams in the United States are county-based. Other jurisdictions include cities, regional teams of two or more counties, judicial districts and reviews organized by agency districts (a community health department region for example).

There are also wide variations across and within states on the types of deaths that are reviewed, by age, manner and cause, place of death and the timeframe from death to review. *Chapter 8*, *Conducting a Case Review*, describes these variations and possibilities in more detail.

Often the variation in cases reviewed depends on the primary purpose of the review program. For example, those teams that are more focused on investigations and better identification of child maltreatment deaths may review a more specific group of child deaths.

The four models of CDR programs include:

1. Local only reviews of individual cases, state reviews of local findings and state and local responses to findings.

A state agency provides oversight and coordination to a network of local review teams. The state provides protocols or guidelines for local reviews, with varying degrees of authority. States usually provide training and technical assistance to their local team members and have a state CDR coordinator staff position.

Most reviews are conducted at the local level and recommendations are made for improvements to local policies and practices. Prevention initiatives are implemented locally.

Local review teams may serve county, city and/or regional jurisdictions and the agency coordinating the local teams varies.

These teams usually submit case review reports to a state agency or state CDR program office. Then a state advisory team reviews the aggregate or individual findings of local teams and makes recommendations for improvements to state policies and practices. Most states using this method produce an annual report with child mortality data, CDR findings and recommendations. States utilizing this approach may focus on child abuse deaths or on all preventable deaths.

This manual is primarily focused on effective case review meetings. It does not go into extensive detail on establishing and maintaining advisory teams. However, *Chapter 18, Tools for Teams,* includes a description of advisory board purposes and functions, a sample meeting agenda and a job description for a state level program coordinator.

States vary as to whether local teams receive funding for reviews, but in all but a few states, they do not. States also vary in whether local reviews are mandated or are voluntary.

Teams may also have sub-committees reviewing specific causes of deaths and report these findings to their local or state CDR team.

Most review meetings are held as *Retrospective Reviews*. These usually take place after the investigation is mostly completed and case information is readily available.

Some teams have *Immediate Response Reviews* that typically occur shortly after a death, usually of those that are unexpected or unexplained. Using this method, the team is able to discuss case information immediately, thereby affecting the processes and procedures used during the active investigation of a child death. This type of review may also assist protective services in their work to protect other children involved. Because immediate response review meetings are unscheduled, the team coordinator usually contacts each team member to arrange these reviews. Teams should establish criteria to identify deaths that require immediate response reviews. Often only a select sub-group of the full team will participate in these types of reviews.

If a team chooses an immediate response review but has standing meeting dates for retrospective reviews as well, then it is likely that the case will go through both types of review. In this way, the CDR process acts as a tool for coordinating death investigations and delivery of services, as well as a source of information for identification of risk factors and prevention of other deaths in the future.

2. State and local review of individual cases and state and local response to findings.

A state-level committee reviews certain types of deaths or a representative sample of cases, while local teams review cases independent of the state team. There may be little or no coordination between the local and state reviews or the state may review the local findings. The local review teams may not operate under mandated or suggested state guidelines. Local teams rarely receive state funds for their reviews. As with the other approaches, the agency lead varies by jurisdiction.

3. State only reviews of individual cases and state-level responses to findings.

A state-level CDR committee reviews child death cases and issues a state-level report of findings, and no community reviews take place. These review panels usually involve state agency representatives. Most state-level reviews started as child abuse reviews but some have expanded into other preventable causes of death. In a number of states, comprehensive case records are made available to an abstractor who prepares

the case for the review team. In other states, agencies bring their own records to the review. The types and numbers of deaths reviewed usually represent only a proportion of all deaths in the state.

A variation of this model is that a state agency may have an internal review team comprised of their own agency representatives. In this model, the deaths reviewed are usually of children that were in the care and custody of that agency, for example, deaths of children in foster care.
The state committee may also serve as the state's Child Abuse Prevention and Treatment Act (CAPTA) mandated Citizens Review Panel (CRP) and conduct case reviews or review local case reviews of child abuse deaths.

4. Local only review of individual cases and local response to findings.

These teams operate independently of the state, although in some cases a state-level person may help to bring some of the teams together for training and/or technical assistance. Reviews are conducted in city or county jurisdictions. Some teams issue written reports of their findings.

> **Review Programs in the U.S.**
> **January 2005**
>
> 20 states
> Local only review of individual cases; state review of local findings; and state and local response to findings.
>
> 13 states
> Both state and local review of individual cases; and state and local response to findings.
>
> 15 states
> State only review of individual cases; and state-level response to findings.
>
> 2 states
> Local only review of individual cases and local response to findings.

Authority for Reviews

The locus of control for the authority to support, manage and conduct reviews varies widely across the United States. You should review your current legislation, agency promulgated rules and policies to identify where authority for review lays and to identify what components of the review process your state mandates, encourages or prohibits. *Chapter 12, CDR Legislation and Public Policy* and *Chapter 18, Tools for Teams,* describe the components of legislation that can provide for full state support of a child death review program.

Usually one state agency has to assume the leadership role in establishing and managing the review program and/or in conducting actual case reviews. Absent legislation, a state or local agency with an interest in supporting the CDR process and a commitment to the prevention of all causes of deaths may be the best candidate to facilitate the process. For example, the Maternal and Child Health Program (Title V) or Injury Prevention Program within the state health department may be a logical choice.

Although one agency should assume the leadership role, the multidisciplinary nature of the review process makes it imperative that ownership for the process and the findings are shared across agencies.

Chapter 4
Establishing a Team & Coordinator Duties

This chapter describes steps to establish a team that will review child death cases and describes the role of the coordinator to ensure that the review team process is efficient and effective. It does not focus on the establishment of a child death review (CDR) program office at a state-level or of a state advisory team.

Organizing a Review Team

1. Designate a team organizer.
2. Contact your state program coordinator.
3. Study CDR program materials.
4. Conduct an assessment of child mortality and your readiness to establish a team.
5. Contact an existing review team.
6. Contact core local agencies that may serve on the team.
7. Collect mortality data.
8. Schedule an organizational meeting.
9. Conduct an organizational meeting.
10. Follow-up prior to your first review meeting.

Steps to Organize a Review Team

Establishing a review team requires planning and coordination with numerous agencies. Usually one person or persons from an agency take the lead in planning for a team. Your state may or may not have a mandated agency lead.

The following describes the activities, that when implemented, can lead to an effective CDR review program.

1. Designate a Team Organizer

Review teams are created through both individual efforts and voluntary cooperation among agencies and professionals involved with child deaths. To establish a multi-agency, multidisciplinary child death review team in your jurisdiction, one person must be willing to commit the time and effort required to form a team. Individuals interested in organizing review teams can come from any profession. Teams have been initiated by public health professionals, medical examiners, prosecutors, law enforcement personnel, social service and child advocates. Your state may legislate who the lead should be and interested persons should contact this person/agency.

2. Contact Your State Program Coordinator

The local review team organizer should contact the state or regional Child Death Review Program Coordinator for team information and membership recruiting materials if available. A community's local political climate and relationships among the heads of core agencies can strongly impact the approach to creating a CDR team. Each community should adopt an approach that best suits its unique characteristics.

3. Study CDR Team Materials

The team organizer should become thoroughly familiar with the operation of a CDR team by studying the informational materials supplied by the state program and other materials available through resources, such as the National Center for Child Death Review. Supplemental information regarding other professions, how they function and their role in CDR should also be studied.

4. Conduct an Assessment of Child Mortality and Your Readiness to Establish a Team

Prior to your first meeting, you should begin an assessment of your community's readiness and need for CDR. An assessment tool, *Planning for a New CDR Team*, is located in *Chapter 18, Tools for Teams*. Using this tool as a guide, strengthen your community's CDR readiness by compiling your child mortality data to understand the scope of deaths in your community. The tool can also help you identify partnerships and secure commitments to participate.

5. Contact an Existing Review Team

The team organizer should contact the CDR team coordinator of a successfully operating team and request to attend a review meeting. Observing an existing review team will answer many questions regarding how teams operate and may also provide direction on recruiting potential team members. Locating a team in a jurisdiction with similarities to yours may be helpful. It may be useful to observe more than one CDR team.

6. Contact the Core Local Agencies that may serve on the Team

The team organizer should contact the directors of local core member agencies to discuss establishing a CDR team. Team organizers should become familiar with potential agency roles and the need for their participation on the team. In recruiting team members, request that the highest possible level of agency staff join the team. They will have the authority to implement changes, if necessary, and commit their agencies to cooperative activities, projects and protocols. When an agency director is not available, a staff member authorized to make agency decisions should be recruited.

This individual should be knowledgeable about, experienced in and have direct responsibility in areas related to child health, safety and protection. For example, if the chief prosecutor cannot attend, the designee should be a person with responsibility for child and juvenile proceedings. The team coordinator should contact core members to ensure that delegated tasks are completed before the

first team review is held. A letter of invitation to participate is located in the *Planning Tool* in *Chapter 18, Tools for Teams.*

7. Collect Mortality Data

To help plan the scope of your review programs, it is necessary to know the numbers and types of deaths and the profile of the children who die in your community. You can contact your state or community public health agency to assist you in gathering mortality and morbidity data over a specific length of time. For example, they can help you identify deaths and death rates by age, race, sex, cause and manner. Request that your State Child Death Review Program provide you with child mortality data for your jurisdiction.

8. Schedule an Organizational Meeting

Most organizational issues should be addressed prior to your first case review. After all core agencies have been contacted, the team organizer should schedule an organizational. Meetings should only be held if most of those invited are able to attend. Request that the State CDR Program Coordinator attend your first meeting to provide guidance.

9. Conduct an Organizational Meeting

Several organizational meetings may be necessary before your team is actually ready to begin reviewing deaths. *Chapter 18, Tools for Teams*, includes a sample *Organizational Meeting Agenda*. This includes:

- *Introduce potential members.*
- *Provide an overview of the purpose for and history of child death review teams in your state and describe how a review team operates*: Share and discuss your statues, administrative rules or policies that may address how your team may or should be operationalized.
- *Present child mortality statistics for the jurisdiction*: Share the child mortality statistics for your county or region obtained from the State Child Death Review Program Office, your health department and/or from your planning tool.
- *Discuss current response to child deaths*: Develop a road map of actions taken by agencies in your community from the time a 911 call comes in or a child arrives at the hospital, to when a child dies. This is a good way to help member agencies understand their different roles and the systems that respond to a child death.
- *Describe the current resources available in the community related to death investigation, services and child health and safety.*
- *Describe other review processes that may be occurring in your community or state.*
- *Discuss the benefits of CDR team involvement for participating agencies*: Allow time for each person attending to express concerns or raise issues. Make sure each person has an opportunity to ask questions and participate. If you do not have the answers to all the initial questions, explain that you will learn what other teams or agencies are doing and report back to the group.
- *Discuss the benefits of both immediate response and retrospective reviews and make a decision on the process(es) your team will follow.*
- *Determine the types of cases to review:* This is discussed in more detail in *Chapter 6, Case Selection and Records for Review*.
- *Determine how to identify cases:* Decide how to identify cases through both the medical examiner's/coroner's office and the county clerk's office. The coordinator should contact the county clerk and the county medical examiner or coroner to establish a procedure for identifying all child deaths and for

obtaining death certificates before they are sent from the county to the Office of the State Registrar. A sample letter requesting records from your county clerk is located in *Chapter 18, Tools for Teams.*

- *Establish a meeting schedule:* Teams should schedule regular meeting times based on the type of reviews they choose to conduct and/or develop a process for calling immediate response reviews. Attendance will be higher if a regular time and place is agreed upon for meetings. If a jurisdiction has very few deaths, the team can decide to meet only in the event of a death. In this case, one person should be designated to call meetings as needed. If no additional organizational meetings are required, schedule the first meeting to review deaths.

- *Select Additional Members:* Compile a list of potential additional or ad hoc team members and develop a plan for enlisting their participation.

- *Discuss, revise and agree on a Team Interagency Agreement and a Confidentiality Agreement:* These documents must be signed prior to conducting CDR reviews so that official working relationships may be established and so that members agree to the confidentiality provisions for your team. Samples are located in *Chapter 18, Tools for Teams*. Discuss possible legal and institutional barriers to these agreements and develop solutions.

- *Agree on materials to compile and distribute to team members at the first review meeting:* Materials should include basic information about child death review teams, the authorizing legislation, the data collection form and the preliminary agreements made at the initial meeting. This effort can serve to create a CDR Team Manual that is always provided to new members.

- *Share the CDR Case Report Tool your team will be using*. These are usually available from your state program office. See *Chapter 11, CDR Data and Reporting* for more information.

- *Select a team coordinator and chairperson:* Select these persons if not already mandated by your legislation. The team coordinator and chair may be different persons. The coordinator should be someone with the time to obtain case records as necessary, prepare for meetings and complete follow-up. The chair should be a person with excellent leadership skills and a person highly respected in your community.

10. Follow-up prior to your first review meeting.

The team coordinator should contact members to ensure that they understand their roles and are prepared to review cases at the first meeting.

Duties of the CDR Chair or Team Coordinator

The chair and/or team coordinator may be a designated or a volunteer agency representative.

In some states, all CDR team coordinators are from the same agency, for example, the county health department director or the chief prosecutor. In other states, this role is not defined in law or policy and agency leads may vary team by team. Regardless, the role of the CDR team coordinator is usually an additional responsibility to one's job. Few coordinators can find this role defined in their job descriptions, yet the CDR team coordinator is very much the glue that holds the entire process together.

Some teams are very effective in dividing responsibilities. For example, the CDR team coordinator may be a person very adept at organizational skills but not skilled in facilitating meetings. This person may then

only be responsible for handling the logistics of the meetings and a person with stronger leadership skills may chair the meetings. Another example would be that a person with strong data skills might complete and submit the case review reports. A sample *Job Description for a CDR Team Coordinator* is in *Chapter 18, Tools for Teams.* The following list describes the most common duties of the Chair and/or CDR Team Coordinator.

- Determine meeting dates and send meeting notices to team members.
- Obtain names and compile the summary sheet of child deaths to be reviewed and distribute to team members two to three weeks prior to each meeting.
- Ensure that notices of child deaths are available for team review.
- Ensure that new members receive a team manual and an orientation to the CDR team prior to their first meeting.
- Ensure that all new CDR team members and ad hoc members sign a confidentiality agreement.
- Encourage the sharing of information for effective case reviews.
- Chair the team meetings and facilitate resolution of agency disputes.
- Complete and submit data reports to the State Child Death Review Program Office as directed.
- Ensure that the CDR team operates according to protocols as defined by the team or law.
- Promote CDR team success in following through with recommendations and prevention initiatives and activities.
- Facilitate contacts with the media.
- Maintain contact with the state CDR Program Office.

Planning Meeting Agenda

1. Welcome and introductions.
2. Overview of purpose and history of child death review teams.
3. Description of how a review team operates.
4. A presentation on child mortality data.
5. Community response to a child's death: What actions occur when a child dies and what are the roles and responsibilities of agencies?
6. Benefits of implementing a review team
7. What will our team look like?
   - What types of cases will we review?
   - How will we identify deaths?
   - When and where will we meet?
   - What members should be involved?
   - What will our timeline be from a death to review?
   - Who will coordinate the team?
   - Who will facilitate the meetings?
8. Discussion of confidentiality statements and interagency agreements to participate.
9. Discussion of the case reporting form to be used.
10. Agenda items and materials for next meeting
11. Schedule next meeting
12. Adjourn

Factors that Contribute to Successful Development of a CDR Program		
Factor	**Example**	**Why This Contributes to Success**
State Support	Maternal Child Health, Department of Justice or other state-level organization agrees to support the program.	Although a bottom-up process, agreement to participate is often top-down. When a state entity makes CDR a priority to their functioning, the institutionalization can ensure the future of its existence.
Legislation	Enabling, protecting and/or information-sharing legislation relating to CDR is passed at the state-level.	Gives legal basis for conducting reviews, sharing sensitive information and protecting confidentiality; this may legitimize the process for some.
Financial Support	Funds to cover community consultants for technical assistance and support are appropriated by participating agency(ies).	Expertise of CDR consultants facilitates formation and sustainability of teams, especially in the face of member turnover.
Housing of Program	State CDR program and staff are housed in a neutral location, with a committed housing organization.	More likely to be non-threatening to the other disciplines. It may help lessen turf issues if they have existed in the past.
Organizational Seminars	A state with few or no local teams holds regional seminars, inviting a range of local human service representatives to familiarize them with the CDR process.	Introduces the idea of the CDR process to multidisciplinary audience at one time; can answer pertinent questions in open, discussion-style format. Gives representatives from rural areas opportunity to network, possibly forming regional teams.
Organizational Meeting	Team convenes their first meeting as organizational only; no reviews are done.	Provides opportunity for team members to get acquainted and set process parameters before attempting reviews.
Interagency Agreement	Agency directors sign joint agreement to participate in the CDR process.	Solidifies multi-agency commitment and idea of shared ownership in the process. Can ensure participation of field staff.
Confidentiality Statements	All members sign confidentiality statements on a regular basis, before sharing information.	Further assures those still wary of liability associated with CDR. Provides safe environment, encourages members/agencies to share sensitive information.
Training	Statewide training provided to new local and state-level team members annually.	Informs members about new research on various types of death; builds skills for conducting reviews; provides opportunity for networking, sharing experiences.
Retrospective Practice Reviews	Team chooses a number of deaths from the recent past as first set of reviews.	Raises comfort level of members with the process, without the pressure of discussing ongoing investigations, etc.
Buy-in of Core Members	Agency representatives required by law to participate are committed to CDR; attend all meetings.	Sets tone for other members to follow; raises perceived importance of process; more likely that relevant information will be available to be shared.
Additional Membership	Team coordinator invites individuals who were involved in each of the cases reviewed to those meetings.	Gives team clearer picture of events, adds to completeness of information on report form; facilitates prevention discussions.
Access to Records	Adequate records on each death are made available to the team for review.	Increases usefulness of aggregate CDR data. Makes it easier for teams to identify risk factors, move from findings to recommendations to action.
Dissemination of Findings	Findings and recommendations are disseminated to professionals, legislators, agencies, the public, etc.	Maximizes impact of the review process; reinforces members' commitment, fosters feeling of productivity and accomplishment.

Chapter 5
Team Membership

A child death review team is going to be effective when it has the right multidisciplinary membership. The team has a foundation for success when members are:

- Drawn from the community or state agencies with responsibilities for the investigation and/or prevention of child deaths.
- Broadly representative of the community or state agencies responsible for protecting the health and welfare of children.
- Broadly representative of the populations most at risk and impacted by child deaths.
- Willing to be open, honest and cooperative with each other.
- Willing to advocate for or work directly for change in order to prevent child deaths.

This chapter describes the types of agency and community representatives you should consider when developing your CDR team membership.

Identifying CDR Team Members

To establish a CDR team, one must first identify the types of representatives who should serve on the team. As a start, consider:

- What are membership requirements according to legislation or policy?
- Who in the jurisdiction is responsible to respond to child deaths?
- Who is knowledgeable, creative and works in child heath, safety and protection?
- Who in the community is appropriately positioned to help obtain support for the team's practices and potential recommendations?
- Who can represent and speak for the population of children most at risk for injuries, illness and death?

In jurisdictions where teams are required by law, the legislation generally identifies the core team members. Other jurisdictions establish their own CDR teams without the benefit of legislation. But whether or not there is legislation, CDR team members can be seen as being from one of three categories:

1. Core members who are usually required by your laws or rules.
2. Persons not required by law to participate, but who should be considered for team membership.
3. Ad hoc members who participate on a case specific basis.

If you have a state CDR advisory team, many of the member agencies on local teams should be considered for your state team. You should also attempt to include members with key leadership positions in state agencies and advocates from a number of child health and safety arenas. You should also consider including coordinators of other types of review programs to serve on your committee, e.g., the state Fetal and Infant Mortality Review Coordinator (see *Chapter 16, Coordinating with Other Reviews*).

Core members of CDR teams are responsible for responding to child deaths or for protecting children's health or safety. A CDR team should always have representatives from the following agencies or professions:

- Law Enforcement
- Child Protective Services
- Prosecutor/District Attorney
- Medical Examiner/Coroner
- Public Health
- Pediatrician or Other Family Health Provider
- Emergency Medical Services

Additional and ad hoc members from other agencies, providers and professions involved in protecting children's safety and health should be considered for CDR team membership and certainly provisions should be made for their inclusion on a case appropriate basis:

- Attorney for Child Protective Services
- Child Care Licensing Investigators
- Domestic Violence Expert
- Education
- Fire Department
- Juvenile Justice
- Local Hospital
- Maternal and Child Health
- Mental Health
- Child Abuse Prevention Organizations
- Private Non-Profit Community Group
- Housing Authority
- Home Visiting/Outreach Programs
- Court Appointed Special Advocate
- Disabilities Protection and Advocacy Agency
- Disabilities Expert
- Substance Abuse Treatment Program
- Sudden Infant Death (SIDS) Program
- Vital Records
- Prevention Partners
- Other members as required or as appropriate on case-specific basis

To focus on membership, examine and address the role each professional plays on a CDR team, noting:

- Information the professional can bring to the CDR team: What information does the professional have about the actions taken by her or his agency regarding the child/family or contacts between the child/family and the agency?
- Expertise the professional can bring to the CDR team: What specialized knowledge or expertise does the professional have that the team can use in its work?
- Assistance the professional can provide to the team: What help can the professional give the team to accomplish its goals?
- Bridges that can be built through the professional's participation on the team: What connections between agencies and other providers can be built through the participation of the professional on the team?

In recruiting team members, you should present them with a full purpose of the review team process so that you empower them to know what their expertise can bring to the review of a child death.

The Role of Core CDR Team Members

1. Law Enforcement:

Law enforcement is often the first to respond to a scene and has responsibility for ensuring public safety, investigating the deaths of children, determining if crimes have occurred and making arrests.

The law enforcement member can:

Provide the team with information on:

- The case status and investigation of the death scene.
- The criminal histories of family members and suspects.

Provide the team with expertise on law enforcement practices such as:

- Death scene investigation, interviews and interrogations of witnesses and others.
- Evidence collection.

Support the team with assistance, particularly by acting as a liaison to other law enforcement agencies by:

- Persuading officers from other agencies and/or jurisdictions to participate on the CDR team when there is a death in that jurisdiction.
- Providing access to and information from other law enforcement agencies.
- Providing assistance to member agencies in working with area law enforcement.

Help build bridges by:

- Learning about the policies and practices of other agencies through team participation.
- Acting as liaison between the CDR team and the jurisdiction's other law enforcement agencies.
- Explaining to the team how to improve coordination with law enforcement agencies.

Identifying a law enforcement representative can present challenges. Many jurisdictions include more than one law enforcement authority. The city or county police, sheriff's office, highway patrol or state police may each exist within a jurisdiction. Which department should serve on the team?

There is no optimal single approach to this situation. Each jurisdiction needs to develop the approach that best satisfies their needs. Possible approaches include: selecting a permanent member from the largest police force or the police force that sees the largest number of child deaths or asking the police forces that operate in the jurisdiction to select a permanent member and then invite other officers as needed.

If a child's death occurs in a jurisdiction not covered by the permanent member, consider inviting ad hoc members from the police force responsible for the death investigation.

Within a single police department there may be several units involved with children. For example, the juvenile division may investigate crimes against children other than homicide, while the homicide division may investigate the killing of children. Each division will have useful information for the CDR team. Work with your law enforcement jurisdictions to determine who can best serve on the team.

2. Child Protective Services:

CPS is responsible for investigating allegations of child abuse or neglect and for recommending or providing services to children and families when abuse or neglect is alleged or confirmed. In addition, CPS is the liaison to the broader

child welfare agency and many community resources.

The CPS member can:

Provide the team with information on:
- The case status and investigation summary for deaths the CDR team is reviewing.
- The family's and child's history and socioeconomic factors that might influence family dynamics, including unemployment, divorce, previous deaths, history of domestic violence, history of substance abuse and previous abuse of children.
- Other children in the home and previous reports of neglect or abuse in the care of an alleged perpetrator and the disposition of those reports.

Provide the team with expertise by:
- Using specialized knowledge to design better intervention and prevention strategies and identify ways to integrate these strategies into the system.
- Identifying local and state issues related to preventable deaths.

Support the team by:
- Educating the team regarding child protection issues and how the CPS system works.
- Working to improve the human services system's responsiveness to a suspicious child death.
- Training other team members about warning signs of abuse and neglect.
- Providing linkages to the juvenile court system when it is needed to assure protection of surviving children.
- Protecting potentially at-risk siblings or other children in the home.
- Providing or identifying services that can be offered to the family.

Help build bridges by:
- Learning about the policies and practices of other agencies through CDR team participation.
- Explaining to the CDR team how to improve coordination with social service agencies.
- Assisting the criminal investigation by sharing specialized knowledge on child maltreatment.
- Acting as a liaison between other jurisdictional CPS units and other local and state child welfare agencies.

3. Prosecutor/District Attorney:

This office is responsible for prosecuting the deaths of children when a criminal act was involved. This office often defines, by the cases they take to trial, what the standards of acceptable practices regarding child safety are in a community.

The prosecutor/district attorney can:

Provide the team with information on:
- The case status for deaths the team is reviewing.
- Previous criminal prosecution of family members or suspects in a child death.
- Explanations when a case can or cannot be prosecuted.
- Legal terminology, concepts and practices.

Support the team by:
- Assisting in the development and implementation of strategies in the legal and criminal justice systems to prevent child deaths and serious child injuries.
- Assisting in the development and implementation of strategies to improve the prosecution of child deaths and serious child injuries.

Help build bridges by:
- Learning about the policies and practices of other agencies through CDR team participation.
- Acting as a liaison between the team and prosecutor/district attorney's offices in other jurisdictions.

- Meeting and becoming comfortable with professionals in other agencies on whom the prosecutor may rely in child homicide cases.

4. Medical Examiner or Coroner:

This office is responsible for determining the cause and manner of death for children who die under suspicious, unexplained or unexpected circumstances. Usually a coroner is an elected official who is not required to be a physician or have specialized training in forensics. A medical examiner is usually a physician and may have training or licensure in pathology and/or forensics.

The medical examine or coroner can:

Provide the team with information on:
- The status and results of the office's investigation into a child death and explanation of the manner and cause determination..
- The autopsy report and other investigation records, such as toxicology reports, scene investigations and medical history records.

Provide the team with expertise by:
- Educating the team on the elements and procedures followed by the Medical Examiner's or Coroner's office in investigating a child's death.
- Giving specific information as to the nature of the child's injuries to aid investigators.
- Educating the team on causes of child death.
- Educating the team on medical issues including child injuries and child deaths, medical terminology, concepts and practices.

Support the team by:
- Providing the team with records, such as the child's medical records, which are accessed by the medical examiner or coroner in their investigation.
- Providing access to and information from other medical examiners or coroner offices.

Help build bridges by:
- Learning about the policies and practices of other agencies through team participation.
- Explaining to the team how to improve coordination with medical examiner/coroner offices.

5. Public Health:

This agency is responsible for birth and death records, other health statistics and for developing and implementing public health strategies to prevent injuries and deaths. The agency also is the lead agency for maternal and child health (MCH) and is responsible for programs which improve the health and safety of pregnant women, infants and children. The agency may have established Fetal-Infant Mortality Review Teams (FIMR). Public Health can often provide information on neighborhoods and families. Public Health nursing staff may have information from home visits. Some public health agencies may provide direct health care services. Most will have immunization records.

The public health member can:

Provide the team with information on:
- Contacts made between the family and the public health agency.
- Birth and immunization records and death certificates.
- Statistical data.
- Access to epidemiological/health surveillance data.
- Programs for high-risk families.

Provide the team with expertise by:
- Providing information on the development and implementation of public health prevention activities and programs.

- Providing information and assistance on data collection and analysis.

Support the team by:
- Accessing information from other health professionals who provided services to the child and family.
- Accessing statisticians and epidemiologists to assist in data collection and analysis.

Help build bridges by:
- Learning about the policies and practices of other agencies through team participation.
- Acting as liaison between the team and the community's other health care providers.

6. Pediatrician or Other Family Health Provider:

These professionals have expertise in health and medical matters concerning children. When selecting these professionals, seek out persons who have practices that serve high numbers of children or who are active in the community.

The pediatrician or other family health provider can:

Provide the team with information on:
- Services provided to the child or family if seen by the health professional.
- General health issues, including child development, injuries and deaths, medical terminology, concepts and practices.

Provide the team with expertise by:
- Offering expert opinion on medical evidence in a child death.
- Giving a medical explanation and interpretation of events from the point of view of examining thousands of living children.
- Sharing general knowledge of injuries, SIDS, child abuse/neglect and childhood disease.

Support the team by:
- Accessing medical records from hospitals and other medical care providers.
- Providing the medical information needed for a successful prevention campaign.

Help build bridges by:
- Learning about the policies and practices of other team member agencies through team participation.
- Acting as a liaison between the team and the jurisdiction's medical community.
- Explaining to the team how to improve relationships with the community's medical providers.

7. Emergency Medical Services:

EMS personnel are often the first on the scene when a child dies or is seriously injured. EMS usually prepare run records of their response that they can share at reviews.

The EMS member can:

Provide the team with information on:
- EMS run reports.
- Details on the scene, including the persons at the scene.
- Medical information related to the emergency procedures performed.

Provide the team with expertise by:
- Giving detailed explanations of EMS procedures and protocols.
- Sharing general knowledge based on EMS training and experience.
- Helping the team understand and/or participate in critical stress debriefings.

Support the team by:
- Understanding EMS procedures and protocols.
- Addressing issues regarding scene preservation practices.

Help build bridges by:

- Learning about scene preservation practices essential to investigation and prosecution.
- Acting as liaison between the team and the jurisdiction's EMS community.
- Working with law enforcement and district attorneys to resolve issues related to scene investigation.

Additional Members

There are other persons that can share important case information at a review and/or have valuable perspectives on systems, services or programs. These include:

Attorney for CPS:
The CPS agency has the responsibility for taking action to protect the siblings of children who die from abuse or neglect. If those actions include removing surviving children from the home or terminating parental rights, the process can be shortened if the CPS attorney is present to hear the information first hand. Additionally, the CPS attorney can provide legal information to the team, particularly about the legal process followed in child welfare court proceedings.

Child Care Licensing Investigators:
Many states have professional staff responsible for investigating injuries and deaths in child care facilities and home childcare as part of the licensing system. Such individuals can provide information on specific cases and assist with an understanding of systems issues affecting children.

Domestic Violence Program Experts:
Children may be at increased risk of injury or death in homes in which there is domestic violence. The domestic violence program expert's participation on a team may enable the team to further research the link between domestic violence and child abuse or injuries, identify children at risk of injury and increase the communication between the domestic violence and the child welfare communities.

Education Representatives:
A representative from the public education agency can provide school information about a deceased child, the family, siblings and fellow students. The education representative is also a conduit to prevention activities that a team can foster in the schools or with school-age children. Additionally, an education team member can help increase communication between the education and child welfare systems. Your team will need to determine which educational system/personnel should attend. This could include county school district personnel, school administrators, social workers or nurses.

Fire Department Staff:
The fire department has the needed expertise on the investigation and determination of cause of fire-related deaths and prevention efforts related to those deaths. Fire departments can provide information on whether or not safety devices, such as smoke detectors, were present and working.

Juvenile Justice Program Staff:
Juvenile justice agencies provide programs for victims and are responsible for oversight of juvenile perpetrators. They are linked with judges, referees, attorneys, probation and parole officers and social workers that may have information of relevance to the team.

Hospital Staff:
The local hospital may have medical records from the Emergency Department, inpatient or outpatient clinics regarding the child's conditions and treatment. Additionally, the hospital member can be useful in accessing records, educating first responders and other team members on medical issues and hospital practices and in facilitating the team's efforts to impact hospital practices.

Mental Health Professionals:
The mental health agency representative or mental health professional can interpret

the results of psychological examinations for the team, provide information on a family's history of mental health treatment or facilitate access to such information and help assess the family's current need for mental health services. The mental health professional can also provide information regarding grief counseling and trauma and assist with CDR team debriefing after a death.

Child Abuse Prevention Organization Representatives:
Many organizations exist to promote awareness, provide education and mobilize community resources to prevent child abuse and neglect. Participants from these groups bring particular knowledge and expertise about their local communities and may be key prevention partners.

Private / Non-profit Community Groups:
A community may have a private/non-profit child welfare program that is effective in developing and implementing successful prevention programs. These organizations may also be effective in marshaling community support and interest, including advocating for increased funding.

Court Appointed Special Advocate (CASA):
These individuals legally represent the child's interests in court and may have information pertinent to the team. However, due to their unique legal and often personal relationships with children, their participation may raise special issues of confidentiality and disclosure.

Disability Protection and Advocacy Agency:
The protection and advocacy agency works to protect the rights of people with physical, mental or developmental disabilities. Staff familiar with service providers in the community can network with protection and advocacy agencies in other jurisdictions.

Disabilities Expert:
Expertise on disability issues can be a benefit to the team when reviewing cases involving disabled children, parents or caregivers.

Substance Abuse Treatment Program Staff:
Teams often find it difficult to access information from substance abuse agencies. Access to such information may be increased if the team has representation from a substance abuse program. Program representatives can also provide needed expertise on the substance abuse-related issues that arise in team deliberations.

Sudden Infant Death Syndrome (SIDS) Resources Staff:
The representative can provide expertise on SIDS and its effect on families. The representative may be able to provide access to training on grief and grieving for other team members, educate the team on SIDS and share information about cases that involve possible SIDS.

Vital Records Staff:
The vital records agency collects and maintains birth and death certificates and often has demographers, statisticians and epidemiologists on staff. The team may benefit from their expertise and assistance in accessing vital records. This person could be from the health department of the county clerk's office.

Prevention Partners:
The team may wish to include key prevention partners as members of the team. In some jurisdictions, this may include members of the legislature, but could also include others such as injury and violence prevention (SAFE KIDS coalition members) and content experts (e.g., asthma, genetics). Prevention partners can be very effective in helping your team move from the case review to action and help move their agendas for child safety. Contact your injury prevention director at the state health department and your state SAFE KIDS coalition to locate key community individuals (www.stipda.org and www.safekids.org). The table at the end of this chapter lists the benefits of having a

local SAFE KIDS prevention coalition participate on the team.

Ad Hoc Members

Periodically, CDR teams may consider inviting individuals with particular expertise to participate in a specific review or to brief the team members on the subject of their expertise. Ad hoc members can help the team when thoughtfully included. Be sure to orient these persons to the CDR process and your confidentiality provisions.

Ad hoc members include those persons directly involved in a death. Those persons may want to attend with their supervisors or their agency team representative. For example, you could invite the person that conducted the scene investigation or the case worker that provided services to the family.

Team Size

You may be fortunate to have the problem of too many people wanting to participate in your reviews. However, very large groups may also be problematic. You may have many people not bringing information or participating in the discussion. Others may be reluctant to share information if the group is too large. Your ability to build trust among members may be more difficult. One solution may be to invite some participants to a meeting to share general findings from the review and engage participants in prevention planning. Another may be to invite persons to attend only those meetings in which they can bring relevant information.

Ten Reasons SAFE KIDS Coalitions Should Participate on Child Death Review Teams

One
To gather better information on the circumstances of child deaths in the state or community in order to improve surveillance systems.

Two
To bring additional SAFE KIDS information on preventing non-fatal injuries to the Child Death Review Team.

Three
To implement proven prevention strategies in the community by SAFE KIDS coalitions and chapters.

Four
To expand membership of the SAFE KIDS coalition both in terms of adding new organizations as well as recruiting new members from current partners.

Five
To ascertain the diagnosis of the true cause of death in developing prevention programs.

Six
To help ensure that other children in the home are protected from unintentional injury.

Seven
To forge linkages for the bereaved family with other support services in the community.

Eight
To promote awareness at the state level that injury risks are common in various counties and communities.

Nine
To apply principles learned through the Child Death Review Team process and elevate them to public policy priorities.

Ten
To provide SAFE KIDS coalition members with professional growth opportunities.

*Compiled by SAFE KIDS Coalition Members and CDR Team Members for the 2003 National SAFEKIDS Leadership Conference

Worksheet for Your Team: Team Membership

Team Coordinator:

Team Chair, if Different:

Core Team Agencies:

Additional Members:

Possible Ad hoc Members:

Chapter 6
Case Selection & Records for Review

Case Selection

A child's death is a sentinel event that can identify other children at risk for injuries or illness. Because the mission of Child Death Review (CDR) teams is to prevent deaths, your knowledge and understanding of the risks to children will increase with the number of cases you review.

There are several factors that will influence your case selection. You will need to determine which cases you will review with respect to:

1. Total numbers of deaths in your jurisdiction.
2. Ages of children.
3. Manner and causes of deaths.
4. Your access to case information.
5. Place of death.
6. Cases under litigation.
7. Team membership.
8. Frequency of team meetings.

1. Selection by the Number of Deaths in Your Jurisdiction:

Selecting what types of deaths to review may be dependant on your geographic area and the actual number of deaths you have to review.

If you are a small jurisdiction, you may be able to review all of your child deaths and you are encouraged to do so. Some very rural communities may have only one to three deaths per year but find that conducting reviews are powerful community events to help other children at risk. Teams with small numbers of deaths face the dilemma of maintaining team effectiveness if they are not meeting often. They may choose to meet to focus on prevention, review serious injuries or form a regional team with other communities.

Large areas will have to develop a process to review as many deaths as is feasible. Many teams in larger communities do not have the resources or time to review all fatalities and thus they must develop some priorities in selecting deaths to review. If your team is unable to review all deaths, at a minimum you should try to review deaths that have elements of preventability associated with them.

2. Selection by Age

Generally, states define a child as under the age of 18. Although your decision may depend on your expected caseload, reviewing deaths in all age categories up to or through age 18 is recommended. As of January 2005, all but one state in the U.S. reported that their review programs encouraged reviews to age 17.

Some teams may even choose to review young adults through age 19 or 24. Most deaths in these older age groups are preventable and most are going to be motor vehicle, homicide and suicide deaths.

3. Selection by Manner and Cause

Some teams started reviewing only abuse and neglect fatalities and still review just these fatalities. Many state CDR laws allow for or require that at a minimum child abuse deaths be reviewed. Some state laws may even limit reviews to these cases. Many states allow complete flexibility to their teams as to which deaths are to be reviewed.

The majority of CDR programs now review fatalities from a variety of different causes. If you have flexibility in deciding what cases to review, only the number of deaths in your jurisdiction may limit you.

If your jurisdiction has a large number of deaths, you may need to develop selection criteria that could include selecting cases using some of the following criteria: all homicides, unintentional injuries, suicides, SIDS, medical examiner or coroner cases and all cases with CPS or law enforcement involvement.

In 2005, the U.S. Center's for Disease Control and Prevention added a developmental objective for CDR to the U.S. Healthy People 2010 Objectives. This objective states that by 2010:*

Extend to 50, the number of states and the District of Columbia, where 100% of deaths to children aged 17 years and younger that are due to external causes are reviewed by a child fatality review team and (Subpart A**)**
Extend to 50, the number of states and the District of Columbia, where 100% of sudden and unexpected infant deaths (e.g., ICD-10 codes R95-R99 among those under 1 year of age) are reviewed by a child fatality review team.

If your team had a large number of deaths, you may consider sub-committees that do extensive reviews and pass on to the full team those cases that are more problematic or that may provide important information on ways to prevent future fatalities. You also may consider sub-committees to review specific types of deaths, for example a group with more expertise related to motor vehicles would review all motor vehicle-related deaths and pass their findings on to the full team. You could also consider selecting a representative sample of cases.

Many programs in the United States still do not review natural deaths with the exception of SIDS. Yet there are elements of preventability in many natural deaths. Your team should consider developing an approach to review them. For example, many deaths due to perinatal conditions

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*U.S. Department of Health and Human Services. *Healthy People 2010: Understanding and Improving Health*. 2nd ed. Washington, DC: U.S. Government Printing Office, November 2000. Volume II, Focus Area 15.6. http://www.healthypeople.gov/Document/HTML/Volume2/15Injury.htm

such as prematurity and low birthweight are associated with preventable factors in the prenatal period. A review of these deaths may lead to improvements in systems of care for pregnant women. Reviews of asthma-related deaths or those due to infectious diseases may provide productive insights on disease management in health care, schools and homes. Review of even "non-preventable" or "expected" natural deaths, such as those due to cancer or congenital malformations may help identify if patterns exist, e.g., geographic clusters of deaths due to cancer or if health care services were available and appropriate.

4. Selection Based on Access to Information

Your team may have strict limits on its ability to access good case information on specific causes of deaths, which may preclude your ability to conduct an effective review. For example, you may not be able to access prenatal medical records. This will limit reviews of deaths due to perinatal conditions.

5. Selection by Place of Death

You will need to decide whether you will review the fatalities of children who are residents of your jurisdiction or of all children, regardless of residence, who die in your jurisdiction. You may also need to consider whether you will be able to conduct effective reviews of your residents who die in other states, because of the complexities in obtaining meaningful information. *Chapter 18, Tools for Teams*, provides a sample letter and form for cross-jurisdictional issues related to accessing case information.

There are advantages to reviewing, at a minimum, all preventable deaths occurring in your jurisdiction. For example, your community may find that most drowning deaths occur to summer visitors. The issues relating to preventability have direct consequences for your community. However, if your community serves as a major trauma or neonatal center, then you may have a high number of deaths, but the incidents related to the deaths or issues relating to perinatal systems of care do not directly apply to your community. In this situation, you may choose not to review these deaths.

Out-of-state fatalities can be problematic, in that it is difficult to obtain information, including death certificates. Many states have *interstate compact agreements* between state registrars that may limit or facilitate your ability to obtain death certificates of your residents. Out-of-state fatalities are particularly important to consider if your team is near a state border. You may need to directly contact the CDR team in that jurisdiction or that community's registrar, medical examiner or coroner to establish a system for referral.

Every team is encouraged to develop cooperative relationships with other jurisdictions. This can be facilitated by proactively sharing information with relevant jurisdictions when requested.

6. Selection of Cases under Litigation

Some states, because of state regulations, are only allowed to review cases that are not, or will not be, in civil or criminal litigation. Other states review current cases and their findings may help the district attorney determine their approach to a death. Some state teams have subpoena power and this may have an impact on the types of cases that they review. You should consult with your prosecutor or district attorney for their advice and opinion.

7. Selection Based on Team Membership

The specialists represented on the CDR team may determine the types of cases that can be effectively reviewed. For example, some jurisdictions ask teams to consider the particular concerns, interests and expertise of team members in determining which cases to review.

Some teams only review cases that are known to member(s) on that particular team. You are encouraged to plan your meeting schedules so that your team is able to maximize the number of preventable deaths they are able to review.

8. Selection Based on How Often the CDR Team Meets

Your team's decision on how often and for how long they are willing to meet may limit your case selection. Does the team meet monthly, bi-monthly or on an "as needed" basis? Some teams have regularly scheduled meetings, others meet only when particular cases of interest become available (e.g., highly publicized cases). Some teams may choose to meet even when there has not been a death, either to review cases of severe injury or to discuss and plan prevention activities.

Areas with larger populations will likely need to meet on a monthly basis in order to review as many deaths as possible. Smaller population areas may meet bi-monthly, quarterly or even bi-annually, as cases warrant.

Although there are many ways in which teams decide about when to review deaths, the timing of reviews will depend in part on how many deaths occur in your jurisdiction.

Summary

A primary goal of CDR teams is to reduce the number of preventable child fatalities by conducting systematic, multi-disciplinary reviews of child deaths. Because of time and resource limitations, some jurisdictions cannot review every child death. Thus they must prioritize the types of cases they will review. Legislation may require certain types of cases be reviewed. Most jurisdictions, though, have some flexibility about which cases to review and may make their decision based upon the interest and expertise of the review team or on a particular pattern of fatalities they see in their data.

Information Necessary for Reviews

Your reviews will be most effective when team members bring their own case-specific information relevant to the circumstances of the child's death and individually share this information at the review.

The information shared at the meeting may fall into several categories. Below are examples of three:

1. Case specific information on the death of the child, including records relating to the child, family, investigation, services and agency responses to the death. This is often presented in the form of reports and investigative materials.
2. Data on other deaths or injuries similar to the death being reviewed. These data may show trends that will help the team in advocating for necessary changes in state policies or procedures (e.g., graduated driver licensing, firearm storage procedures or how the media reports suicides).
3. Information on local and state resources, services, programs and policies relevant to the prevention of this type of death and/or the delivery of services.

In reviewing this information the team will ultimately ask the question of whether or not this death could have been prevented. What could have been changed that would have prevented the death and what changes are necessary to prevent future deaths?

At a minimum the following types of information are needed to conduct a comprehensive review:

- Death investigation reports, including scene reports, interviews, information on prior criminal activity.
- Autopsy reports.

- Medical and health information concerning the child, including birth records and health histories.
- Information on the social services provided to the family or child, including Women, Infants and Children (WIC), Family Planning and Child Protective Services.
- Information from court proceedings or other legal matters resulting from the death.
- Relevant family information, including siblings, biological and stepparents, extended family, living conditions, neighborhood, prior child deaths, etc.
- Information on the person(s) supervising the child at the time of death.
- Relevant information on the child's educational experiences.

Although there will usually be a core set of information needed for every review, the following identifies the types of records, by cause of death, that will help ensure that your review is comprehensive.

Natural Deaths to Infants
- Birth records
- Pediatric records for well and sick visits
- Death certificates
- Prenatal care records
- Hospital birth records
- Public Health immunization records
- Emergency Department records
- Any support services utilized, including WIC (Women, Infants and Children Nutrition Program) and Family Planning
- Police reports
- Prior CPS reports on caregivers
- Maternal Home Interview, if available
- Home visitation reports
- Records related to special needs services

Natural Deaths Ages 1-18
- Birth records
- Pediatric records for well and sick visits
- Death certificates
- Hospital birth records
- Emergency Department records
- Public Health immunization records
- Names, ages and genders of other children in home
- Police reports
- CPS reports on caregivers and child
- Home visitation reports
- School records
- Records related to special needs services

Asthma
- Death certificates
- Pediatric records for well and sick visits, including information on medications, asthma management plan, pulmonary function testing, specialty referrals
- Emergency Department/EMS records
- Any support services, such as school asthma management programs
- CPS reports on caregivers and child

Children with Disabilities
- Autopsy reports
- Birth records if under age one
- Emergency Department records
- Police reports
- Prior CPS reports on caregivers
- Any support services utilized
- Medical records and medication records
- School records

Sudden Infant Death Syndrome
- Autopsy reports
- Scene investigation reports and photos
- Prenatal, birth and health records
- Interviews with family members
- Child Care Licensing investigative reports
- EMS run reports
- Emergency Department reports
- Prior CPS history on infant, caregivers and person supervising infant at time of death
- Criminal background checks on person supervising the infant at the time of death
- Reports of home visits from public health or other services
- Any information on prior deaths of children in family
- Downloaded information from apnea monitors, if applicable

Suffocation

- Autopsy reports
- Scene investigation reports and photos
- Interviews with family members
- Child Care Licensing investigative reports, if occurred in child care setting
- EMS run reports
- Emergency Department reports
- Prior CPS history on child, caregivers and person supervising child at time of death
- Child's health history
- Criminal background checks on person supervising child at time of death
- Reports of home visits from public health or other services
- Any information on prior deaths of children in family
- Any information on prior reports that child had difficulty breathing
- Downloaded information from apnea monitors, if applicable

Fire and Burns

- Autopsy reports
- Scene investigation reports and photos
- Fire Marshall reports that include source of fire and presence of detectors
- EMS run reports
- Emergency Department reports
- Information on zoning or code inspections and violations
- Prior CPS history on child, caregivers and persons supervising child at time of death
- Names, ages and genders of other children in home
- Criminal background checks on persons supervising child at time of death
- Reports of home visits from public health or other services
- Any information on prior deaths of children in family

Drowning

- Autopsy reports
- Scene investigation reports
- EMS run reports
- Prior CPS history on child, caregivers and persons supervising child at time of death
- Names, ages and genders of other children in home
- Information on zoning and code inspections and violations regarding pools or ponds

Motor Vehicle-Related

- Autopsy reports
- Scene investigation reports and photos
- Interviews with witnesses
- EMS run reports
- State Uniform Crash Reports with road and weather conditions at time of crash
- Emergency Department reports
- Blood alcohol and/or drug concentrations of driver and victim
- Previous violations such as drunk driving or speeding
- Any out-of-state driving history
- Graduated licensing laws and violations
- Information on crashes at same site
- Lab analysis of safety belt, safety seat, booster seat or helmet or other equipment damage

Child Abuse and Neglect

- Autopsy reports
- Scene investigation reports and photos
- Interviews with family members
- Names, ages and genders of other children in home
- Child Care Licensing investigative reports
- EMS run reports
- Emergency Department reports
- Prior CPS history on child, caregivers and person supervising child at time of death
- Child's health history
- Criminal background checks on person supervising child at time of death

- Home visit records from public health or other services
- Any information on prior deaths of children in family
- Any pertinent out-of-state history

Teen Homicides

- Scene investigation reports
- Police and crime lab reports
- CPS histories on family, child and perpetrators
- Names, ages and genders of other children in home
- Ballistics information on firearms
- Prior crime records in neighborhood
- Juvenile and criminal records of teen and perpetrators
- Interviews with witnesses
- Information from gang squad

Suicides

- Autopsy reports, including toxicology screens
- Scene investigation reports and photos
- Suicide note(s)
- Ballistics information on firearms
- Computer downloads
- Interviews with family and friends
- EMS run reports
- Emergency Department reports, including prior hospitalizations
- Prior CPS history on child, caregivers and person supervising child at time of death
- Child's mental health history if available
- Child's sexual orientation
- School records and/or information from school representative at meeting
- Names, ages and genders of other children in home
- History of prior suicide attempts
- Substance/alcohol abuse history
- Any information on recent significant life events, including trouble with the law or at school
- If a firearm was used in the suicide, information on the storage of the firearm

Access to Information

CDR teams provide a forum for the sharing of information essential to the improvement of a community's response to child deaths. In this spirit, your review team needs to share information about the child death so conclusions can be drawn about the preventability of the death being reviewed.

Team members may provide the coordinator with information before a review or bring their own records to the review. Depending on your CDR policies regarding confidentiality, the team may request a summary of all relevant data prior to the meeting, may receive a case abstract of information or may wait until the meeting to hear each member share their information. In some cases, no paper records are shared among team members and all sharing is verbal. Individual team members leave with only their own records. Regardless, all team members should take the lead in presenting their own agencies' information.

When considering what information a CDR team will need to effectively carry out their mandate, there are a number of factors to consider:

- What specific information does the team need? Your decisions, based on the previous section, should answer this for you.

- What agency or individual has access to the pertinent information? Much of the data will either come directly from team members or will be available from the agency that the team member represents. Are there liaisons to agencies that are not represented on the team? Enlist the support of persons not on your team, but with access to

pertinent information. For example, your county clerk may be the best source for death certificates. You may need to meet with him or her to describe your program and establish a system to receive routine notification of all deaths that would qualify as reviewable by your CDR team. There is a sample letter to the county clerk in *Chapter 18, Tools for Teams.*

Develop a relationship with the Director of Medical Records at your local hospital or ask your team physician to do so for you. Use your team members to help you identify sources of information and to develop relationships with persons to obtain the information. There is a sample request form for medical records in *Chapter 18, Tools for Teams.*

- Are there any restrictions on access to information? Are there laws or policies that make it difficult or impossible for the team to access specific information? This may be true, for example, of mental health records. *Chapter 7, Confidentiality,* may address these issues for you.

- If there are restrictions on access, are there any methods that teams can use to gain access? For example, will the team need legislation or memorandums of agreement to obtain information?

You can create a standard letter or form to request information from various state or local agencies. These letters/forms could be one-time requests or requests of a more permanent nature. A sample request for death certificates and request for medical information is included in *Chapter 18, Tools for Teams.*

Teams should have every member sign a confidentiality statement to ensure that information shared at a team meeting is kept confidential. Individuals who are not standing team members but participate on an ad hoc basis should also sign confidentiality statements.

The team needs to consider what information can or cannot be shared with non-team persons and determine if meetings and minutes are open to the public. The team needs to determine if meeting minutes can be subpoenaed in any litigation involving the death. State confidentiality laws need to be considered in the types of information discussed at the meeting and the information that goes into the meeting minutes. Many teams specifically choose not to record minutes. This is discussed in further detail in *Chapter 7, Confidentiality.*

Chapter 7 Confidentiality

Confidentiality is always an issue when discussing the work of a Child Death Review team. This issue is even more likely to surface since the enactment of the Health Insurance Portability and Accountability Act (HIPAA), which will be addressed in the second half of this chapter.

Sensitive information is the currency of CDR teams. Teams collect and compile sensitive information through their activities. And team members are not the only ones interested in the information. Child deaths are often in the public eye and may be controversial. The public and the press may want to know what the team knows.

When we talk about confidentiality in relation to the CDR process, we are generally referring to two separate but related concepts:

- The team's access to comprehensive information for effective case reviews.
- Others' outside the CDR process access to the review discussion and findings.

For both concepts of confidentiality, there are important policy considerations:

- The team cannot do its work without having access to information about the child, the family and the death.
- Agencies and individuals will probably not share information nor freely discuss the issues involved in child deaths if their work is open to the public or subject to litigation.
- The public has an interest in knowing how and why children are dying and what can be done to prevent those deaths.

Confidentiality is crucial to the CDR process and does not have to be a barrier or

roadblock to conducting child death reviews. Although there are valid concerns that have to be addressed to ensure smooth team operations, those concerns do not have to impede the review process.

Sometimes people perceive confidentiality as a barrier because they do not know what the ground rules are and sometimes people treat confidentiality as a barrier so they do not have to participate on a team. In other words, they use it as an excuse to avoid being involved in a process that they do not want to be involved in to begin with. You may find it useful to identify individual motivations and provide strategic solutions.

The Team's Access to Case Information

Your team's ability to access case information for quality reviews is addressed in Chapter 4 and the last part of Chapter 6. For the purposes of this chapter, we will mention this topic only briefly.

There are many ways to approach access to information for case reviews. Some teams may have mandated access; others may enter into agreements with the providers of the information. For teams without legislative authority to obtain information, they may have to resort to court orders, Attorney General Opinions or the subpoena powers of certain team members in order to obtain valuable information that has been elusive.

We should note here that there might be federal restrictions that supersede state or local laws or rules allowing access to information. For example, team members from substance abuse services or education may not be able to share case-specific information at reviews without written parental consent. In those cases, they may instead be able to provide information about their services and can give ideas about improving linkages and referrals in the future.

Others' Access to Information from Your Reviews

The ability of outside persons and entities to access the information from a child death review is one reason some jurisdictions are hesitant to conduct reviews.

Access to team information can include access to the team's written materials, access to the team's unwritten information and attendance at team meetings.

So how does the team maintain the confidentiality it needs to do its job? The following is a three-part approach.

1. The information the CDR team has:

The starting point for determining whether there will be problems related to the access to team information by outside persons or entities is to identify the kinds of information that the team has. Generally, the information will be in one of two forms. It will either be:

- Identified: information that identifies the child, the family and service providers, e.g. a CPS caseworker.
- De-identified: information that is stripped of data elements that can lead to the identification of the child, the family and service providers.

Some teams are mandated to use de-identified information as a means of reporting and surveillance; many others complete records using case-specific identifiers. A team may feel differently or have fewer constraints regarding the sharing of de-identified information than it will with regards to the sharing of case-identified information.

2. Entitlement or restrictions to access:

The steps to determine whether any agency or individual is entitled to or restricted from accessing CDR information should be

identified. There are four groups that might be entitled to access:

- Team members.
- Other government officials or agencies.
- The press.
- The public.

In considering these possibilities, a team should turn to their state, local and agency statutes, regulations, policies, case law, court rules and memorandums of agreement. There are statutes that may give the public access to your review information and you should be sure to consult with your agencies to be sure that you are not subject to these.

Public information acts, also called Freedom of Information Acts, or FOIA, are state and federal laws that give the public access to records maintained by government entities. Many states that have enabling CDR legislation have specific exemptions from FOIA coverage.

Open meeting laws make the meetings of government organizations open to the public. These laws often include a listing of exemptions for certain types of meetings, of which CDR meetings may be a part. And again, CDR enabling legislation may also hold the review meetings exempt from these laws.

Statutes may also restrict the access of others to team information. The law may even stipulate with whom team information can be shared, for example, other local CDR teams within a state (especially if there are cross-jurisdictional issues), the State Office of the Children's Ombudsman or state social services agency, the agency that sponsors the CDR process, and/or the CDR support staff.

3. **The possible approaches to gaining or restricting access:**

- State statutes or regulations: Consider if your state statutes or regulations should be amended to allow certain people to have access to the team's identified information or to protect the disclosure of the team's identified information.
- Confidentiality agreements: As discussed earlier, these can remind team members to keep confidential the information that is not to be shared beyond the team.
- Court orders: These can identify the information that is available to the public and that which is not.
- Providing de-identified information and prevention approaches to the public: We started this chapter by identifying reasons why the public should have team information. You should consider sharing with the public de-identified information about the deaths and your team's recommendations and prevention suggestions to the public.

Ensuring Confidentiality in Your Team's Review Process

Confidentiality can sometimes be perceived as a barrier to conducting effective and comprehensive death reviews. However, there are ways to ensure confidentiality.

Legislation

If you are just starting a team, it may be to your benefit to look into obtaining statutory support for the team's activities. There is a Legislation Checklist and sample legislation included in *Chapter 12, CDR Legislation and Public Policy* and *Chapter 18, Tools for Teams*. Legislation may specifically address matters that can cause a person or entity to be wary of either participating in the process directly or providing case information to the team. Some legislation may speak to exemptions of the review meetings from open meetings acts or team records from FOIA. They may go further, providing the team legal authority to access certain records for use in conducting reviews. They may even hold team members exempt from tort liabilities as a result of their participation on the team. Research what is already in place in your

state regarding special protections for access to records for certain types of public health surveillance that may cover your team's activities.

If there is nothing in place and your team (or potential team) believes that legislation would assist them in conducting the work of the team, research what other states' provisions in law are regarding CDR.

It is almost always easier to get legislators to consider statutes if you can point to many other states that use similar language. If you are going for legislation, try to build into your bill all the necessary components to allow confidential reviews and to protect your team members. It's easier to get the most comprehensive legislation the first time rather than to go back and ask for amendments.

Confidentiality Agreements

CDR team members should sign a confidentiality agreement before sharing information in a review meeting. A sample confidentiality agreement is provided in *Chapter 18, Tools for Teams.* An agreement should include:

- The stated purpose of the review process.
- References to the statutes that pertain to CDR, especially those that address confidentiality.
- References to the consequences of breaking the confidentiality agreement (removal from the team, disciplinary action within the team member's agency, misdemeanors, etc.).
- Circumstances under which it is permitted to share team information and the type of information that can be shared.

Teams may require that confidentiality agreements be signed once by each team member and kept on file for the duration of that person's service on the team. Others may renew these documents on an annual basis, in order to have recent signatures and to remind members about their responsibilities of maintaining confidentiality.

Teams may wish to include this language at the top of their sign-in sheet for every meeting. This helps to ensure that all members are participating under current agreements, including ad hoc members that may be called in for one case only or on a sporadic basis. CDR programs may also require their support staff to sign such documentation.

Assurances of Document Storage and Security

It may be helpful to have written statements available to describe exactly how all information, records and documents for CDR cases will be stored, e.g. locked files in locked offices. These should already exist if your sponsor organization has put the activities of the review team through the approval process of their Institutional Review Board (IRB). Policies in place regarding specifics of who has access to these files and how the team's information will be turned into aggregate data for wider distribution should be included.

Connecting with Others Involved in the Process

Sometimes, a person or entity new to CDR may be reticent to become involved because they have no experience with the process and they feel they are going out on a limb by sharing sensitive information. Often, the best way to resolve this is to connect that person or organization with others in their specific professions who have already been involved in CDR.

For example, a wary hospital representative may feel differently if other doctors, nurses, emergency department staff or administrators describe how the process works and explains that they have not suffered any adverse consequences from

being a part of the CDR team. Of course, providing information about the confidentiality provisions of the process is also important. But often the assurances of someone from one's own profession that defuses these types of uncertainties the fastest.

The HIPAA Health Privacy Rule*

The Health Privacy Rule of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) went into effect April 2003. This rule protects the privacy and security of individual health data and establishes accountability and penalties for failing to use the rule to protect personal heath information privacy. The HIPAA Privacy Rule may impact the ability of CDR programs to obtain and use health data when individuals are not clear on HIPAA exemptions and permissible disclosures.

What is the HIPAA Health Privacy Rule?

The Health Privacy Rule was enacted into law to accomplish two major goals:
1. To ensure health insurance coverage after leaving an employer.
2. To improve the efficiency and effectiveness of health care related electronic transactions.

Congress recognized that improvements in electronic transactions, with a shift away from paper records, had the potential to erode the privacy of personal medical information. They mandated the adoption of federal privacy protections for the acquisition, use and exchange of patient information.

* Materials from this section were adapted from: Centers for Disease Control and Prevention. HIPAA Privacy Rule and Public Health: Guidance from CDC and the U.S. Department of Health and Human Services. MMWR Supplemental. May 2, 2003, Vol. 52 and *The Fetal and Infant Mortality Review Process: The HIPAA Privacy Regulations*, the National Fetal Infant Mortality Review Program, April 2003. Steven Pierce, Privacy Officer for the National Center for Child Death Review, assisted in authoring this section.

The Department of Health and Human Services (DHHS) developed the *Standards for Privacy of Individually Identifiable Health Information*, better known as the *HIPAA Privacy Rule*. These are the first national standards to protect personal health information.

The Privacy Rule regulates how certain groups or persons, known in the rule as *Covered Entities* and their *Business Associates* can use and disclose individually identifiable health information, known as *Protected Health Information, PHI.* The Privacy Rule:

- Gives patients more control over their own health information.
- Sets boundaries on the use and release of health records.
- Establishes safeguards that most health care providers must achieve to protect health information.
- Allows civil and criminal penalties to be imposed on covered entities that violate the rule.
- Allows for disclosure of PHI for public health, safety and law enforcement purposes.
- Enables patients to make informed choices and to know how, when and to whom their PHI is used.
- Limits the release of PHI to the minimum necessary for the purposes of the disclosure.

What are Covered Entities?

DHHS has authority to enforce the Privacy Rule only to Covered Entities and their Business Associates. There are extensive definitions for these terms in section 160.103 of the Privacy Rule, but a few examples will help you understand who might be members of each category.

Covered Entities include only:
- Health Plans: An individual or group plan that provides or pays for the cost of medical care that includes the diagnosis, cure, mitigation, treatment or

prevention of disease. Health plans include private and governmental organizations. Medicaid and Medicare are specifically named as health plans in the Privacy Rule, but most other health insurers will also be covered entities. For example, Blue Cross/ Blue Shield and Delta Dental are two large organizations that provide health plan coverage throughout large portions of the United States.

- Health Care Clearinghouses: A public or private entity, including billing services, re-pricing companies or health information systems that processes non-standard data from another entity into standard transactions or data elements or vice versa. One common example would be a billing service company hired by a small physician's office to conduct electronic billing on behalf of the physician.

- Health Care Providers: Health care service providers or any other persons that furnish bills or are paid for health care that transmits health information in *electronic* form in connection with certain transactions. Health care providers would be physicians, dentists, nurses and other health care professionals. However, they are only covered entities if they use one or more of the electronic transactions being standardized by HIPAA. Examples of those transactions might include submitting claims and receiving payment electronically, checking a patient's eligibility for health plan coverage or requesting a referral authorization from a patient's health plan. The larger a health care organization is, the more likely it is to be using electronic transactions. Organizations like hospitals, large clinics, local public health departments and community mental health service programs are all likely to be covered entities.

- Business Associates: Non-employee business associates whose relationships with covered entities require the sharing of protected health information. These may include accountants, billing companies, lawyers and other contractors. It is the responsibility of a covered entity to obtain written assurance that their business associates comply with the duties of the Privacy Rule.

What is Protected Health Information?

For most practical purposes, PHI is any kind of health information that can be associated with a specific person and relates to the:

- Past, present or future physical or mental health or condition of an individual.
- Provision of health care to an individual.
- Payment for provision of health care to an individual.
- Transmission by or maintenance in, electronic media or any other form or medium.

You may be surprised to learn that the HIPAA Privacy Rule protects the privacy rights of deceased persons because in many other laws that is not the case. The representatives of deceased persons are those recognized under applicable laws as the executors, administrators or other persons with authority to act on behalf of the deceased individuals or of their estates. In most cases, this means that the default personal representative for purposes of a CDR case would be a parent or other legal guardian of the deceased child.

Another important principle embodied in the Privacy Rule is that those who do need access to PHI should only have access to the kinds and amounts of information that they actually need. The *Minimum Necessary Standard* is found in section 164.502 (b)(1) and requires that a covered entity must make reasonable efforts to limit protected health information to the minimum

necessary to accomplish the intended purpose of the use, disclosure or request. If requested, responsibility likely will fall on the CDR program to provide a justification for why certain kinds of data are needed and to ensure that only minimum PHI needed for effective reviews is requested from a covered entity.

De-identified Health Information requires no individual privacy protection and is not covered by the Privacy Rule, if it has been stripped of identifiers.*

Requirements of Covered Entities in the Privacy Rule

Covered entities must:

- Notify individuals regarding their privacy rights and how their PHI is used or disclosed.
- Adopt and implement internal privacy policies and procedures.
- Designate an employee(s) to understand these policies and procedures.
- Identify employees responsible for implementing the policies.
- Establish requirements for dealing with business associates.
- Have in place administrative, technical and physical safeguards to protect PHI.

Most CDR programs will not, by definition, be covered entities. Yet, most CDR programs will want to access and use PHI related to children and their families and will need to obtain this information from a covered entity. Most covered entities will be reluctant to readily share PHI with CDR because of their concern that they may be violating the Privacy Rule and subject to criminal and civil penalties. Thus, many covered entities are responding to the Privacy Rule by clamping down on the flow of information to other organizations because they want to limit their risk of violating the Privacy Rule.

HIPAA may seem daunting and appear to present an impossible barrier to your team's access to good case information. The burden will likely fall on your CDR program to identify if and how covered entities (usually hospitals, health care providers and EMS) can disclose PHI to your CDR team and to ensure that if you yourselves are covered entities or business associates, you abide by the rules. You will most likely have to educate a health provider that giving you case information for CDR is not prohibited by HIPAA.

HIPAA allows for disclosure of Protected Health Information for public health, safety and law enforcement purposes.

There are three strategies that you can use to work with HIPAA, rather than having HIPAA work against you. The following sections describe these. Make sure that you consult your agencies' legal counsel to ensure that your strategies are in compliance with the law.

Strategies to Obtain Protected Health Information

Congress recognized that individual privacy rights need to be balanced with essential public needs, such as public health, law enforcement and the protection of public safety. The Privacy Rule was not intended to impede access to care, prevent people from receiving appropriate treatment, discourage quality improvement initiatives in health care or prevent our ability to protect people in harm's way. It simply was meant to ensure that the uses and disclosures of health information are justifiable, appropriate and respect patients' rights to privacy.

* The identifiers are: names; all geographic subdivisions smaller than a state; all elements of dates (except year) directly related to an individual, including birth and death dates; telephone numbers; social security numbers; medical record numbers; health plan beneficiary numbers; full face photographic images and any comparable images; and any other unique identifying number, characteristic, or code.

The Privacy Rule describes how PHI can be shared for specific purposes without patient consent and what the responsibilities of covered entities are when sharing PHI for these purposes. A covered entity must be able, however, to point to a specific paragraph within the Privacy Rule that explicitly permits or requires a use or disclosure of PHI without first informing the patient and get a signed authorization from the patient for each such use or disclosure.

Most of these exceptions are listed in section 164.512 of the Privacy Rule. Understanding these exceptions, both in terms of what they do and do not permit, is essential to developing a clear idea of how CDR will be affected in different states. Communicating with concerned Covered Entities will help ensure that CDR can continue effective reviews.

In some cases, you may find that more than one approach could apply to your team process. Remember that you only need one of the exceptions to apply in order to make a particular use or disclosure of PHI legal under the Privacy Rule. So if at least one applies, CDR work can usually move forward. You should evaluate the options with an eye toward the fact that some exceptions are more restrictive than others and select the approach that best suits your situation.

The following provides three strategies that may help you obtain the case information you need for quality reviews, within the context of the new HIPAA rules.

Example One: Child Death Review as a Public Health Activity

The public health exception can work for your program if your CDR program operates within your public health agency, because PHI may be provided to a public health authority. The following quote from the preamble to the Privacy Rule is a DHHS response to a public comment they received on their draft of the Rule:

"*Comment:* One commenter remarked that our proposal may impede fetal/infant mortality and child death reviews. *DHHS Response:* The final rule permits a covered entity to disclose protected health information to a public health authority authorized by law to conduct public health activities, including the collection of data relevant to death or disease, in accordance with section 164.51.2(b). Such activities may also meet the definition of "health care operations." We therefore do not believe this rule impedes these activities."

Can your CDR Team use the public health exception? You should first ensure that your CDR is under your public health authority.

HIPAA describes a *Public Health Authority* to mean "an agency or authority of the United States, a State, a territory, a political subdivision of a State or territory or an Indian tribe or a person or entity acting under a grant of authority from or contract with such public agency, including the employees or agents of such public agency or its contractors or persons or entities to whom it has granted authority, that is responsible for public health matters as part of its official mandate."

Secondly, you should ensure that your CDR is a public health activity. HIPAA states that "A covered entity may disclose protected health information for public health activities and purposes described in this paragraph to: a public health authority that is authorized by law to collect or receive such information for the purpose of preventing or controlling disease, injury or disability, including, but not limited to, the reporting of disease, injury, vital events such as birth or death and the conduct of public health surveillance, public health investigations and public health interventions; or, at the direction of a public health authority, to an official of a foreign government agency that is

acting in collaboration with a public health authority; or a public health authority or other appropriate government authority authorized by law to receive reports of child abuse or neglect…”.

Using the public health activities exception requires demonstrating that CDR teams have statutory authority for child deaths and injuries. Some states have enacted statutes that explicitly establish CDR teams as a formal governmentally appointed task force or work group, through public health. Thus, by citing that legislation, you could meet the criteria for being a public health authority.

An important criterion for invoking the public health activities exception is that the purpose for which the data are being disclosed must be a public health activity. You may show this, for example, if your CDR team’s goal is to improve the understanding of how and why children die, to demonstrate the need for and to influence policies and programs to improve child health, safety and protection and to prevent other child deaths.

This clearly indicates that CDR is designed to achieve a public health goal of preventing child deaths. Therefore, with this statement of purpose (or something similar from your own state) you could make a compelling argument that CDR meets the second criterion from the Privacy Rule’s public health activities exception.

This means that team members who are also covered entities may be able to disclose protected health information to the CDR team for use in the review without obtaining authorization from the deceased child’s parents.

Example Two: Child Death Review of Child Abuse and Neglect as a Public Health Activity

Because significant portions of CDR cases are the result of abuse and neglect, this second example illustrates how to use a public health approach in these circumstances under HIPAA.

In the preamble to the Privacy Rule, DHHS adopted the stance that child abuse and neglect are public health matters, which means that the second criterion in the public health activities exception is automatically met for certain types of CDR cases. Thus, the public health activities exception allows covered entities to disclose PHI in order to report child deaths related to abuse and neglect to a government agency with authority over child abuse and neglect as permitted by section 164.512(b)(1)(ii), which is quoted above in Example One. Note here that your CDR team would still need to be part of a governmental agency, but the authorizing legislation can either grant specific authority over child abuse and neglect cases or meet the broader definition of a public health authority. Either one will suffice to permit invoking this exception. Thus, if the CDR team is part of such an agency, it can obtain the information it needs by showing covered entities its authorizing legislation and citing this specific paragraph from the Privacy Rule to defuse any concerns that HIPAA prevents such disclosures.

Example Three: Child Death Review as a Law Enforcement Activity

Now suppose that for some reason the CDR team is not part of a government agency with a specific authority over either child abuse and neglect or public health. Perhaps it is a function performed by more traditional law enforcement officials. In this example, we assume that either the CDR team is composed of or it works closely with law enforcement officials.

As defined in section 164.501, *law enforcement official* means an officer or employee of any agency or authority of the United States, a State, a territory, a political subdivision of a State or territory or an Indian tribe, who is empowered by law to:

1. Investigate or conduct an official inquiry into a potential violation of law; or
2. Prosecute or otherwise conduct a criminal, civil or administrative proceeding arising from an alleged violation of law.

A covered entity that suspects a child death was caused by criminal conduct could disclose PHI to a law enforcement official to alert the official of the suspicious death. Such a disclosure would be permitted by section 164.512(f)(4) and would not require authorization from the deceased child's parents. The covered entity could also respond to direct inquiries from the law enforcement officials by disclosing additional information about the victim as permitted by 164.512(f)(3)(ii). The official would first need to offer assurances that the information is necessary to determine if a crime has occurred, that immediate enforcement activity would be adversely affected by not getting authorization from a personal representative and that the disclosure is in the best interests of the victim (presumably, investigation and prosecution of a crime would meet this criterion). However, a covered entity must limit disclosures of PHI about the suspected perpetrator of the crime to the types of information listed in paragraph 164.512(f)(2)(i) and can only make these disclosures if the law enforcement official first requests such information for the purpose of identifying or locating a suspect, fugitive, material witness or missing person.

Finally, paragraph 164.512(f)(1)(ii) permits a covered entity to disclose information requested via a court order, a subpoena or administrative request issued according to a process authorized by law. In these instances, the disclosure must be limited to what is both specifically requested and relevant to a legitimate law enforcement inquiry and can only be made if de-identified information could not reasonably be used instead.

Overall, a CDR team composed of law enforcement officials would need to know when the PHI it needs can be obtained by making a direct request of a covered entity and when it would need to rely on a more formal process involving court orders and similar elements of due process.

Conclusion: HIPAA Allows for Child Death Review

CDR team members should consult with their legal counsel regarding HIPAA. Although there are other Privacy Rule compliance issues that CDR team members may need to address (such as maintaining disclosure history records about what was disclosed to the CDR team), several options exist for teams conducting CDR without violating the Privacy Rule. Whether the CDR team is itself composed of covered entities or simply relies on obtaining information from covered entities, we believe that CDR activities can and should continue but that state-level laws will affect which strategy is most applicable to each program.

Chapter 8
Conducting a Case Review

This chapter describes the process for conducting a case review of a child's death. It describes the steps that a team should follow in completing reviews.

Prior to your review meeting, however, you want to make sure that:

- You have identified all the deaths.
- You have sent team members enough case information to enable them to look through their own agency records for information. A *Meeting Summary Sheet*, in *Chapter 18, Tools for Trams*, can be sent to members before the meeting. The right people are coming to the review.
- You have looked through your records.
- You have enough information for a quality review.
- You have addressed any concerns from the district attorney or law enforcement.
- You identified similar deaths or injuries.

Although the primary purpose of your meetings will be conduct case reviews, there are a couple of items you should address at every meeting. You should review any old business. You will probably always have cases that you did not complete the reviews for at previous meetings, and you should be sure to re-review these at later meetings. You should also make time at every meeting to discuss past recommendations and prevention actions. There is a Case *Tracking Table* in *Chapter 18, Tools for Teams,* that may help you keep track of your reviews and recommendations.

Review Meeting Steps

There are different approaches used by teams around the country to conduct death reviews. But there are certain basic steps that if followed, will help lead to complete and thorough reviews that address the maximum number of issues involved in children's deaths:

Six Steps to Effective Reviews

1. Share, question and clarify all case information.
2. Discuss the investigation.
3. Discuss the delivery of services.
4. Identify risk factors.
5. Recommend systems improvements.
6. Identify and take action to implement prevention recommendations.

1. Share, Question and Clarify All Case Information

The goal of this step is to understand all of the circumstances leading to or involved with the death incident. Team members should know before the meeting which cases will be reviewed, so that they are sure to bring all case relevant information to the meeting. Included in *Chapter 18, Tools for Teams*, is a sample Meeting Summary Sheet that can be sent by the team coordinator to all team members several days, or even a few weeks, before the meeting.

At the review, agency representatives take turns sharing the information they have on the child, the family and the circumstances of the death. Due to confidentiality constraints, most teams either do not share written material or distribute the material only for review during the meeting, collecting and destroying it at the end of the meeting. Case reviews are only effective if team members show up for the meetings and bring all pertinent information with them. *Chapter 18's Guides for Effective Child Death Reviews* and *Chapter 6: Case Selection and Records for Review* provide you with tools to identify the specific records necessary for complete reviews.

It is important to try and share information in a logical order. One suggestion for the order of this information sharing process is:

- Medical Examiner/Coroner
- EMS/Fire
- Law Enforcement
- Health Care Providers
- Social Services
- Public Health
- Prosecuting Attorney
- Others

In order to be most effective, team members should feel free to ask questions of the person presenting the case information, either during their presentation or after they have finished, depending upon the level of formality of your team. The person sharing information can then clarify what they know about the child, family or incident.

If after all members present have shared their case information, the team still feels that there are gaps in their understanding of any aspects of the death, it may be best to table the discussion until the next meeting. Then information not able to be shared at that time due to team members' absences or any other reason may be brought to the following meeting, allowing for a more complete review of the death. You may wish to assign the obtaining of that needed information to a specific team member so that there is a higher likelihood that it will be available at the next meeting.

A CDR team may also review a case where information is abundant, but there are complex issues involved that the team wishes to explore in greater depth. Such cases may be brought back to review agendas multiple times, over a period of months, until the team is comfortable that all areas of concern have been properly addressed.

2. Discuss the Investigation

Questions that need to be asked regarding the investigation of the death include:

- Who is the lead investigative agency?
- Was there a death scene investigation?

- Was there a death scene recreation with photos (especially important for infant sleeping deaths)?
- Were other investigations conducted?
- What were the key findings of the investigation(s)?
- Does the team feel the investigation was adequate?
- Is the investigation complete?
- What more do we need to know?
- Does the team have suggestions to improve the investigative system?

This clarification process is not meant to determine if a person or agency handling the investigation of a death made mistakes in some way. It is to determine if all pertinent questions that the team needs to know about the circumstances of the death have been answered. Does the reading of the investigative reports give the team a clear picture of what led to this child's death? If not, it may be appropriate for the team to recommend to the lead agency that further investigation is warranted or they may suggest that agency policy and protocol be examined to be sure that future child death investigations are as complete as possible.

3. Discuss the Delivery of Services

Questions that need to be asked regarding the delivery of services include:

- Were there any services that the family was accessing prior to the death?
- Were services provided to family members as a result of the death?
- Were services provided to other children (schoolmates, etc.)?
- Were services provided to responders, witnesses or community members?
- Are there additional services that should be provided to anyone?
- Who will take the lead in following up on these service provisions?
- Does the team have suggestions to improve service delivery systems?

As with the clarification of the investigative process, these questions are not meant to place blame, but to ensure that those who may be touched by a death receive needed support services.

We can look at who that might be as a series of concentric circles. Siblings or any other family member being at the center, then friends and schoolmates of the deceased, responders to the death or administrators involved in the life or death of that child, finally to the larger community. Obviously, the smaller the circle, the more intensive the services may need to be. A community member who did not know the child may benefit from information about the type of death and ways it can be prevented, such as a media campaign. A parent or sibling may need one-on-one counseling for an extended period of time in order to cope with the death.

4. Identify Risk Factors

Identifying the risk factors involved in a child's death during the review can lead to recommendations that the team believes could reduce those same risk factors for other children, thereby preventing future deaths. That is why this step is so important. It can sometimes be difficult to see the big picture where risk factors are concerned. The team may have to think outside the usual boundaries in order to touch on all risk factors that may have contributed in some way to the death. Grouping risk factors into general categories can help guide this discussion:

- Health
- Social
- Economic
- Behavioral
- Environmental
- Systemic (Agency Policies and Procedures)
- Product Safety

This is not an exhaustive listing and these are meant only as broad groupings. The

team can discuss why they believe the risk factors involved may or may not fit into one or more of these categories. Indeed, that is one of the main functions of identifying them in this way. Although it is always easiest to just mark "behavioral" and move on ("if person x hadn't done y, then z would still be alive," etc.), teams should challenge themselves to look deeper into what may have influenced the behavior in question and any other angles on the situation that may not be immediately obvious. Teams should try to examine the death from as broad an ecological perspective as possible.

It is important to identify the risk factors involved in each death, as these become the basis upon which a team will formulate its findings. These findings are in turn used to generate recommendations for improved investigations, service delivery, changes in systems, local ordinance or state legislation or community or state prevention initiatives. These systems improvements and prevention programming are the ultimate goal of a CDR process that is based on the public health model, to keep children safe, healthy and protected.

5. Recommend Systems Improvements

Once all the facts of the case have been shared and discussed, there may be issues involving agency response that need to be addressed. Generally, the team member representing the agency in question will explain their protocols to the team. In this way, team members learn more about what the parameters of others' responsibilities are, including the legal purviews of the organizations that each member represents. Then, as mentioned previously in the steps regarding clarification of the investigation and service delivery, the team may identify gaps in policy and procedure in response to the death.

The result of this discussion may be that an agency representative brings the review findings back to their supervisors. If the findings relate to a very large and bureaucratic agency or one that does not have official representation on the team, the team may have to make efforts to contact the agency in question regarding their recommendations. Phone calls or an invitation for an agency representative to attend the next meeting may be the best way to approach this. If inadequate response is received from the agency from these initial attempts, a letter regarding the matter may need to be sent from the review team to the director and/or appropriate supervisor(s) at the agency.

It is important that these recommendations be handled in a diplomatic fashion, recognizing that each agency is doing their best with what resources are available. Try to convey that your team wishes to give the agency a "heads up" on a matter that might cause them difficulty in the future. Suggest that their purposes could be met more fully if the issue is addressed. Try to keep your comments limited to the perceived gap or barrier and not include too much direction on what the team thinks should be done to address it. Request that the agency provide feedback to the team regarding any decisions that the agency may make on the matter.

6. Identify and Take Action to Implement Prevention Recommendations

Chapter 10, Taking Action to Prevent Child Deaths, addresses in detail the prevention aspect of the CDR process. For the purposes of this chapter, we will present the basics.

A review should never be considered complete by the team until the important question is asked: "What are we going to do to prevent another death?"

The review team does not necessarily have to be the group that sees the prevention action through from start to finish. Instead, they can play the important role of being the catalyst for change, the spark that starts a prevention campaign. In other words, the team's effectiveness in prevention can be simply in knowing where to send its recommendations for maximum impact.

There are a number of places to send such recommendations and the team should be aware of these options in their area:

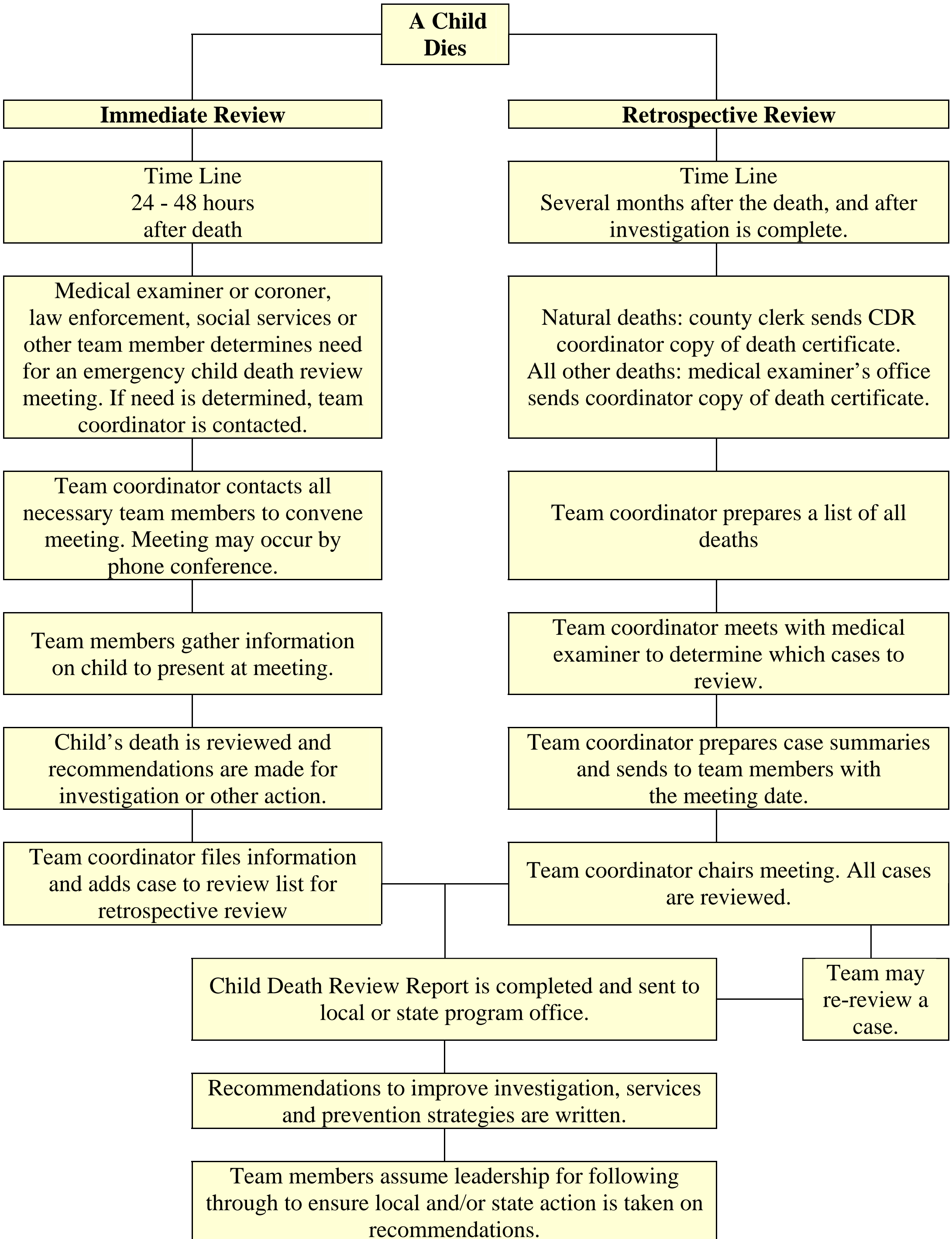
- Key Individuals
- Agencies
- New Coalitions
- Existing Groups

The team should always follow up on their recommendations. Such follow-up fosters accountability and provides recognition to those implementing the CDR recommendations.

At each case review, members should seek to answer:

1. Is the investigation complete or should we recommend further investigation? If so, what more do we need to know? What recommendations do we have to improve our investigation practices?
2. Are there services we should provide to family members, other children and other persons in the community as a result of this death? What services are lacking in our community?
3. Could this death have been prevented and if so, what risk factors were involved in this child's death?
4. What changes in behaviors, technologies, agency systems and/or laws could minimize these risk factors and prevent another death?
5. What are our best recommendations for helping to make these changes?
6. Who should take the lead in implementing our recommendations?
7. Do we need to discuss this case at our next meeting?

A Sample Review Team Process*



* *Chapter 18, Tools for Teams* has examples of the review process from other states.

Chapter 9
Effective Teams & CDR Programs

If you have established your Child Death Review (CDR) team, by this point:

- Your local team members have been identified and appointed.
- Your team has established operational procedures outlining lead agency responsibilities and program support, meeting frequency and meeting location.
- You drafted a mission statement, solidified team objectives, identified team members and established criteria for case review.
- Your team has reached consensus on the data collection tool and formulated a team review process.
- You have established confidentiality provisions and know where you will obtain your case information.

The hard work is behind you. Let the case reviews begin! If only it were that easy. After all the hours of discussion, agreement, disagreement and eventual consensus, the hard work is just beginning.

Maintaining an effective CDR team requires creativity, dedication and perseverance. No matter the demographics of the jurisdiction, the designated lead agency, relevant state statutes or individual personalities on the team, successful CDR is a complex and dynamic process.

Moreover, changes over time will often affect the functioning of your team. It will help you to be effective over the long term if you periodically address how your team is functioning, both formally and informally.

Listed below are some practical solutions to some of the most common barriers to maintaining an effective CDR team. There are, however, a few strategies that can be used during the early stages of team development to lay a foundation for continued positive interactions. During the initial phase of development when member agencies are newly committing resources and appointing individual representatives to the team, be sure they realize that:

- Team membership is a long-term commitment.

  A review team is not an ad-hoc committee that collects data on child deaths for a designated period. It is a panel of professionals dedicated to establishing a better understanding of the causes of child deaths in their community. Discovering the patterns that cause or contribute to preventable child deaths is an ongoing process. Patterns change over time within a community. The aggregate knowledge acquired by team members provides structure for achieving effective results.

- Team membership fosters ongoing professional development.

  Participation on a CDR team ensures ongoing professional development through a growing awareness of community resources or lack of resources and an opportunity to learn through professional networking and educational presentations at regular team meetings.

- A team is both a message to the community and a message from the community.

  By participating on a CDR team, local professionals who take responsibility for the protection, health and safety of their community's children agree to better understand child deaths. Team participation represents their commitment to eliminate obstacles to integrated community responses to child deaths and to creating opportunities to prevent the deaths of other children.

Developing Effective Coalitions, an Eight Step Guide is a resource that may help you establish and maintain an effective multi-disciplinary team, downloadable at www.preventioninstitute.org.

The table on the following pages is adapted from Michigan's child death review team training materials, with additional input from the California Department of Health Services.

Factors to Help Maintain an Effective CDR Team		
Category of Concern	**Example**	**Possible Solutions**
Ownership/ Focus	State agency tries to direct focus of CDR team to review child abuse and neglect deaths only.	• Appoint representatives with past success in public health prevention programming. • Share success stories with state agency regarding public health prevention programs initiated by other state or local teams.
Funding	CDR team loses momentum due to lack of staff support for core team functions.	• Divide administrative duties, costs among several member agencies. • Seek monies in the form of mini-grants from state or local foundations.
Confidentiality	CDR team member leaks confidential information learned at a review meeting to media reporter.	• Designate one member as media contact; should be media savvy and follow pre-set plan agreed upon by team. • Require team members to sign confidentiality statements regularly; remind team on an on-going basis about the importance of confidentiality and establish sanctions.
Leadership	Agency taking the lead designates a chairperson who lacks leadership skills.	• Form sub-committees to address certain issues, formulate recommendations based on team findings. • Team appoints vice-chair who volunteers to help chairperson with tasks of team.
Trust	Agencies without a history of working together (or of prior conflict) do not trust each other.	• Have representatives share their agencies' policy and procedure information, to increase awareness of others' responsibilities. • Choose a simple initiative to collaborate on that impacts both agencies, building trust.
Reporting	State CDR team lacks the ability to consistently obtain reports (data) from local CDR teams.	• One local CDR coordinator acts as reporting liaison between state and local CDR teams. • Share statewide and local level aggregate data with local teams, emphasizing the importance of the local reporting.
	CDR team conducts thorough reviews, but fails to complete/submit case reports.	• Appoint agency data analyst to team whose sole task is case report completion and submission.
Reviews to Action	CDR team has difficulty taking CDR findings and turning them into concrete prevention action.	• Invite state and local experts on an ad-hoc basis to suggest possible paths of direction. • Help team develop recommendations.
	CDR team lacks knowledge regarding effective prevention strategies.	• Provide/obtain information on successful prevention initiatives. • Seek trainings/seminars for members.
	CDR team lacks awareness of groups that could help turn their findings and recommendations into action.	• Team works together to research what is available on state and local levels. • Invite members from these organizations to speak to team.

Factors to Help Maintain an Effective CDR Team		
Category of Concern	**Example**	**Possible Solutions**
Overload	Where no local CDR teams exist, state CDR team can't effectively review all deaths in state.	• National Center assists state team in building participation at local level. • State team reviews those cases that are representative of that cause of death.
Buy-in	CDR team member was appointed by supervisor, does not truly buy into CDR process.	• Send team member to state or national CDR training. • Provide technical assistance and support, including information on causes of death, prevention initiatives/activities.
Population	Urban CDR team overwhelmed by caseload.	• Team focuses on one cause of death per meeting. • Team coordinators screen cases under the jurisdiction of coroner/medical examiner, choosing to review those with complex or difficult issues.
	Rural CDR team meets infrequently if at all, due to lack of caseload.	• Team begins reviewing serious injury cases. • Team meets when no deaths have occurred, to talk about prevention opportunities.
Productivity/ Accountability	CDR team has consistent problem with key members missing meetings.	• Have members designate alternates to attend when they cannot. • Establish formal interagency agreements that outline role and commitment of agency/members.
	CDR team members do not come to meetings with case information.	• Team chair emphasizes which records will be of importance for each case in the meeting notices. • Team chair obtains key records before meeting.
	Members fail to follow through on promised actions.	• Designated team member sends reminder emails week before meeting to those who volunteered to take action. • Team keeps running account of actions taken on findings, so that follow-through becomes part of team process.
	Meetings begin to lack overall focus, productivity.	• Reiterate goals of process before each meeting. • Send team members to CDR training.
Coordination	Team feels disconnected from state-level team due to lack of inter-communication.	• Local chair compiles team findings, sends them to state team and asks for feedback. • Invite state team representative to meet with local team.
Quality Assurance	Team unsure of how the quality of their reviews compares to other teams in state.	• Attend regional or statewide team coordinator meetings for networking. • Team members make contact with other teams, attend their reviews.
Access to Information	Team encounters problems with sharing case information across county/state lines.	• Establish a standard records-sharing protocol signed by all appropriate counties.
	Team does not get timely notification of deaths that occur out-of-county.	• Contact CDR teams in regions where tertiary care centers exist, ask that they inform them when a child is transported to and dies in their county.

Chapter 10
Taking Action
To Prevent Child Deaths

The most important reason to review child deaths is to improve the health and safety of children and to prevent other children from dying.

Child Death Review team members may come to the table mostly interested in improving investigations, services or in finding those at fault for a child's death.

Moving the focus of reviews to prevention can be a new arena for many team members and is hard work. Focusing on prevention is how your team will find meaning and purpose over the long haul. You may find that your first year or so of meetings will focus on other areas, but over time as systems improve for responding to child deaths, CDR team members will begin to ask, *so now what are we going to do to prevent these deaths?*

CDR is a great opportunity to mobilize persons from across your communities. Team members that might not traditionally think of themselves as prevention specialists have a lot to contribute to the design of prevention programs. For example, law enforcement knows the causes of motor vehicle crashes. The prosecutor has insight into the families involved in child abuse and neglect. The medical examiner knows the general history of the teens that die from suicide. These professionals have respect and standing in the community that can increase the chances of success of a prevention initiative.

For example, if your team publicizes that it is important for the county to place improved warning signs at certain train crossings, this may give the idea greater weight and may lead to quicker action.

Focusing your reviews on prevention means that your team has to act on the following:

Determine if the Death was Preventable

The definition of preventability may vary by CDR program. The Arizona CDR program developed a definition now in use by many teams. It states that *a child's death is preventable if the community or an individual could reasonably have done something that would have changed the circumstances that led to the death.*

We often think that injury events are random "accidents." However, most injuries to children are predictable, understandable and therefore preventable.

You will probably focus prevention efforts on manners of death we usually think of as preventable: accidents, homicides and suicides. CDR teams should also consider risk factors that can be addressed to prevent natural deaths. For example, it is estimated that one-half of all perinatal deaths could be prevented if attention had been paid to factors related to maternal health in the prenatal period. We also now know that there are factors that can reduce the risks of a SIDS death, including sleeping position, smoking and overheating. For deaths due to medical conditions, your team may discuss the availability and adequacy of health care, compliance with medical treatment regimens and barriers to persons seeking or obtaining quality care.

Identify Modifiable Risk Factors

Reviewing the circumstances of each death helps teams focus on the specific factors that caused the death or made the child more susceptible to harm. Once the team has identified these factors, the team should decide which factors they believe they can modify or impact. Not all risk factors are easy to impact; some may require long term, systemic change. Thus, the prevention of risk may be easy or it may be complicated and long term.

Once you know the risk factors, it is also important that you assess the extent of the problem and who it most impacts. You may want to focus your prevention strategies on certain populations of children to have the most impact. To do this:

- Collect information to know where and how often the types of deaths and related injuries occur. Obtain morbidity data to understand the full extent of the problem. For example, you may have reviewed one suicide, but further analysis of the number of teens who seek services at your local hospital emergency room for suicide attempts will help you to understand the full extent of the risks.
- Determine then which children are most at risk and why.

Determine the Best Strategy(ies) for Prevention

There are numerous frameworks you can use to determine the best strategy for prevention. For example, the field of injury has identified the Four E's: impacting education, engineering, enactment and enforcement.

The Spectrum of Prevention[*] is a model that your team can use to create long-lasting, positive changes in the community. The *Spectrum of Prevention* describes seven levels at which prevention activities can take place, and moves beyond individual services and community education.

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[*] The Spectrum of Prevention model was created by Larry Cohen, M.S.W. and is based on the work of Dr. Marshall Swift. Mr. Cohen may be reached at larry@preventioninstitute.org.

Cohen, L. and Swift, S. (1999). The Spectrum of Prevention: Developing a Comprehensive Approach to Injury Prevention. *Injury Prevention*; 5:203-207.

Rattray, T., Brunner, W. and Freestone, J. (2002). *The New Spectrum of Prevention: A Model for Public Health Practice*. Contra Costa Health Services; 1-6

The *Spectrum of Prevention* encourages creative and effective prevention projects and can help communities develop activities that are likely to be more successful since they complement the prevention efforts that already exist within a community.

The seven levels in the spectrum are:

1. **Strengthening Individual Knowledge and Skills**

   Assisting individuals to increase their knowledge and capacity to act can lead to behavior change. Many health providers and community agencies currently apply this strategy through education, counseling and other individual services to encourage individuals to change their behavior.

2. **Promoting Community Education**

   Reach groups of people with information and resources to build support for healthier behavior and community norms. Since the media is so predominant in our society, skillful attention to the media can advance community education efforts.

3. **Training Providers**

   Providers can influence others. They can be professionals, paraprofessionals, community activists or peers. It is critical to ensure that those who provide training, advice or serve as role models have the information, skills, capacity and motivation to effectively promote prevention with youth, parents, colleagues and policy makers.

4. **Fostering Coalitions and Networks**

   Creating or strengthening the ability of people and organizations to join together to work on a specific problem is useful for accomplishing a broad range of goals that reach beyond the capacity of any individual member or agency. These goals may range from information sharing to coordination of services to community education or advocacy for major regulatory or legislative changes.

5. **Changing Organizational Practices**

   Change internal business and agency policies, regulations, practices and norms. Looking at the practices of key groups, such as law enforcement, health departments and schools has potential for affecting the health, safety and satisfaction of the greater community. Also every organization should look at its own practices and see what could be changed or strengthened.

6. **Mobilizing Neighborhoods and Communities**

   Engage community members in the process of identifying, prioritizing, planning and making changes. The provision of technical assistance to facilitate this process can be a catalyst for neighborhoods and communities to be empowered to make a difference.

7. **Influencing Policy and Legislation**

   Work to change laws or regulations at the local, state and national levels. Sometimes the greatest improvement in prevention, affecting the largest number of people, can be accomplished by attention to policy issues and regulation.

How the Levels Work Together

The activities at each level of the Spectrum can support one another. Success at one level can encourage activities that lead to further change at other levels. For example, "media advocacy" is a strategic use of the media for community education (level 2) that may be directed at a change of policy (level 7). Effective policy discussions often lead to further individual and community education (levels 1 and 2) through media attention to

an issue. When a policy is changed, it often changes organizations' practices (level 5) and creates the need to train providers (level 3) on the implementation of new policy.

Given the complexity of child deaths, the best solutions are usually those that are comprehensive. As such, the most effective prevention activities are those that address an issue at all seven levels of the *Spectrum.* As the levels fit together, they build upon one another and together produce greater change. Some projects work through a coalition to address all levels of the Spectrum. Each individual organization may work at one or more levels. A community, county or even statewide coalition may assure that all levels are addressed, maximizing potential outcomes.

Identify Specific Prevention Activities

Regardless of the model you use to identify your key prevention strategies, you will then need to identify what specific *activities* need to be implemented.

To determine the specific prevention strategies, your team should review the prevention literature to make sure your recommendations have been proven to be effective. This means that they have been implemented, evaluated and preferably published in a peer-reviewed journal. Try to select interventions that have demonstrated efficacy and are appropriate to your community.

A number of websites can help you identify proven strategies. For example, injury prevention strategies can be found at the Harborview Injury Prevention Research Center web site: http://depts.washington.edu/hiprc/practices/index/html.

To identify the best prevention strategies and activities, teams should weigh the following:

- Effectiveness
- Ease of implementation
- Cost
- Sustainability
- Community acceptance
- Political reality
- Unintended Consequences

A matrix to help you evaluate your team’s suggestions for prevention is located in *Chapter 18, Tools for Teams.*

Even with a desire to take action, there are some other things that have to be kept in mind when planning prevention:

- Don't reinvent the wheel. Prevention programs have been developed and implemented throughout the country. In researching prevention activity outcomes, you can learn from others' mistakes and build on what has been successful elsewhere.

- Don’t look for nor expect quick and easy long-term solutions. The situations that lead to child deaths are complex. Prevention programs take time and effort to design and implement and often even more time to impact the lives of children. Moreover, the changes that occur most likely will permanently require consistent attention at some level.

- Prevention research has shown that combinations of strategies and activities will be more effective than any one single activity.

The following table from *The National Center for Child Death Review’s Case Reporting System* represents the types of prevention actions your team could consider, across four areas: education, agency change, new laws and changes to the environment. Oftentimes, the best recommendations will be a combination of these actions.

Education	Media campaign School program Community safety project Provider education Parent education Public forum Other education
Agency	New policy(ies) Revised policy(ies) New programs New services Expanded services
Law	New law/ordinance Amended law/ordinance Enforcement of law/ordinance
Environment	Modify a consumer product Recall a consumer product Modify a public space (s) Modify a private space(s)

Take Action or Share Your Findings to Ensure that Action will be Taken

Teams do not have to implement their proposed prevention strategies and activities, but the team should make sure they follow through to make sure that someone or some agency has assumed responsibility. The team can serve to foster accountability as well as recognize and reward community efforts. It is important that your team:

- Identifies someone willing to take the lead.
- Identifies resources.
- Identifies someone to follow-up and report back to the team.
- Provides recognition to those implementing the CDR recommendations.

The multidisciplinary nature of CDR provides a powerful platform to make a difference. As previously mentioned the team can be an effective catalyst for change while fostering accountability and recognizing and rewarding community efforts. Scarce resources require sharing of findings and recommendations to be strategic.

Your findings should be shared, along with your written recommendations, with the appropriate agencies or individuals that are best positioned to take action. If you are a local team, you can send your recommendations to local agencies for local action. You can send them to the state, which can then use them to advocate for or develop state-level prevention actions. Many state teams have recommendations in their reports to the legislature, government agencies and the public. The following is a list of possible recipients:

- Local CDR team member(s).
- State CDR team(s).
- The media.
- Professionals.
- Academics/educators.
- State organizations (AAP, ACOG, SAFE KIDS, etc.).
- State Agencies (child protection, public health, public safety and others)
- Community leaders.
- Parents/teachers/student organizations.
- Not for profit organizations.
- Fundraising groups.
- Civic organizations.

In sharing your findings, choose an appropriate forum, such as

- Formal presentations.
- Formal letters to agencies.

- Radio, television, newspaper, newsletter.
- Public service announcements.
- Annual reports or summary reports.

Use the stature of individual team members to help advocate for your recommendations. For example, your district attorney may have political influence with a state legislator or be a popular elected official and able to garner support from the general public.

Good leadership is essential for successful prevention activities. The leader does not have to be the team chair or coordinator and the leader does not have to be the same for every prevention effort. Leaders do not even have to be individuals. They can be the entire team, a sub-committee of a team or persons not even on the team.

Good leaders share some traits. They are:

- Able to inspire others and maintain enthusiasm.
- Able to provide coordination.
- Able to access data and connect with decision makers.
- Sensitive to political realities.
- Collaborators.

Write Effective Recommendations

The very best prevention ideas that result from your reviews can go to naught, unless you develop well-written recommendations. Your team should put in writing the findings that led your team to identifying the need for prevention, the strategies and activities that will address the risk factors and the plan to insure they are implemented. While the core of a written recommendation can be a simple statement, an effective recommendation should have three important components. This will help ensure that your recommendations will be understood, adopted and implemented:

1. Your assessment of the type of deaths you are trying to prevent.
2. Your action-oriented recommendation.
3. Your plans to follow-up on the recommendation.

By putting your ideas in writing, your team will be able to better monitor and track how your recommendations are implemented.

Your recommendation should be as specific as possible. For example, a recommendation that "newly licensed teen drivers should not have other teen passengers in the car during their first month of licensure" is an important objective, but is not an effective recommendation. It doesn't address how you will accomplish the objective and is not action oriented.

The following summarizes the dimensions of effective written recommendations.

Guidelines for Writing Effective Recommendations*

1. Your assessment of the type of deaths you are trying to prevent	
Problem Statement	Includes problem definition, local, state and national data; and risk and protective factors.
Best Practices	Demonstrates knowledge of "best" or "promising" practices for addressing the problem.
Capacity	Demonstrates knowledge of existing local efforts, resources, capacities, "political will," and/or identifies potential for taking advantage of serendipitous circumstances.
2. Your action-oriented written recommendation	
Who will take action (the actors)	Identifies the persons and/or organizations to take action.
Who will benefit from the action (the recipients)	Identifies the recipient of the intended action, e.g. a person, community group or agency.
What specifically should be done	Details a plan of action that is described in sufficient detail to allow follow-up consistent with issues identified in problem assessment. The actions should be appropriate for actors and recipients. A timeframe for the actions should be identified. Use the *Spectrum of Prevention* to guide your planning.
3. Your plans to follow-up on the recommendation	
Accountability	Assigns and obtains buy-in of someone (i.e., team member or other individual) to be accountable for follow-up and tracking of progress on actions taken with a timeframe identified for follow-up.
Dissemination	Specifically states that will receive the recommendation and includes not only the potential actors and recipients but also appropriate decision makers, funders and potential supporters.
Outcomes/ Impacts	Identifies a mechanism/procedure to document the impacts and outcomes that result from action on team recommendations.

*Adapted from work completed by the staff at the Injury Surveillance and Epidemiology Section, Epidemiology and Prevention for Injury Control (EPIC) Branch , California Department of Health Services

Chapter 11
CDR Data & Reporting

The individual case review of a child's death can often catalyze local and state action to prevent other deaths. It is important, however, to systematically collect data and report on the findings from your reviews over time. It is also important to compare your review findings with your child mortality data from vital statistics and other official records.

When data from a series or cluster of case reviews are analyzed over time, significant risk factors or patterns in child injury and safety can be identified. The collection of findings from case reviews and the subsequent reporting out on these findings can help:

- Local teams gain support for local interventions.
- State teams review local findings to identify trends, major risk factors and to develop recommendations and action plans for state policy and practice improvements.
- State teams match review findings with vital records and other sources of mortality data to identify gaps in the reporting of deaths.
- State and local teams use the findings as a quality assurance tool for their review processes.
- Local teams and states use the reports to demonstrate the effectiveness of their reviews and advocate for funding and support for their CDR program.
- National groups use state and local CDR findings for national policy and practice changes.

As of January 2005, review teams in forty-four states in the U.S. were using some type of case reporting tool, although no two states were using the same tool. States were using these case reports to develop annual reports to state legislators, governors, state agencies and the public. Thirty-nine states

were publishing annual reports with findings and recommendations. Eighteen states had legislation in place requiring these reports.

Individual Case Report

The individual case report is completed on all deaths reviewed by a team. It should include information on the child, caregivers, supervisors, circumstances of the event leading to the death and team findings related to services and prevention.

When completed following case reviews, tabulations of and analysis of the data from the case reports will provide:

- Comprehensive information on the child, family and supervisor.
- Risk factors in the child deaths reviewed.
- Descriptions of the investigation activities conducted as a result of this death.
- Descriptions of the services provided or needed as a result of the deaths reviewed, and the review teams recommendations for new services or referrals.
- The team's recommendations and actions taken for the prevention of other deaths.
- Factors affecting the quality of the case review meetings.

You should ensure that the legislation and/or rules regulating your CDR process allow for the collection of a case report. Some states do not allow for case identifiable data to be collected or shared at the state level, so the case report will need to have these identifiers removed.

The case report can be partially completed prior to the case review. Your team coordinator may provide these forms to team members prior to the meeting, but should be sure to take the necessary steps to protect confidentiality.

The case report should be completed during or shortly after a review. The data elements in the form can be helpful in guiding a discussion. However, the case report tool should not be the focus of the review, nor inhibit the flow of discussion.

The person responsible for the case report should enter data from the report into a pre-designed database for child death review. This data can then be tabulated and analyzed for specific time periods, e.g. annually, for inclusion in a report on CDR for either local or state distribution.

There is now a standardized case report tool available to states through the National Center for Child Death Review. A work group of over 30 persons, representing 18 states, worked to develop a set of standardized data elements and data definitions from 2003-2004.

The case report is part of the *Child Death Review Case Reporting System*, a web-based application. The system allows local and state users to enter case data, access and download their data and download standardized reports via the Internet. Users are able to complete data analysis and develop their own reports. With data use agreements between states, users may be able to compare their data with other states and with national compilations. This standardized *CDR Case Reporting System* is being piloted in up to 19 states in 2005 and 2006, and will be revised and available for widespread use. More information on this system is available from the National Center for Child Death Review at www.childdeathreview.org or via email at info@childdeathreview.org.

Annual State or Local Reports

Compiling and disseminating CDR case findings into reports is an effective means of educating policy makers, agency staff and the general public about key risks factors and opportunities for prevention.

Most of these compilations are done as annual reports or as a two or three-year summary of findings. These reports can include the following (described also in *Chapter 18, Tools for Teams*):

- Executive Summary that includes child mortality data, CDR findings, prevention recommendations and an overview of the CDR process.

- Summary of child mortality data, including numbers and rates for all child deaths.

- Summary of child death review team findings for all deaths by key indicators collected in the case report tool.

- Child mortality data including numbers and rates and child death review findings by specific manners and causes. For every section include:

  - Mortality data by year and trends over ten years if possible.
  - A general description of the cause of death, relative to national data, key risk factors, known proven interventions to prevent the deaths, and resources available for more information.
  - Breakdowns by age, race, ethnicity and gender.
  - Key risk factors identified through the review process.
  - Actions taken as a result of the reviews locally or at the state level.
  - Recommendations for state and local leaders.
  - Recommendations for parents and caregivers.

- Appendices could include a list of figures and tables, number of cases reviewed and reported by teams, total number of deaths among state residents, ages 0-18, by county of residence and age group, total number of deaths among state residents, ages 0-18, by county of residence and year of death and list of review team coordinators.

Preparing the report on CDR findings can be difficult and time consuming, especially for persons not accustomed to data analysis systems. Public health departments often have data analysis staff and epidemiologists that may be able to assist in the preparation of the report.

Caution should be taken when presenting both mortality data from vital statistics and child death review data. Often these two sources of data cannot be compared one-to-one. Often the year of deaths and year of reviews may differ, there may be children in one or the other data set that are not residents of the jurisdiction being reported on and there may be significant delays in obtaining mortality data, as compared to CDR data.

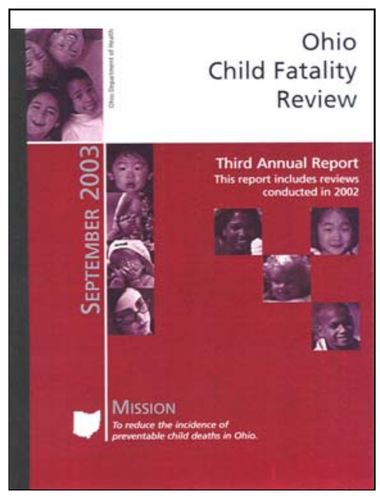
Despite these caveats, it is important to present both mortality data and CDR data. By doing this you will be able to estimate the percent of reviews being completed in comparison to all child deaths, you may be able to identify areas that may be underreported through the vital statistics coding system (child abuse fatalities for example) and you will have a more complete understanding of all the child deaths in your reporting area.

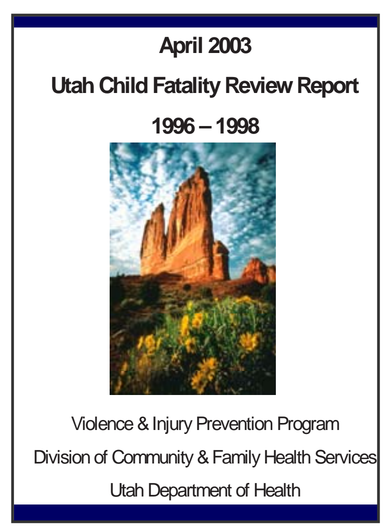
It is important to have a plan in place for disseminating the reports and for following up on the recommendations in the report.

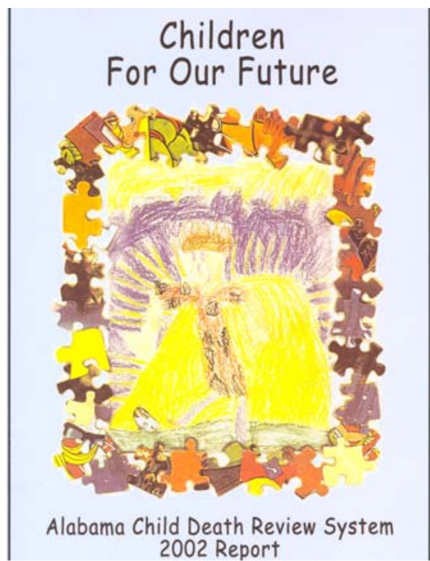
Many states have been effective in distributing the reports to state legislators, state executive offices, state agency administrators, state child advocates, the press and local CDR team members. You should work with your state agency to develop a press release and events to publicize the report's release.

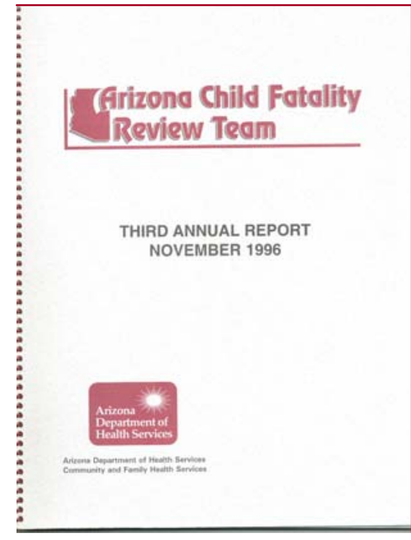
Samples of state reports are available on the National Center for Child Death Review's website:
www.childdeathreview.org/state.htm

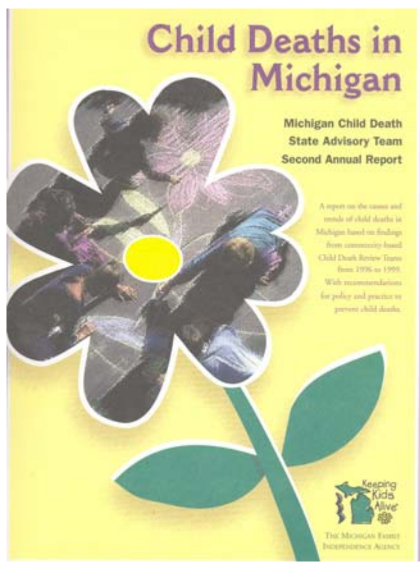
Examples of States (and the District of Columbia) that have Annual CDR Reports

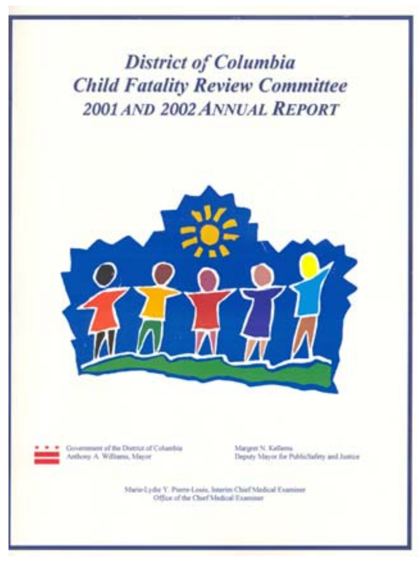












Chapter 12
CDR Legislation & Public Policy

Child death review interfaces with legislation and public policy in two important ways. First, legislation can be an important tool in establishing and supporting the child death review process. Legislation can establish parameters for reviews, such as stipulating the state agency that has authority for the review program, ensuring confidentiality of reviews and even stipulating funding streams for a review program.

Secondly, legislation, administrative rules, local ordinances and other public policies are important mechanisms teams can use to implement the findings of the reviews. Some of the most effective prevention interventions are based in law or pubic policy. Teams should develop the political skills to work with legislators or policy makers to implement their recommendations.

Legislation or Administrative Rules to Support CDR

As of January 2005, 39 states had legislation or administrative rules in place to mandate or enable the child death review process. These statutes or administrative rules vary greatly. Some are located in public health codes, some are in state child protection acts. A couple of states have laws establishing independent CDR entities. Most all address the confidentiality of the reviews but not all address access to case information. The statutes or rules usually describe the types of deaths to be reviewed by age of child and cause of death. Most identify the type of reports expected from the review process. *Chapter 18, Tools for Teams* includes a checklist for CDR legislation. The following table briefly describes what a good CDR statute should include:

Elements to Include in Legislation for a Comprehensive CDR Program

Purpose of the review program.

Funding sources for the program.

Lead agency responsibilities.

Advisory team purpose, duties, membership, chairperson designation and length of service.

Review team purpose, duties, membership, chairperson designation and length of service.

Support provided to advisory and review teams, including training and technical assistance.

Team access to case specific records and other pertinent information.

Confidentiality provisions for team meetings and case review records.

Reports of individual case reviews.

Reports to the Advisory Team

Reports to the government, including legislators, governor and state agencies.

Influencing Legislators and Policy Makers

Many of the recommendations that teams develop include changes to public policies and laws. Although some team members are unable to work directly with policy makers due to agency procedures and certain prohibitions on lobbying, it is important to identify persons able to advocate for your policy-related recommendations.

These persons could be independent child health and advocacy groups, leaders of local and state governmental agencies and/or private citizens. Your team should take care to ensure that persons advocating with your policy makers are legally able to do so, and have the skills to be effective.

It is important to consider the following when working with legislators:

- Legislatures have the authority to establish/modify programs.
- Legislatures vary in budgetary authority.
- Issues may fall along divided party lines.
- Legislative power varies from state to state and administration to administration.

If your state has term limits, legislators may face:

- Steep learning curves.
- Massive reorganization every session.
- Chairs and leaders assume leadership much earlier in careers.
- Complex issues are handled without knowledge or institutional memory or time to learn it.
- Influence of the executive branch, interest groups, lobbyists and legislative staff increases due to relative inexperience of legislators.

When working with legislators:

- Use varied media.
- Aim for the middle ground on the knowledge scale.
- Avoid acronyms or specialized jargon.
- Include separate technical assistance sessions for legislative staff.
- Remember political diversity and fiscal responsibility and that legislators are foremost accountable to their constituents.
- Remember there is tremendous variation in knowledge level and interest.
- Back up claims with facts and grassroots communication to legislators and staff. Annual reports of CDR teams may be very influential.
- Provide legislators with the evidentiary basis for the proposed law; credibility is essential.
- Work with any and all legislators and political parties.
- Work toward consensus among groups.
- Personal stories can have a tremendous impact, as can legislators who have had personal experiences with your cause.
- Collaborate with other organizations or interest groups that may have similar concerns, needs and interests.

Sample Legislation from Arizona

Arizona Statute § 36-3501 to 36-3504 (1993)

36-3501. Child fatality review team; membership; duties

A. The child fatality review team is established in the department of health services. The team is composed of the head of the following departments, agencies, councils or associations or that person's designee:

1. Attorney general.
2. Office of women's and children's health in the department of health services.
3. Office of planning and health status monitoring in the department of health services.
4. Division of behavioral health in the department of health services.
5. Division of developmental disabilities in the department of economic security.
6. Division of children and family services in the department of economic security.
7. Governor's office for children.
8. Administrative office of the courts.
9. Parent assistance office of the supreme court.
10. Department of juvenile corrections.
11. Arizona chapter of a national pediatric society.

B. The director of the department of health services shall appoint the following members to serve staggered three year terms:

1. A medical examiner who is a forensic pathologist.
2. A maternal and child health specialist involved with the treatment of native Americans.
3. A representative of a private nonprofit organization of tribal governments in this state.
4. A representative of the Navajo tribe.
5. A representative of the United States military family advocacy program.
6. A representative of the Arizona sudden infant death advisory council.
7. A representative of a statewide prosecuting attorneys advisory council.
8. A representative of a statewide law enforcement officers advisory council who is experienced in child homicide investigations.
9. A representative of an association of county health officers.
10. A child advocate who is not employed by or an officer of this state or a political subdivision of this state.
11. A public member. If local teams are formed pursuant to this article, the director of the department of health services shall select this member from one of those local teams.

C. Beginning not later than January 1, 1994, the team shall:

1. Develop a child fatalities data collection system.
2. Provide training to cooperating agencies, individuals and local child fatality review teams on the use of the child fatalities data system.
3. Conduct an annual statistical report on the incidence and causes of child fatalities in this state during the past fiscal year and submit a copy of this report, including its recommendations for action, to the governor, the president of the senate and the speaker of the house of representatives. The team shall submit this report on or before November 15 of each year.
4. Encourage and assist in the development of local child fatality review teams.
5. Develop standards and protocols for local child fatality review teams and provide training and technical assistance to these teams.
6. Develop protocols for child fatality investigations including protocols for law enforcement agencies, prosecutors, medical examiners, health care facilities and social service agencies.
7. Study the adequacy of statutes, ordinances, rules, training and services to determine what changes are needed to decrease the incidence of preventable child fatalities and, as appropriate, take steps to implement these changes.
8. Provide case consultation on individual cases to local teams if requested.
9. Educate the public regarding the incidence and causes of child fatalities as well as the public's role in preventing these deaths.

10. Designate a team chairperson.

11. Develop and distribute an informational brochure which describes the purpose, function and authority of a team. The brochure shall be available at the offices of the department of health services.

D. Team members are not eligible to receive compensation, but members appointed pursuant to subsection B are eligible for reimbursement of expenses pursuant to title 38, chapter 4, article 2.

E. The department of health services shall provide professional and administrative support to the team.

F. Notwithstanding subsections C and D, this section shall not be construed to require expenditures above the revenue available from the child fatality review fund.

36-3502. Local teams; membership; duties

A. If local child fatality teams are organized, they shall abide by the standards and protocol for local child fatality review teams developed by the state team and must have prior authorization from the state team to conduct fatality reviews. Local teams shall be composed of the head of the following departments, agencies or associations, or that person's designee:

1. County medical examiner.
2. Child protective services office of the department of economic security.
3. County health department.

B. The chairperson of the state child fatality review team shall appoint the following members of the local team:

1. A domestic violence specialist.
2. A psychiatrist or psychologist licensed in this state.
3. A pediatrician certified by the American board of pediatrics or a family practice physician certified by the American board of family practice. The pediatrician or family practice physician shall also be licensed in this state.
4. A person from a local law enforcement agency.
5. A person from a local prosecutors office.
6. A parent.

C. If local child fatality teams are authorized, they shall:

1. Designate a team chairperson who shall review the death certificates of all children who die within the team's jurisdiction and call meetings of the team when necessary.
2. Assist the state team in collecting data on child fatalities.
3. Submit written reports to the state team as directed by that team. These reports shall include nonidentifying information on individual cases and steps taken by the local team to implement necessary changes and improve the coordination of services and investigations.

36-3503. Access to information; confidentiality; violation; classification

A. Upon request of the chairperson of a state or local team and as necessary to carry out the team's duties, the chairperson shall be provided within five days excluding weekends and holidays with access to information and records regarding a child whose death is being reviewed by the team, or information and records regarding the child's family:

1. From a provider of medical, dental or mental health care.
2. From this state or a political subdivision of this state that might assist a team to review a child fatality.

B. A law enforcement agency with the approval of the prosecuting attorney may withhold investigative records that might interfere with a pending criminal investigation or prosecution.

C. The director of the department of health services or his designee may apply to the superior court for a subpoena as necessary to compel the production of books, records, documents and other evidence related to a child fatality investigation. Subpoenas so issued shall be served and, upon application to the court by the director or his designee, enforced in the manner provided by law for the service and enforcement of subpoenas. A law enforcement agency shall not be required to produce the information requested under the subpoena if the subpoenaed evidence relates to a pending criminal investigation or prosecution. All records shall be returned to the agency or organization on completion of the review. No written reports or records containing identifying information shall be kept by the team.

D. All information and records acquired by the state team or any local team are confidential and not subject to subpoena, discovery or introduction into evidence in any civil or criminal proceedings, except that information, documents and records otherwise available from other sources are not immune from subpoena, discovery or introduction into evidence through those sources solely because they were presented to or reviewed by a team.

E. Members of a team, persons attending a team meeting, and persons who present information to a team may not be questioned in any civil or criminal proceedings regarding information presented in or opinions formed as a result of a meeting. Nothing in this subsection shall be construed to prevent a person from testifying to information obtained independently of the team or which is public information.
F. A member of the state or a local child fatality review team shall not contact, interview or obtain information by request or subpoena from a member of a deceased child's family, except that a member of the state or a local child fatality review team who is otherwise a public officer or employee may contact, interview or obtain information from a family member, if necessary, as part of the public officer's or employee's other official duties.
G. State and local team meetings are closed to the public and are not subject to title 38, chapter 3, article 3.1 if the team is reviewing individual child fatality cases. All other team meetings are open to the public.
H. A person who violates the confidentiality provisions of this section is guilty of a class 2 misdemeanor.

36-3504. Child fatality review fund

A. The child fatality review fund is established consisting of appropriations, monies received pursuant to section 36-342, subsection E and gifts, grants and donations made to the department of health services to implement subsection B of this section. The department of health services shall administer the fund. The department shall deposit, pursuant to sections 35-146 and 35-147, all monies it receives in the fund.
B. The department of health services shall use fund monies to staff the state child fatality review team and to train and support local child fatality review teams.
C. Monies spent for the purposes specified in subsection B of this section are subject to legislative appropriation. Any fee revenue collected in excess of one hundred thousand dollars in any fiscal year is appropriated from the child fatality review fund to the child abuse prevention fund established pursuant to section 8-550.01, subsection A, to be used for healthy start programs.

Chapter 13
CDR Program Evaluation

The study on Child Death Review (CDR) teams published in July 2003 in the *American Journal of Preventive Medicine* made it clear that evaluation is an essential part of prevention and surveillance programs such as CDR.[*] Evaluation is a tool used to let the team know if they are doing what they purport to do and how well they are doing it. Some of the questions posed by an evaluation include:

- How do we know if we are meeting our goals and objectives?
- How effectively is the CDR team functioning?
- What are the effects of CDR on policy and procedure?

There are three different types of evaluation useful for specific purposes:

- A process evaluation may analyze the efficiency of team process and functioning, gaps in team representation or quality of data.

- An impact evaluation may help teams evaluate if the information produced by the team (annual report, press releases, etc.) reaches the appropriate audience and if the information is affecting policy, public awareness or prevention programs. Thus it can help the team determine if their reviews are leading to changes in policies, services and programs.

- An outcome evaluation may identify if CDR led to improvements in child health and safety such as child death rates. Outcome evaluations are the most difficult to conduct and may not be possible nor a direct indicator of the effectiveness of CDR.

[*] Webster, Romi et al. (2003) *Child Death Review: State of the Nation*. American Journal of Preventive Medicine, Vol. 25, Issue 1, July 2003, Pages 58-64.

There are so many confounding variables in child health and safety that it may be difficult to establish a direct cause and effect relationship of CDR to a reduction in the rate of child fatalities. It may be more effective to evaluate the intermediate outcomes that measure how CDR influences policies aimed at reducing child fatalities.

Why Evaluate?

Evaluation of the functioning of a CDR team should be built into the CDR program as a core function of the team. Evaluation can provide its members, outside agencies and other interested parties with information about how well the team functions in relation to its goals and objectives and the needs of the community.

Your team must develop goals and objectives that are clear, concise and measurable. Your team may, for example, have an overall goal of reducing preventable child deaths in your jurisdiction. With this goal in mind, you develop a set of measurable objectives. The state of Washington, for example, has as an overarching goal to "reduce preventable child death in Washington State" and their objectives are:

- Ensure identification and uniform review of all unexpected child deaths.
- Improve communication and information sharing among agencies.
- Improve the coordinated response to child deaths.
- Identify and report recommended changes to legislation, policy and practice.

When you begin to develop an evaluation plan consider:

- What will be evaluated?
- What criteria will be used in the evaluation?
- What are the standards of performance that must be reached for the program to be considered successful?
- What evidence will indicate successful performance relative to the standards?
- What conclusions about the program can be used?

Process Evaluation

Process evaluation examines how the team works, what its components are and if the team functions efficiently. CDR teams can develop evaluation questions based on the essential elements of the team. For example, the purpose of the multidisciplinary, multi-agency structure of CDR is to improve communication and cooperation between agencies and among disciplines. A process evaluation can give the program information on if and how communication and cooperation has changed with the inception of CDR. Here are some examples of evaluation questions for each team component:

Team Structure

- What is the structure of the team(s)?
- Is the team functioning effectively and efficiently?
- Does the team have an oversight or executive committee?
- Is there legislation, a mandate or a statute supporting and/or requiring CDR?
- Do these elements support team function and team purpose?

Team Composition

- Does the team have appropriate representation for effective review and information gathering?
- Does the team have the appropriate agencies represented on the team?
- Are agency representatives familiar with agency protocols?
- Can members bring the necessary information to the team meetings?

- Does the CDR process increase interagency communication and cooperation?

Team Functioning

- Does the team collect the necessary information to conduct reviews?
- Is the meeting run effectively?
- What type of review is the team conducting?
- Is the team conducting reviews appropriately?
- Does the team make effective recommendations?
- Does the team get the recommendations to the appropriate agencies and individuals?
- How is the team disseminating information and to whom?
- Is there a feedback loop for learning if the information had any effect and what it was?
- Is there an atmosphere of trust? Can people be honest?
- Is there consistency of membership?
- Is attendance consistent? Is there a protocol for the number of meetings participants can miss?

Data Collection

- What is the quality of the data collected?
- Does CDR help identify all child deaths?
- Does CDR insure uniformity of review?
- If a data collection tool is used, is it appropriate, user friendly, etc.?
- How accurate are the data?

Data Analysis

- Is the database appropriate for your analyses?
- Are you collecting the appropriate data for your analyses?
- Are your results useful to the target audience and to your team?

Confidentiality

- Does your team have procedures that insure confidentiality for the cases as well as the participants?

Dissemination of Data

- Is your data reaching appropriate organizations, communities and policymakers?
- Are you using an appropriate format for the audience and the information?

Impact Evaluation

How do teams know if they are effecting change? As discussed earlier, it is difficult if not impossible to determine if CDR had a direct impact on child death rates, the stated goal of most CDR teams. Most teams conduct reviews in hopes of discovering system improvements that can be remedied through agency, program or policy change. For instance, the effectiveness of CDR teams can be measured by the recommendations that are made and the impact of the recommendations on policy and procedures. Thus an impact outcome evaluation is based on tracking the progress of the adoption of recommendations formulated by the team(s), see *Chapter 10, Taking Action to Prevent Child Deaths*. For instance, if the CDR team had supported legislation on Graduated Driver Licensing, an evaluation based on consistent tracking of CDR recommendations would give the program information on how the team influenced legislation that will potentially decrease child deaths.

Evaluation questions for impact evaluation may include:

- Is the CDR team making appropriate recommendations?
- Are the recommendations being used? If not, why not? If so, how?
- Has there been an increase in the number of prevention programs recommended by the CDR team?

- Was legislation passed due to CDR team data and/or recommendations?

Outcome Evaluation

Health outcomes or long-term outcome evaluation is generally conducted on healthcare or prevention programs. It is used to measure an increase or decrease in the rates related to the program goal. For instance, the goal of CDR is often stated as, "to reduce rates of childhood deaths." As mentioned earlier, it may not be possible to measure the effectiveness of CDRs using a health outcome evaluation because death reviews seek to understand the causes and manner of specific types of death, identify risk factors, systems and services failures and prevention strategies. While local and statewide teams promote interagency and multidisciplinary communication and cooperation and recommend systems and prevention improvement, these successes may not be measurable in health outcomes.

With the data gathered from the case reviews and team discussion, teams disseminate the information to policy makers, agencies, providers, communities and the public. It is difficult to link the reduction or the increase in child deaths to CDR when there are a multitude of diverse agencies and programs that address the issues involved in child fatalities. CDR teams are designed to influence policy and procedure, although interagency communication within team meetings may directly affect agency policy and address system improvement issues.

Methods and Resources

Evaluation Methods

- *Documentation:* Review written documents, for example: records, minutes, annual reports, data, etc.
- *Observation:* Outside evaluator or participant observes team process, takes notes and analyzes the results.
- *Surveys:* In a survey, each respondent is asked the same question and given the same response options. Survey responses can be elicited from members, staff and/or stakeholders. They can be as simple as a few structured questions answered by team members anonymously and periodically to provide data on how team members perceive the functioning and effectiveness of the team. They can be administered by mail, face-to-face or by phone. Surveys are a quantitative method.
- *Interviews:* Typically interviews consist of pre-developed questions with probes to illicit information. Conducted in-person or via telephone, interviews are usually a qualitative method of data collection.
- *Focus groups:* Small groups representative of the CDR program or recipients of the annual report respond to open-ended questions which are then analyzed and results reported. Focus groups are conducted in-person and are qualitative in nature.

Each team needs to evaluate the resources they have available for evaluation, especially in the area of time, funding and expertise. The evaluation can be as simple as an anonymous survey of team members or can involve a combination of all five methodologies. For more in-depth evaluations the team can utilize the expertise of an outside evaluator to design tools and analyses, develop and implement evaluations and report on findings. It is important to involve stakeholders in the evaluation design and interpretation of the results. The complexity increases as the scope of the evaluation broadens to include a statistically relevant number of stakeholders, the type of instrument devised and the analysis necessary to interpret the results. Prior to initiating any evaluation, be clear on how the data will be used, both generally and specifically.

Steps in Evaluation

In 2001, the Washington State Child Death Review Program conducted an evaluation of its program. The following are the steps they outlined for their evaluation process:

- ***Determine the purpose of the evaluation:*** What is the overarching question for this evaluation? What does CDR want to know? For instance, how is the team functioning, how could it improve and what is the impact of the program?
- ***Describe the program:*** Describe how CDR works. Identify its goals and objectives.
- ***Focus the evaluation:*** Develop specific questions based on a logic model, including measurable objectives, action steps, data sources and analysis. Analyze resources for evaluation (time, expertise, money). Prioritize evaluation questions and design evaluation based on need and resources.
- ***Gather evidence and justify your conclusions:*** Conduct the evaluation, analyze the results and write the report.
- ***Disseminate and use results:*** Present results to stakeholders. Interpret the results with the input of stakeholders. Use the results to improve the CDR program.

Resources

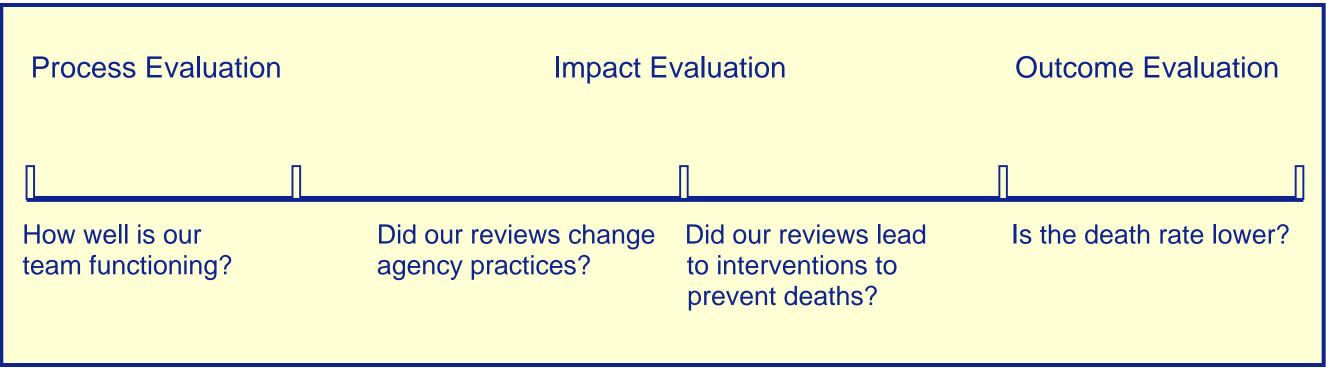
Examples of Evaluations

1. Examples of Fetal and Infant Mortality Review (FIMR) programs nationwide www.med.jhu.edu/wchpc www.jhsph.edu/wphc./projects/fimr.html
2. The Best Intentions: An Evaluation of the Child Death Review Process in Georgia http://www.sph.emory.edu/CIC/gafatality.html

Help with evaluations

1. CDC Evaluation Framework
2. Community Toolbox: www.ctb.ku.edu
3. Chen, H. Y. (1990). Theory-Driven Evaluation. Newbury Park: Sage Publications.
4. Fetterman, D. (1996). Empowerment Evaluation, a chapter in Wandersman, A. (Ed.). *Empowerment Evaluation: Knowledge and Tools for Self-Assessment & Accountability* . Thousand Oaks, CA: Sage Publications.
5. Goodman, R. (1998). Principles and Tools for Evaluating Community-Based Prevention and Health Promotion Programs. *Journal of Health Management Practice*, 4(2), 37-47.
6. Patton, M. (1997). *Utilization-Focused Evaluation: The New Century Text*. (3rd ed.). Thousand Oaks, CA.: Sage Publications.
7. Patton, M. (2002). Qualitative Research & Evaluation Methods. (3rd ed.). Thousand Oaks, CA: Sage Publications.
8. Weiss, C. (1998). *Evaluation: Methods for Studying Programs and Policies*. (2nd ed.). Upper Saddle River, NJ: Prentice Hall.

The Range of Evaluation Possibilities for
Child Death Review:
From Process to Outcomes



Chapter 14 Ethical Dilemmas For CDR Teams

Child Death Review (CDR) creates ethical dilemmas. "Ethics" is commonly defined as a set of moral principles or a system of moral values that govern an individual or group. The CDR process is designed to explore many aspects of a death and the interdisciplinary nature of CDR increases the opportunities to explore these multiple dimensions. Some of the areas that CDR impacts includes:

- Professional practice
- Agency mission and function
- Team membership and participation
- Community obligation and commitment
- Personal, familial, spiritual or faith-based values

Individually, many of the professions represented by members of CDR teams have thought long and hard about the ethical issues faced in their work and in established written standards reflected in their profession's code of ethics. Most practitioners would agree that their work should protect the welfare of the individual and the community. What that means, however, is open to interpretation and sometimes individual and community welfare may be at odds with each other.

The work of CDR teams substantially influences social policy. Ultimately, how and what we do cascades through the community in a myriad of ways. We influence policy and legislation and change organizational practices at the local, state, regional and national levels. Because social policy has such broad influence, it is imperative that our work reflects thoughtful, ethical professional practice.

It is not uncommon for CDR teams to face ethical dilemmas throughout their process of conducting reviews. This section is designed to encourage you to think through some of the potential areas of ethical concern ahead of time. This chapter does

not pose solutions. Rather, it offers some scenarios in the hope that you and your team will explore possible resolutions.

Ethics vs. the Law

Sometimes the relationship between ethics and what the law requires may not be the same or may not be clearly distinguished. While closely related, ethical responsibilities usually exceed legal duties and too often we may observe that what may be legal, may not necessarily be ethical. Moreover, ethical practice includes both acts of omission and commission that further adds to the challenge.

Examples of Ethical Dilemmas

Sharing information is often the first ethical dilemma that emerges as team members work together. Legislative authority may address this issue and the creation or adaptation of this authority often assists individual practitioners and teams to resolve concerns. Confidentiality and HIPAA issues are discussed at length in *Chapter 7, Confidentiality*. There remains, however, much to be considered.

It is not always clear what teams and their individual members can and cannot do. Individual team members should always consult with their agency and consider both the legal requirements of their agency and their professional Code of Ethics. The following examples are potential areas of the CDR process that may create an ethical dilemma for either the entire CDR team or an individual team member.

Ethical Dilemmas

Topic	Situation	Dilemma
Team Membership	Your team plans to conduct a case review of a ten-year-old pedestrian that was killed by an intoxicated driver. This driver is the cousin of a CDR team member.	Should the team ask this person to recuse himself from the meeting?
	You are a small county, reviewing 4-5 deaths a year. You are planning to review a SIDS death at your next meeting. You receive a call from the father of this infant, asking that he and his wife attend the meeting so that they can learn more about your findings in an effort to understand why their child died.	Should parents be informed that you are reviewing their child's death? Upon request, should parents be invited to attend your meetings? Should parents be provided with findings resulting from your review?
	Children from racial and ethnic minority groups have much higher death rates in most categories of deaths in your jurisdiction. Your team is reviewing findings and making recommendations. However, your team has no representatives from these racial and ethnic groups.	Should your team make recommendations for prevention on all deaths they review or seek broader representation?
Case Selection	You are planning to review two deaths due to fires at your next meeting. You do not have any persons on your team with expertise in fire investigation or prevention. You think you should add someone to the team, but others feel that a new member would upset the excellent team dynamic you have all worked hard to achieve.	Should you review a case in which your team lacks expertise?
Sharing Information	You are a Child Protective Services supervisor serving on your county's CDR team. Next month, the team is reviewing a child abuse homicide. You have knowledge that a caseworker under your jurisdiction did not follow agency policy when investigating prior charges of abuse with this child.	Do you share this information about your employee with the team?
	You are the public health representative on your team and as a nurse conducted many home visits supporting a young mother and her infant. The infant died at 10 months due to a treatable infectious disease.	Do you present information at the review that was shared by the young mother during your home visits with her?
	You are the county prosecutor, waiting for information on a potential child neglect death. You know you could get information at the review that may either help you build a case or give you exculpatory information you may have to share with the defense.	Should you attend the review?
Use of Information	During your review of a homicide, conflicting opinions are shared by team members as to the circumstances of this death. Your prosecutor is not in attendance.	Should someone on your team inform the prosecutor of the information, some of which may by law need to be shared with the defense (exculpatory)?
	You are a member of your county's Fetal and Infant Mortality Review Team. Case information shared at that review is de-identified. You obtain information on a specific case at CDR.	Do you share this with the FIMR coordinator or at the FIMR review?
	You participate on the review team, representing the county prosecutor's office. You obtain information at the review related to product safety, leading you to believe the family could successfully win a civil settlement for damages.	Should this information be shared with the family or their attorney?
	You live in a very small county. The press would like to write a story to promote safety and has asked your team to share general findings. You are concerned that everyone in your community would know which death is being discussed.	Do you provide the press with your findings?

Worksheet:
Ethical Dilemmas Our Team Has Experienced

The Dilemma	**Our Resolution**

Chapter 15 Working with The Media

The work of Child Death Review involves sensitive issues, many of which are of great interest to the public and to the media. Additionally, teams are likely to be promoting prevention programs that require the attention of the media increases public awareness. But at the same time, teams work under the confidentiality constraints of law and policy that can make it difficult to respond to the media.

It is important for the team to have a media strategy. This strategy should include:

- How a team responds to media requests for information.
- How the team proactively works with the media to present CDR findings and involve the media in prevention activities.

Responding to Requests from the Media

More than likely, a time will come when your team will be approached by the media for information. Even though CDR teams have been around for more than two decades, they may not be well known and they are still a fairly new concept in many jurisdictions. We can expect that as teams become better known among the general public and journalists, they will be looked to more and more as a source of information about child deaths, child health and safety and the prevention of child deaths. Despite your confidentiality provisions, persons in the media will more than likely be persistent in trying to obtain information. Because you may need the media to further your prevention goals, you will want to maintain positive relations with the media. So how do you respond to requests, even when you may not have a response the media will want,

and still maintain a positive relationship for your prevention efforts down the road?

Your Media Policy

It is suggested that a team have a written procedure or media policy. The policy should recognize confidentiality needs and address the positive aspects of working with the media and the benefits of honest, open communication with the press and public. Some principles that might help guide a team in developing a media policy include:

- Preventing child deaths is a primary goal of the CDR team, but is also a responsibility of the entire community.
- The review team supports the public's right to know what it does generally.
- Confidentiality concerns are important to protect the exchange of information among team members and with the professional community. Encourage open participation but keep matters private which are not public business
- The team will always answer the media's questions honestly, including, as appropriate, telling the media when it cannot answer questions. Deception, pretension and omission hinder good media relations and public education.
- All team members are aware of the team's confidentiality policies and statutory mandates establishing them, even if they are unlikely to speak with the media.
- The team needs a cooperative media and a supportive general public to reach its goals.

In developing your team's policy, several factors are critical.

- *Chain of command* for release of information is important. For example, if an inquiry comes in regarding a particular agency or team member, will the response have to go through that agency and, if so, in what way? If the inquiry concerns a recent death, will the response have to go through the investigating agencies and, if so, who will be contacted? If a question has a political element (for example, does the team support the governor's position on the death penalty) how does the team decide whether and how to answer? Your team should detail the process for releasing information, including who must approve the release and under what circumstances.
- *Procedures* outline the basic steps to be followed when information is requested. For example, how will information be sent to the spokesperson? Will requests for information be logged and if so, how e.g., by name of reporter, date of request, nature of request? Remember that a "one size fits all" procedure does not work. The team will need different procedures for different types of information requests.
- *Confidentiality* defines the basic limits on the information that a team may give to the media or public. Applicable statutes and the team's confidentiality policy set these limits. The media policy should restate its confidentiality policy and the statutory mandates under which it is established.
- *Restrictions* on the release of information besides the requirements of confidentiality should be defined. For example, perhaps no one except the spokesperson should speak to the media about anything related to the CDR team. Look beyond confidentiality to determine what information will be made available to the press and establish concrete guidelines. Remember that reporters' questions may initially be routine but can be followed immediately by more complicated ones. Once someone begins to answer questions, it is hard to stop.

Your team should have one spokesperson. This person will be the team's point of delivery of information to the media and the public. The designated spokesperson must be knowledgeable and articulate.

He/she might be the team chair or coordinator, a representative of the agency with administrative responsibility for the team, a member agency's public information officer or a team member who is particularly experienced in speaking to the media.

The spokesperson should also be:

- Sensitive to the needs of children and families.
- Thoroughly familiar with team organization, protocols and with confidentiality requirements.
- Able to express ideas succinctly, quickly and accurately.
- Confident, authoritative and poised in the face of difficult questions and situations.
- Outgoing, warm and relaxed.
- Sensitive to reporters' deadline pressures.

The duties of a CDR team spokesperson will vary from team to team, but generally this person will:

- Collect information or receive it from the team at large and disseminate it to the media.
- Maintain regular contact with the media.
- Update lists of media outlets and contact people.
- Prepare and distribute news releases.
- Maintain an inventory of informational materials, such as brochures about the team and its prevention campaigns.
- Field questions from the media and the public and be available to provide information on team policies and protocols.

If there are a lot of media inquiries, the team may wish to designate additional spokespersons, for example, the chairs of sub-committees that review deaths due to certain causes or manners. But the number of spokespersons should be limited. Reporters need to know who has the authority to make statements on the team's behalf and feel assured that the statements will be accurate. Also, the team needs to be confident that unauthorized information is not being released.

Working with the Media to Promote Prevention

The media can be very effective in promoting the recommendations of the team to the general public and to policy makers. Many of your member agencies will have media experts, such as persons from an office of communication. You should work with these experts to develop strategies to release information and to promote and/or develop prevention campaigns. For example, you can use the media for:

- Presentation to the public of your data, findings and reports.
- Special reports, news stories, editorials, or safety bulletins when your team wants to draw public attention to certain risks identified through the review to encourage the community to become involved in preventing child deaths.
- Support of public education campaigns through print, radio or television.
- Presentations to the public on the CDR process.

To be proactive, you will need to identify the media outlets that are available within the community and the key people within each medium. Be sure to include public access television, public radio stations and both daily and weekly newspapers.

You should identify your target audience. Who do you most want to reach to educate on child death prevention?

Develop the messages for each audience, as different audiences need different messages. Make sure your messages are culturally competent. Identify the message that each target audience will receive.

Select appropriate media outlets and formats, as different audiences also need different media outlets and formats. Choose the outlets and formats that will provide the best coverage to your target audiences.

Determine the timing of media campaigns based on the target audience and the type of campaign. For example, a teen suicide awareness campaign might begin in the fall with the school year. In a cold weather state, pool drowning prevention campaigns might begin right before the pools open in May. The fall and winter months are important for campaigns on the dangers of space heaters.

Assign team roles and responsibilities. While the team will have only one spokesperson, all team members need to be involved in the development and design of the proactive media relations plan. Additionally, because team member agencies will also be impacted by the plan, their staff should be aware of the plan and, as appropriate, participate in its development and design.

Linking Media Outlets to Target Audiences

As mentioned before, different media messages will require different media outlets. How does the team decide which outlets to use? First, learn about the media in the community:

- Which broadcast outlets have special interests, e.g., "all talk" or "all news?"
- Which print outlets most frequently run human interest features?
- Where are the public displays (such as billboards, cab tops, transit cards) and who do they target?
- Which broadcast outlets have existing public campaigns that are related to the team's work?

By looking closely at the media outlets in the community, the team can answer these questions:

- Who reports on child welfare issues? Are there reporters familiar with child health or safety issues? Does any outlet have a police beat reporter with particular interest in cases involving children? Who are the biggest advocates or critics of the team's member agencies?
- What outlets are not right for the team's message? What outlets have private or political agendas with which the team does not want to be associated? Which serve audiences that are too specialized?
- Who are the best contacts for the team's message: a certain reporter, the public affairs director or the news director?
- Where in the community can the team reach its target audience? Would the audience see a billboard at a ballpark? Does the target audience commute to work on public transportation? Are certain highways or roads used most often? Does the target audience go to movies? Listen to the radio? Are there neighborhood or community newspapers?

Chapter 16 Coordinating with Other Reviews

A growing number of states and communities are implementing other mortality and morbidity reviews. Because many of these reviews share similar purposes and include the same agencies as CDR, it is important to identify how CDR can coordinate with these other reviews.

The major types of review programs operating across the United States today include:

- Fetal and Infant Mortality Reviews (FIMR)
- Maternal Mortality Reviews (MMR)
- Pregnancy Associated Mortality Reviews (PAMR)
- Domestic Violence Death Reviews (DVR)
- Citizens Review Panels (CRP) for child maltreatment death reviews

Fetal and Infant Mortality Reviews

FIMRs originated in the medical community and were in place as long as a decade before CDR programs expanded across the United States. The infant mortality rate is a sensitive indicator of a community's wellbeing. FIMR is a process in which community leaders work collaboratively to identify and examine the factors contributing to fetal and infant death through the systematic evaluation of individual cases. The goal of FIMR is to better understand how and why infants die, in order to take action at the community and state level to prevent other infant deaths. FIMRs are not designed to find and place blame, but rather to identify patterns of community needs, deficits and assets in the perinatal health system and the other human services systems in order to develop solutions to improve future birth outcomes. FIMR is a community-based, action-oriented process.

FIMR may result in clinical remedies, but more often than not, a range of improvement strategies will be identified, including changes in the maternal and child health delivery system, public policies and even patterns of community functioning. For example, FIMR may result in enhanced maternal and infant support services, comprehensive teen parent support programs, improved access to prenatal care, development of healthy start programs, smoking cessation programs for pregnant women, improved agency practices in delivering appropriate services to high risk families, establishment of peer support services for parents and SIDS risk reduction programs. In its most basic form, FIMR serves as a tool for making sense of and learning from history. Through examination of past events surrounding an infant death, it is hoped that prevention of other infant deaths will ultimately result.

Several key components of the FIMR model distinguish it from other review processes: the review is de-identified, a complete abstract of the mother's and infant's health history is completed and used at reviews and a home interview is conducted with the mother. FIMRs also have two tiers of review: a technical review committee and a community action team. The community action team receives the findings of the case reviews and develops the plan for systems improvements and other prevention actions.

Support for FIMR teams is provided by the National Fetal and Infant Mortality Review Program, (NFIMR), a collaboration between the American College of Obstetricians and Gynecologists and the Maternal and Child Health Bureau of HRSA-HHS. NFIMR can be contacted via email at nfimr@acog.org or at www.acog.org.

Maternal Mortality Reviews (MMR) and Pregnancy Associated Mortality Reviews (PAMR)

These reviews have also been in place for many years and have a medical/health services orientation. The reviews are similar, although some maternal mortality reviews will study deaths of women up to one year after the birth of a child, regardless of whether it was associated with the pregnancy. These reviews are not typically community-based. They most often occur at a state or hospital level and review members mostly represent the medical community. The reviews are designed to identify failures in the health care system to ensure that women's health is maintained during pregnancy.

Domestic Violence Death Reviews (DVR)

These reviews have been in place since the mid 1990s. Following a national summit in 1998, DVRs have rapidly expanded throughout the United States. DVRs review the murders of persons that occurred during domestic disputes or in relation to ongoing family violence. Most of the reviews are of women and/or their children. Many of these murders are paired with suicides of the perpetrator.

The purposes of DVRs are to prevent domestic violence, to understand the systems failures in providing protections to the victims, to better identify all violence-related deaths, to coordinate information across systems and to ensure earlier interventions for victims of domestic violence.

These reviews are either community or state based. DV reviews often follow the same process as CDR, including establishing legislative support, multidisciplinary team representation, record sharing, confidentiality, etc. They tend to have more representation from law enforcement, the court systems and victim advocates than CDR. A major issue for DV reviews is the timing of reviews in relation to the

disposition of cases in the criminal justice system.

National support is provided by the National Domestic Violence Death Review Initiative, a clearinghouse and resource center on domestic violence death reviews. They can be contacted at www.ndvfri.org or at 1-866-738-7213.

Citizens Review Panels (CRP) for Child Maltreatment Death Reviews

In 1996, the U.S. Congress amended the Child Abuse Prevention and Treatment Act (CAPTA) to require that states, in order to receive CAPTA funds, establish citizens review panels. These panels must meet at least quarterly, produce an annual report available to the public and examine the policies, procedures and, when appropriate, specific cases handled by the state's local child protective service agencies.

The purpose of the CRPs is to determine whether state and local agencies are discharging their child protection responsibilities and to make recommendations for improvements in the state's child protection system. CRPs must address each of three areas: prevention, foster care and adoption, and child maltreatment fatalities. As a result of the CAPTA requirements, most states have established CRPs, including specific CRPs to review child maltreatment fatalities.

These panels are a mix across the U.S. of state and/or local review panels. Many are organized as a part of or in whole with the state's CDR program. CDR teams may be able to help your state meet the CAPTA CRP requirements. For example, in Michigan the state's CRP on Maltreatment Fatalities is the State CDR Advisory Team. This team holds separate meetings for the case review of maltreatment deaths and issues a separate report.

CDR *may* differ from CRP in that CRP is highly focused on CPS agency performance, state CAPTA and Title IV-E Foster Care and Adoption plans and practices. There may also be different organizational homes. CRP is federally required and requires near fatal case reviews.

Support is provided to CRPs through a list serve and through resources at the University of Kentucky in Lexington at www.uky.edu/SocialWork/crp/

Coordination

There are components of all of the above-mentioned review processes that match with child death review. Many states and communities are already finding ways to blend review processes, coordinate activities and/or communicate with each other. In many states, the members of these teams may come from the same agencies and even be the same persons.

Many of the review programs face the same issues, such as confidentiality concerns, case identification and selection, active membership, reporting and creating recommendations. Findings ways to better coordinate the processes can be important for a number of reasons. First, economy of scale can help each review process capitalize on scarce resources. Second, team membership on each type of review may include the same persons or member organizations needed for each review process. Thirdly and most importantly, if the findings from these processes can be coordinated, the opportunity for improvements and prevention can be strengthened if there is one strong voice for children rather than several independent ones.

Following is a short list of ways that you may want to consider coordinating or even linking your review processes together. Each state and community will be different, depending on the scope, purpose and process of their reviews. You may want to consider bringing your key leaders together

to discuss possible coordination and collaboration.

- Purpose of the reviews: Most will focus on prevention and improvements to systems.
- Team membership: You may find that the same persons are attending multiple review meetings. In smaller communities, this can dilute the effectiveness of the review meetings. Some communities conduct joint reviews. For example, one CDR team may also conduct the DV reviews but invite additional persons to attend these reviews. In many communities, FIMR and CDR members may be the same persons. This can make it difficult if there are numerous review meetings to balance.
- Case identification: You may consider working together so that you have one source of case identification available to all of your reviews. You may then be able to find more cases for review. For example, the county clerk may be willing to collect all cases at one time for all the reviews. You may have a point person working with the clerk to bring case records into one place. You may identify one venue for records or you may work collectively with your Public Health Officer to gain access to birth records.
- Triaging of cases: In some communities the FIMR, DV and CDR coordinators meet regularly to discuss potential cases and make determinations on how to distribute the cases for timing of reviews.
- Sharing case information: Although this will require memoranda of agreement and careful attention to confidentiality provisions, review teams may be able to share the case information and findings across reviews. This may help you have more extensive information on your cases.
- Attend meetings of each other's review processes: Team coordinators may find this especially helpful in ensuring that case findings are coordinated, especially as they relate to prevention and changes in policies and practices.
- Training and technical assistance: You may find it useful and cost effective to conduct state-wide or community trainings for all review members in one venue and perhaps share responsibilities of providing technical assistance in the review process.
- Findings and recommendations: You may consider having one community action team that receives the case information from all of the reviews, leading to a coordinated community action plan for prevention and systems improvements.
- Reports: You may want to consider combining all of the review findings into one report. This has the potential of having more impact in reaching key decision makers and policy leaders. This could be especially useful for those review processes that are not as well known or funded in the state or community.

The following diagram depicts a model of coordination between a FIMR and CDR team.

Model for CDR and FIMR Coordination

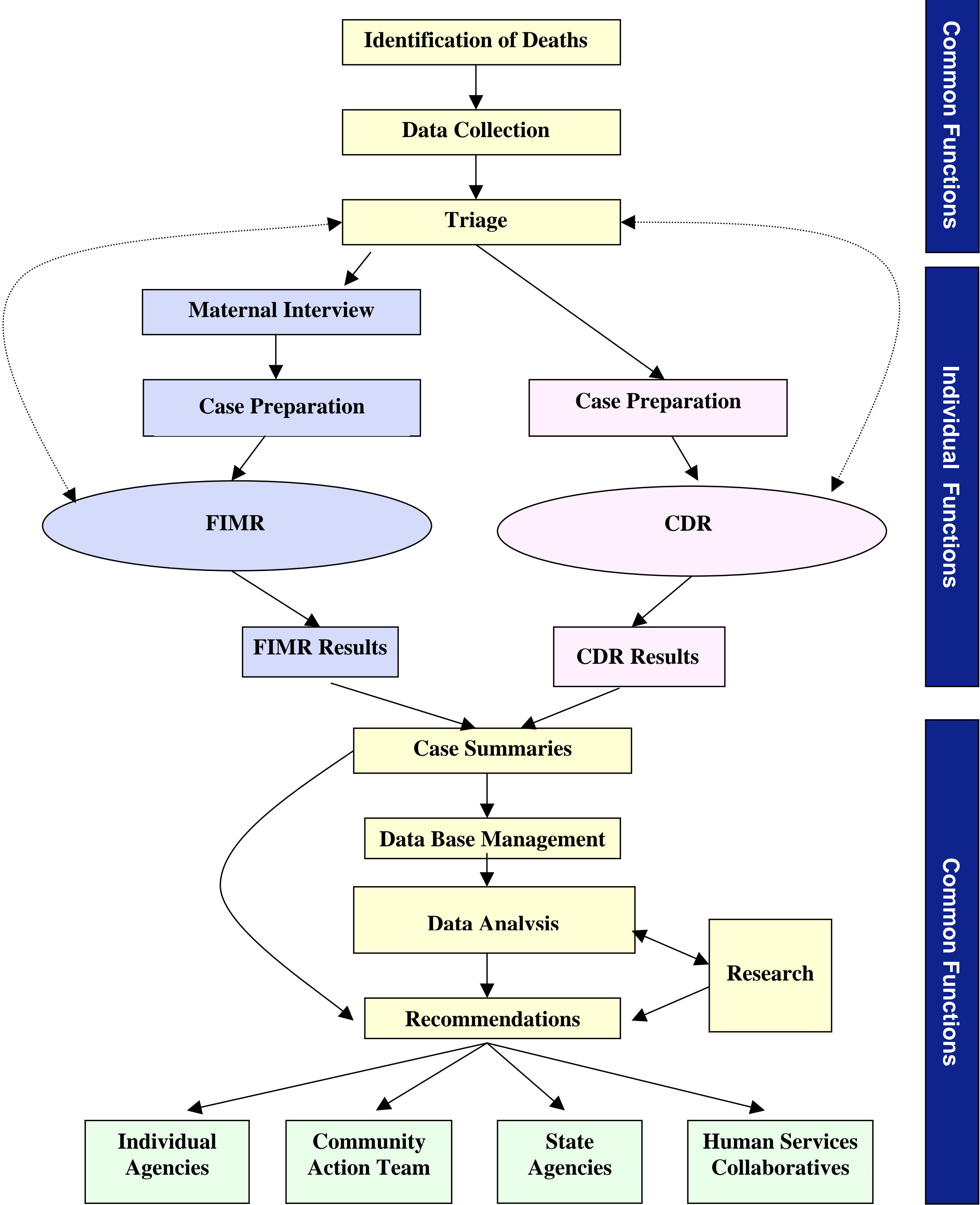
Functions	Coordinated or Separate Processes	
Identification of Deaths	The coordinated model would develop a comprehensive, community-wide surveillance system to quickly detect every death in the community from birth to age 18. This would include cooperative efforts of hospitals, the medical examiner, the local health department and the police, among others. The FIMR coordinator and the CDR coordinator would work together to design and operate the combined surveillance system.	
Data Collection	After identification, a data collection and response mechanism would be developed to solicit data from the appropriate sources and begin a case-file on each death. It is suggested that a database be established and that once identified, an electronic file would be initiated for each death.	
Triage	The two coordinators would initially go over each new case and decide which mechanism of review best fits the death. Once triaged, the case would then enter either the FIMR or CDR pipeline for review. In some cases, a review might be scheduled for both systems or a decision to forward the case to the other system may be made after review, based on the findings or to use the expertise of the other group.	
Case Preparation	For FIMR cases, a maternal interview would be attempted. The FIMR Coordinator would prepare the case in the FIMR format, including de-identification.	For CDR cases, the case would be prepared in the standard CDR format. All review team participants will be contacted and informed about the case and will be instructed to bring relevant information to the review meeting.
Review	The FIMR team would review the case. In some communities, some team members may serve on both FIMR and CDR teams.	The CDR team would review the case. At this stage, CDR members may initiate further action or follow-up on any individual case.
Results from Reviews	The FIMR Coordinator will compile the results from the review team including identified problems and recommendations.	The CDR Coordinator will compile the results from the review team, including identified problems and recommendations.
Case Summaries	A standard case summary is developed which both systems fit into, as well as accommodating dual reviews by both systems.	
Database Management	There should be a single database system for both types of review, which accommodates both similar and different data. The forms used in the review process would conform to the database for easy data entry.	
Data Analysis	The data analysis would be performed on a combined data set for the analysis of global infant and child death issues and the development of recommendations. However, each review system could also do an individual analysis of their cases for purposes of quality control of the process and individual reports to the state FIMR or CDR programs.	
Research	In addition to the data from FIMR and CDR reviews, it is advantageous for a community to have research programs which complement the review systems. For example, continuous analysis of all births and issues such as prematurity, low birth weight, teen pregnancy, etc., could provide important data for consideration. Monitoring births also provides denominators for calculating rates based on live births.	
Development of and Implementation of Recommendations	From the case summaries and data analysis, there would be a prioritizing of combined recommendations from both review systems. Findings will be shared with a Community Action Team (CAT).	
Presentation of Recommendations Translation into Action	When appropriate, a single document presenting combined recommendations would be forwarded to the proper organizations from the CAT. It is also recognized that in some cases each review system may have a specific document required for certain circumstances.	

Coordinated

Separate

Coordinated

Coordinating Fetal-Infant Mortality and Child Death



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Chapter 17
Glossary

Abandonment – The act of a parent or caretaker leaving a child for an excessive period of time without adequate supervision or provision for the child's needs. State laws vary in defining adequacy of supervision and the length of time a child may be left alone or in the care of another before abandonment is determined. The age of the child is also an important factor in determining whether the child has been abandoned.

Abdominal Distention – Swelling of the abdomen (the area located between the chest and pelvis), which may be caused by internal injury, bowel blockage or malnutrition.

Abnormal – Deviating from the standard; not average; typical or usual.

Abrasion – A wound in which either skin or mucous membrane have been scraped off.

Accidental death – A manner of death indicating non-intentional trauma. See **Manner of death** and **Unintentional death.**

Accountability – The measurable extent to which an organization, individual or the general public keeps the promises made to the people served. Most often this involves providing assurance to someone or some organization that expected action occurred.

Accused – See **Defendant.**

Acute – In medicine, refers to a health effect that is brief, intense and short term (as compared to chronic).

Acute Pancreatitis – An acute inflammation of the pancreas (the organ in the body which produces and secretes the enzymes which aid digestion). Symptoms include serve abdominal pains, nausea and fever. In children, trauma should be considered as a possible cause.

Ad hoc members - Non-statutory members of a Child Death Review Team chosen to attend a specific review meeting for their expertise, experience and/or community or case involvement.

Addiction – Overdependence on the intake of certain substances (such as alcohol, nicotine and other drugs) or performing certain acts, such as smoking. Inability to overcome a habit or behavior pattern.

Adjudication (Adjudicatory Hearing) – In a child welfare case, the hearing in which the court determines whether a child has been maltreated or whether there is some other basis for the court to take jurisdiction (or authority) over the case. The grounds upon which the court may take jurisdiction vary from state to state. If the court finds that there is a basis for jurisdiction, the next stage of the process is the disposition hearing.

Adoption – A legal process that vests all legal rights and responsibilities of the parenthood in persons other than the child's biological or previously adoptive parents.

Anemia – Any condition in which the number of red blood cells (carriers of oxygen throughout the body) are less than normal.

Anorexia – Lack or loss of appetite for food.

Anorexia Nervosa – A personality disorder manifested by an extreme aversion to food. It usually, but not exclusively, occurs in young women. May include bingeing and purging (Bulimia).

Anterior – In human anatomy, the front surface of the body.

Apnea – The absence of breathing.

Appeal – In law, resort to a superior (appellate) court or administrative agency to review the decision of an inferior court (trial or lower appellate) or administrative agency.

Arraignment – One of the first steps in the criminal process in which a defendant is formally charged with an offense and informed of his/her constitutional rights.

Asphyxia – Death caused by being deprived of oxygen. Can be caused by strangulation, suffocation, choking or smothering.

Assault – The attempt to inflict bodily injury on another person, with unlawful force and the apparent ability to inflict the bodily injury unless stopped. Assault is both a crime and a tort (private/civil wrong).

Atrophy – Wasting away of flesh, tissue, cell or organ.

Autism – A syndrome appearing in childhood with symptoms of self-absorption, inaccessibility, aloneness, inability to relate to others, highly repetitive play and language disturbances. The cause is unknown.

Autopsy – The dissection of a dead body for the purpose of inquiring into the cause of death. Also, post mortem examination to determine the cause or nature of a disease. An autopsy is normally required by statute for violent, unexpected, sudden or unexplained deaths.

Avitaminosis – A condition caused by the lack of one or more essential vitamins, which may be caused by lack of vitamins in the diet or by the body's inability to use the vitamins because of disease.

Avulsion – A forcible separation or tearing away of a body part or tissue.

Baby Gram – (Slang) One or two x-rays taken in order to see all of a baby's body at one or two angles (often inadequate).

Battered Child Syndrome – A term describing a combination of physical and other indicators that a child's internal and external injuries result from acts committed by a parent or caretaker. In some states Battered Child Syndrome has been judicially recognized as an acceptable medical diagnosis.

Best Interest of the Child – A standard frequently used by child welfare agencies and child welfare courts in determining whether to undertake specific acts regarding a child.

Birth Parent – A parent to whom a child is born. Also called "biological" or "natural" parent.

Blunt Force Trauma – Injury caused by force from a blunt object (such objects may include hands and feet). Includes abrasions, bruises and contusions and lacerations.

Board Certified – A physician who has completed residency training and has passed an official medical board approved examination to be listed as a specialist in a particular field.

Bone Scan – A nuclear medicine study that can assist in diagnosis of early or minimal fractures, especially in children under two years of age where bones have not ossified.

Brain Stem – Portion of the brain connecting the cerebrum and the cerebellum to the spinal cord.

Bruise – An injury that does not break the skin but causes ruptures of the small underlying vessels with resultant discoloration of tissues. Organs can also be bruised, e.g., brain, kidneys. Synonymous with contusion and ecchymosis. See also **Hemorrhage.**

- **Petechiae** – Very small bruises caused by broken capillaries.
- **Purpura** – Petechiae occurring in groups or a small bruise up to one centimeter in diameter.
- **Ecchymosis** – Bruise larger than one centimeter in diameter.

Burn – A wound resulting from the application of heat, cold, electricity or chemicals to the body. Burns are classified in terms of the degree of damage.

- **First Degree** – Injury limited to the epidermis (outer skin layer).
- **Second Degree** – Injury through the epidermis and dermis, typically causing the formation of blisters.
- **Third Degree** – Destruction of the entire skin, including nerve fibers.

Calcification – Process in which organic tissue becomes hardened by the deposition of lime salts in the tissues, e.g., the formation of bone. Seen through x-rays, the amount of calcium deposited indicates the degree of healing of a broken bone or the location of previous healed fractures.

Callus – The hard bone-like substance that forms around the site of fractured bones and gradually fuses with underlying bone as the fracture heals. It is visible on x-ray about a week after the injury. See **Calcification.**

Calvaria (Calvarium) – The upper dome-like portion of the skull, composed of the superior portions of the frontal, parietal and occipital bones.

CAPTA – See **Child Abuse Prevention and Treatment Act.**

Caretaker – In child welfare, a person responsible for a child's health or welfare. This may be the child's parent or guardian, another person within the child's own home or relative in a relative's home, foster care home or residential institution.

Cartilage – Hard connective tissue that is not bone. In the fetus and growing child, cartilage may be the forerunner of bone before calcium is deposited to form bone.

Case – In child welfare, refers to both to the process of a child and family through the child welfare agency and to the process of the child and family through court.

Case Management – A systemic approach to social work in which an emphasis is placed on the system in which a client must function rather than on inner thought process. Case management requires identification and coordination of the multiple services required by the client.

Case Plan – In child welfare, a written document which contains at least: (1) a description of the home or institution in which the child is placed; (2) a plan for assuring that the child receives proper care and that services are provided which will reduce risk, promote healthy family functioning or facilitate the child's return home or to another permanent placement and (3) the child's health and education records.

Case Planning – The continuous process engaged in by a child welfare agency in developing and modifying a child or family's case plan.

Case Worker – The staff member of a child welfare agency who is responsible for working with a child or family.

C.A.T. Scan (Computerized Axial Tomography) – A radiological study using x-rays translated by computer to show body cross sections. See **M.R.I**.

Cause of Death – The effect or condition that brought about the cessation of life (e.g., trauma, asphyxia, cancer).

Cellulitus – Inflammation of cellular or connective tissue.

Central Registry – In child welfare, generally, a listing of names of persons found by a CPS agency to be perpetrators of child abuse or neglect. The existence and use of Central Registries varies from state to state.

Cerebral – Pertaining to the brain.

Cerebral Edema – Swelling of the brain due to accumulation of watery material.

Child – Person under 18 years of age. Synonymous with minor.

Child Abuse – (Common, legal) Intentional injury to a child. Each state has enacted its own definition of child abuse, generally based on the definition found in the federal Child Abuse Prevention and Treatment Act. According to the Child Abuse Prevention and Treatment Act (see **CAPTA**) is any recent act or failure to act on the part of a parent or caretaker which results in death, serious physical or emotional harm, sexual abuse or exploitation; or an act or failure to act which presents an imminent risk of serious harm.

Child Abuse Central Index – A state central index of reports of child abuse/neglect; it generally includes acts or omissions by caretakers that are held to be true and of significance after an investigation by law enforcement or **Child Protective Services (CPS**).

Child Abuse Prevention and Treatment Act (CAPTA) – An act introduced and promoted in Congress by U.S. Senator Walter Mondale and signed into law on January 31, 1974. The Act emphasized multidisciplinary approaches to child abuse and neglect. Codified at 42 USC § 101 *et seq.*

Child Death Review Case Report – A standardized form for collecting data on child fatalities meeting the criteria for review by the Child Death Review Teams as approved by the relevant jurisdiction.

Child Death Review Team (CDRT) – Representatives from the office of the coroner or medical examiner, county department of family and children services, public health department, juvenile court, office of the district attorney and law enforcement. May be formed at a city, county, regional or state-level.

Child Development – Pattern of sequential stages or interrelated physical, psychological and social development in the process of maturation from infancy and total dependence to adulthood and relative independence.

Child Maltreatment – See **Child Abuse**.

Child Neglect – (Common, legal) An injury to a child caused by the omission of necessary acts including failure to provide food, healthcare, shelter or safety. See **Child Abuse.**

Child Protective Services (CPS) – (Common) The welfare department/social service system designed to protect children. In most states, the entity that receives and investigates reports of suspected child maltreatment and provides services to children and families to ameliorate past maltreatment and prevent future maltreatment.

Child Sexual Abuse – The employment, use, persuasion, inducement, enticement or coercion of any child to engage in or assist any other person to engage in, any sexually explicit conduct or simulation of such conduct for the purpose of producing a visual depiction of such conduct; or the rape and in cases of caretaker or inter-familial relationships, statutory rape, molestation, prostitution or other form of sexual exploitation of children or incest with children. *Note: Each state is responsible for providing its own definition of child abuse and neglect.*

Child Welfare Agency – In most states, the public agency responsible for the provision of services such as Child Protective Services (CPS) and foster care.

Child Welfare and Adoption Assistance Act (Public Law 96-272) – A federal law passed in 1980 intended to prevent multiple foster care placements and increase effective permanency planning for children in foster care. Case plans, findings of reasonable effort, retrospective reviews and dispositional reviews are among its requirements for states wanting a share of money appropriated under the Act.

Child Welfare Court – The court that hears child welfare cases (emergency removal, adjudication, disposition, review and termination of parental rights). Sates have different names for this court, including family court, juvenile court and dependency court.

Choking – When the upper airway is blocked by a foreign object.

Chronic – In medicine, developing slowly and persisting for a long period of time.

Citizen Review Panel– In 1996, the United States Congress mandated that states that receive federal Child Abuse Prevention and Treatment Act funding (CAPTA) must establish a minimum of three Citizen Review Panels to develop recommendations for the improvements of a state's child protection system. At a minimum these panels must look at child fatalities, foster care and adoption and child abuse prevention services in order to improve policies and procedures.

Civil Court – Courts established for the adjudication or controversies between individual parties or the ascertainment, enforcement and redress of private rights. The court which hears child welfare cases is a civil court.

Clotting Factor – Material in blood that causes it to coagulate or clot. Deficiencies in clotting factors can cause profuse internal bleeding and bruising, as in the disease hemophilia. Bruises or bleeding caused by clotting factor deficiencies may be mistaken for abuse.

Coagulation – The process of clotting. The body's process of healing itself when blood is released from an injured vessel.

Coagulation Studies – Blood tests done to diagnose or rule out possible clotting factors diseases.

Coining – A Southeast Asian folk remedy in which the edge of a coin is repeatedly rubbed over the body, generally the upper torso, windpipe and inner arm. The result is a series of reddish to purple vertical bruises resembling strap marks, which vary in depth and severity. The bruises are believed to be an indicator of evil spirits of a disease exiting the body.

Colon – The part of the large intestine that connects the small bowel (ileum) with the rectum.

Colposcope – Optical instrument for low power magnification of the external genitalia as well as the vagina and cervix. Used for detection of sexual injuries. Also used for detection of ano-rectal injuries.

Commissioner – See **Master**.

Common Law – In the law, the system of jurisprudence (the form of law) which developed in England and came to American colonies during colonization. Common law is derived and developed from the decisions of judges.

Competent Intent – The desire to cause an event to happen by someone with the ability to form that intent (some say a child under the age of 8 does not have the ability to form competent intent).

Completed Review – Data entered and verified in a Child Death Review Case Reporting System.

Concussion – An injury to the brain caused by a violent jarring or shaking or a blow to the brain. After a mild concussion there may be a brief loss of consciousness with a headache on awakening. A severe concussion may cause lengthy unconsciousness and disruption of breathing or other vital functions of the brainstem.

Confidentiality Statement – A standardized form, approved by the jurisdictional authority, which must be signed by all participants in the review process.

Congenital – Those mental or physical traits, malformations, disease, etc., that are present at birth. May be hereditary or due to some influence during gestation.

Contusion – See **Bruise.**

Coroner – A jurisdictional official, usually elected, whose duty it is to determine the cause and manner of sudden, suspicious or violent deaths. May or may not be a physician. Differs from a medical examiner, in that a **medical examiner** is by definition a physician.

Coroner's Investigator – An official investigator for the coroner, who may have varied backgrounds, levels of education and areas of specialty.

Corporal Punishment – Physical punishment inflicted directly upon the body.

Cortex – The outer layer of an organ.

Costal Cartilage – Cartilage that attaches the ribs to the sternum or to other cartilage.

Cranium – The skull.

Crime Scene – The physical site where a crime may have occurred. See **Death Scene**.

Criminal Court – A court designated to hear matters relating to criminal law, this court hears cases involving the crime of child abuse.

Crisis Intervention – In social work, the purposeful activities and involvement of helping a person at the point that another person or family is caught in acute, disabling distress due to situational events. The intervention includes rapid response to move the client from emotional disorganization to rational problem solving through time-limited counseling and other services.

Cupping – A folk remedy in which an alcohol-soaked material is ignited in a small cup or jar. After the flame is extinguished, the cup is placed over the skin and the resulting suction forces the tissue into the mouth of the cup. The cup is left in place for approximately twenty minutes. Cupping results in a 2-inch circular, unraised, ecchymotic burn. Wounds usually are produced in symmetrical, vertical rows, in clusters of two and four on the right and left side of the chest, abdomen and back or in smaller groupings on the forehead.

Custody – In law, the right to care and control of a child and the duty to provide that child's food, clothing, shelter, ordinary medical care, education and discipline. Parents are the natural custodians of their child. However, a court may grant temporary custody to someone other than a parent, pending further action or review by the court.

Cutaneous – Pertaining to the skin.

Cyanosis – Purplish or bluish discoloration of the skin and mucous membranes, caused by a lack of oxygen in the blood.

Death – The cessation of life, manifested in people by a loss of heart beat, absence of spontaneous breathing and the permanent loss of brain function; loss of life.

Death Certificate – Official document noting the cause and manner of death. See **Cause, Manner and Fetal Death Certificate.**

Death Scene Investigation – An attempt by a person functioning in an official capacity to gather information at the site where a fatal illness, injury or

event occurred, for the purpose of determining the cause and circumstance of the death.

Defendant – In civil proceedings, the party responding to the complaint brought by the plaintiff. In criminal proceedings, the person accused of a crime and synonymous with accused.

Dehydration – A large loss of fluid from the body tissues. It may occur after any condition in which there is a rapid loss of body fluids, including fever, diarrhea or vomiting. Dehydration is particularly dangerous in infants and young children.

Dependency Court – Specialized civil court designated to hear matters pertaining to child abuse/neglect. See **Criminal Court, Family Court** or **Child Welfare Court**.

Depression – In psychology, a mood disorder in which there are extreme feelings of helplessness, hopelessness, inadequacy or sadness.

Dermis – Inner layer of skin.

Diaper Rash – A skin irritation in the diaper area. Possible causes include yeast infections, bacterial infections, urinary tract infections, parasitic infestations, contact irritation from soaps or diaper wipes, infrequent diaper changes or poor hygiene.

Diaphysis – The shaft (long, thin part) of a long bone which is between two flared ends.

Differential Diagnosis – The determination of which two or more diseases with similar symptoms is the one from which the patient is suffering. For example, osteogenesis is a differential diagnosis for child abuse.

Discipline – Behavior that educates and corrects or punishes.

Disposition – In Child Protective Services, the finding of the validity of a report of child maltreatment that is made by the caseworker after investigation. Disposition categories vary from state to state.

Disposition Hearing – In child welfare court cases, a court hearing which determines whether a child needs or requires the court's assistance, guidance, treatment or rehabilitation and, if so, the nature of that assistance, guidance, treatment or rehabilitation.

Disposition Review – In a child welfare court case, a hearing in which the court reviews the child's case to ensure that a permanency plan is being implemented in the child's best interest.

Dissociation – In psychology, the separation of thought or feeling from consciousness, e.g., when a sexual abuse victim "pulls away" from the cognitive and emotional experience of the abuse. "Multiple Personality Disorder" is a severe and rare outcome of dissociation.

Distal – The parts of the body, limbs or organs, that are farthest from the trunk or point of origin.

Due Process of Law – The right of persons under the 5th and 14th Amendments to the U.S. Constitution to procedural and substantive fairness in situations in which the government would deprive the person of life, liberty or property.

Dura Mater – The tough fibrous membrane covering the brain and the spinal cord.

Ecchymosis – See **Bruise**.

Ecological – In the behavioral and social sciences, refers to the consideration of the interaction of personal, physical, behavioral, social, cultural, medical, economic, environmental and systemic determinants when analyzing the behavior of individuals, families, groups and systems.

Edema – Swelling caused by an excess of fluid in the body tissues.

Emergency Medical Services – The complete chain of human physical resources that provide patient care in cases of sudden illness or injury.

Emergency Medical Technician (EMT) – A professional provider of emergency care. An EMT receives formal training and certification. There are three levels of emergency medical technicians.

EMT Basic – Can administer oxygen and initiate defibrillation but is not allowed to perform any type of invasive care.

EMT Intermediate – Has passed specific training programs in order to provide some level of advanced life support, for example, the initiation of intravenous lines and administration of some medications. In some states, this level is currently being phased out.

EMT Paramedic – Has successfully completed paramedic training and has received appropriate certification. EMT paramedics can generally perform relatively invasive field care including insertion of endotracheal tubes, initiation of intravenous lines, administration of medications, interpretation of electrocardiograms and cardiac defibrillation.

Emergency Removal Hearing – An immediate hearing held by the child welfare court which determines whether to continue emergency out-of-home placement for an allegedly maltreated child. State laws vary on the time by which the hearing must be held after the child has been removed from the home in an emergency. Synonymous with shelter hearing.

Emotional Maltreatment – Passive or active patterned, non-nurturing behavior by a parent or caretaker that negatively affects or handicaps a child emotionally, psychologically, physically, intellectually, socially or developmentally. The definition can vary by state.

Encopresis – Uncontrolled or involuntary bowel movements.

Enuresis – Uncontrolled or involuntary passage of urine.

Environmental – Pertaining to all of the many factors that affect the life of a person, including physical and psychological.

Epidemiology – The study of the spread, prevention and control of disease in a community or a group of persons.

Epidermis – The outer most skin layer.

Epiphysis – The rounded ends of a long bone.

Evidence – In law, something that makes another thing evident or tends to prove that a fact at issue is true.

Circumstantial – Evidence of a fact from which another fact can reasonably be inferred.

Direct – Evidence which is presented in the testimony of a witness who has direct knowledge of the fact being proved.

Hearsay – An out of court statement intended to prove the truth of the matter being asserted. Hearsay evidence is usually excluded from court proceedings because it is considered unreliable and because the person making the original statement cannot be cross-examined.

Opinion – Witnesses are ordinarily not permitted to testify as to their personal beliefs or opinions, being restricted instead to reporting what they actually saw or heard. However, a witness can give an opinion if qualified as an expert. See **Expert Witness.**

Physical – Any tangible piece of proof. Physical evidence usually must be authenticated by a witness who testifies to the connection of the evidence (called an exhibit) with other facts of the case.

Prima Facie – Evidence that will suffice as proof of the fact in issue until its effect is overcome by other evidence.

Examination – In law, the questioning of a witness.

Expert Witness – Someone the court determines to have expertise on a subject (does not necessarily require any graduate degree). The witness may qualify as an expert through experience, training or education. Only an expert witness may testify in the form of opinion.

Expungement – Destruction of records. In law, expungement may be ordered by a court after a specified number of years or when the juvenile, parent or defendant applies for expungement and shows that his/her conduct has improved. In child welfare, expungement also means the removal from the Central Registry of certain reports of abuse or neglect.

Extremity – Portion of the body that is not a part of the trunk (e.g., arms, legs).

Failure to Thrive – A medical condition seen in young children where a child does not gain weight. It may be associated with a decrease in the rate of growth or in a growth rate that is significantly below norm. The cause may be organic (natural) or non-organic, such as poor nutrition, inadequate food intake or inappropriate formula preparation.

Family Court – Court designated to hear matters pertaining to family law (e.g., divorce and child custody). See **Child Welfare Court**.

Family Dynamics – Interrelationships between and among individual family members. The evaluation of family dynamics is an important factor in the identification, diagnosis and treatment of child abuse and neglect.

Family Dysfunction – Ineffective functioning of the family as a unit or of individual family members in their family roles because of the physical, mental or situational problems of one or more family members.

Family Preservation Services – Services provided which support the principle that a child should be maintained in the family if the child's safety can be ensured.

Family Reunification Services – Services which support the principle that the preferred permanency plan for a child in foster care is the return to the family if the child's safety can be ensured.

Fatality – Loss of life. See **Death**.

Felony – Generally, any criminal offence for which the penalty is imprisonment for more than one year. Murder, rape and armed robbery are crimes usually considered felonies.

Felony Murder – See **Homicide**.

Fetal Alcohol Syndrome – A congenital syndrome caused by intrauterine exposure to alcohol. Characteristics include growth retardation, microcephaly (small head) and mental retardation.

Fetal Death – (Common) Death of pregnancy after approximately 20 weeks.

Fetal Death Certificate – Official document noting the death of a fetus (note - does not include a space for manner of death.) See **Manner of death**.

Fetal Homicide – (Legal) The death of a viable fetus caused by competent intent. See **Viable Fetus**.

Fingering – See **Spooning**.

Fontanelle (Fontanel) – The two soft areas ("soft spots") on the head of an infant where the bones are not yet joined. One soft spot disappears at about two months and the other at about eighteen months of age. A "bulging fontanelle" may indicate increased pressure in the skull.

Forensic – Having to do with the study of criminal acts.

Forensic Pathologist – A pathologist with training in criminal pathology. See **Board Certified**.

Foster Care – Placement for children under dependency court jurisdiction (. Includes continuous 24-hour care and supportive services provided for a child while the child needs substitute care outside of the child's family.

Foster Care Review Board – A volunteer panel of citizens that reviews the cases of children who have been in foster care under public agency for at least six months. Boards generally seek to determine the efforts that have been made to achieve permanent and stable placements for foster children and to encourage and facilitate the implementation of permanency plans in their best interest.

Foster Care Services – In most states, the entity that provides services to children and families when a child is in foster care.

Foster Family Home – A type of foster care that is provided in a family setting.

Fracture – Any break or crack in bone or cartilage.

- **Basilar Skull** – A fracture to the base of the skull which will often result in spinal fluid leaking from the nose or ear.
- **Bucket Handle Tears** – Total fracture of a long bone so that it is floating loose.
- **Chip** – A small piece of bone is separated from the main body of the bone; avulsion fracture.
- **Comminuted** – A bone broken into a number of pieces.
- **Compound** – A broken bone that protrudes through the skin.
- **Egg Shell** – A fracture of the skull that looks like a broken egg on an x-ray.
- **Greenstick** – The bone is bent and there is an incomplete fracture in the convex side of the curve. Common among young children.
- **Incomplete** – The line of the fracture does not include the entire bone.
- **Occult** – A fracture that is not visible on x-ray.
- **Pathologic** – A fracture occurring at a site weakened by a preexisting disease, as seen in osteogenesis imperfecta, tumors or Gaucher's Disease.
- **Simple** – A break in a bone without displacement of the bone pieces.
- **Spiral** – A break in a long bone which is spiral shape, resulting from twisting of the extremity.

Gaucher's Disease – A rare, familial disease in infants, which may cause fractures. Gaucher's Disease is a differential diagnosis for child abuse.

Gluteal – Referring to the buttock.

Gross Examination – In medicine, a physical examination without the aid of radiologic instruments or surgical entry.

Group Home – A type of foster care in which care is provided in a small group setting.

Guardian – An adult who is legally responsible for a child. A guardian has almost all the rights and powers of a parent, but the legal relationship is subject to termination and change. A guardian may also have physical custody of the child.

Guardian *ad litem* – A lawyer or non-lawyer who represents the best interest of a child in a child welfare court proceeding.

Hematemesis – Vomiting of bright red blood, often resulting from internal injury.

Hematoma – Swelling caused by the accumulation of blood in the body tissues.

Hematuria – Blood in the urine.

Hemophilia – An inherited disorder of the blood in which there is a defect in its ability to clot, resulting in a tendency to hemorrhage.

Hemorrhage – Bleeding.

- **Intraabdominal** – Bleeding within the abdomen.
- **Intracerebral** – Bleeding within the brain.
- **Intracranial** – Bleeding within the skull.
- **Intradermal** – Bleeding within the skin. See **Bruise.**
- **Retinal** – Bleeding into the inner lining of the eye, hallmark of whiplash and Shaken Baby Syndrome.

Hemostaiss Screen – A laboratory study performed to determine whether or not a child has a bleeding or bruising tendency.

Hepatic – Pertaining to the liver.

Homicide (official) – Death caused by another with the intent to kill or severely injure.

- **Murder** – The unlawful killing of a human being with malice aforethought. Malice aforethought requires premeditated intent plus an element of hatred.
- **Felony Murder –** The unintentional killing of a human being during the commission of a felony.
- **Manslaughter** – An unlawful killing of a human being without malice aforethought.
- **Voluntary Manslaughter** – An intentional killing committed under circumstances which, although they do not justify the homicide, mitigate it.
- **Involuntary Manslaughter** – Criminally negligent homicide, such as a death resulting from the negligent operation of a motor vehicle.

Homicide (common but not official) – Death at the hands of another (without reference to intent).

Homicide Detective (Investigator) – A police or sheriff department investigator with an expertise in homicide investigations.

Hospital Shopping – The use by a person or family of different medical facilities so that each individual medical facility's sole contact with the person or family is a single presenting injury.

Hydrocephalus – "Water on the Brain," in infants, an accumulation of fluid in the subarachnoid or subdural spaces of the brain.

Hyperactive – More active than normal. The term becomes synonymous with Attention Deficit Disorder with Hyperactivity (ADDH or ADHD or ADD), that is characterized by inattention, impulsivity and hyperactivity.

Hyperemia – An excess of blood in a part of the body causing reddening of the skin; it disappears when pressure is applied.

Hyperpigmentation – Increased pigmentation of the skin.

Hyperthermia – High body temperature.

Hyphema – Hemorrhaging into the anterior chamber of the eye, often appearing as a bloodshot eye. Blows to the head or violent shaking are two possible causes. See **Hemorrhage - Retinal**.

Hypoactive – Less active than normal.

Hypothermia – Low body temperature.

Hypothalamus – The portion of the brain which controls and integrates functions such as general regulation of water balance, body temperature, sleep, food intake and the development of secondary sex characteristics.

Hypovitaminosis – A condition caused by a deficiency of one or more essential vitamins.

Idealization – In psychology, attributing exaggerated positive qualities to self or other, e.g., a child may idealize an absent or abusive parent.

Identification – In psychology, increasing feelings of worth by identifying oneself with a person or institution of illustrious standing.

Identification with the Aggressor – In psychology, a defense mechanism consisting of imitation of the aggressor.

Impassivity – A state of not feeling or showing emotion.

Incest – Sexual intercourse between persons who are closely related by blood. While incest between parent and child or siblings is almost universally forbidden, various cultures may extend the boundaries to prohibit intercourse with other relatives. In the U.S., the prohibition against incest is specified by state laws as well as by cultural tradition. States usually define incest as marriage or sexual relationships between relatives who are closer than second or sometimes even more distant, cousins. While incest and sexual abuse are often thought to be synonymous, incest is only one type of sexual abuse.

Incidence – In epidemiology, the extent to which a problem occurs in a given population.

Independent Living – A possible permanency plan for a child in foster care in which the goal is self-sufficiency after discharge from foster care.

Indian Child Welfare Act (ICWA) – A federal law which specifies the manner in which child welfare agencies and child welfare courts must handle cases involving Native American and Alaska Native Children.

Infant – Child under one year of age. See **Neonate.**

Infanticide – The killing of an infant or of many infants.

Injury – Refers to any force whether it be physical, chemical, thermal or electrical that results in harm or death.

Institutional Review Board – Under federal guidelines, the groups designated by an institution to review research and practice methodologies relevant to protections to prevent harm and protect confidentiality particularly as they relate to human subjects.

Intentional Injury Death – Public health term used to define death caused by another with the intent to cause harm. See **Competent Intent**.

Intent – Desire to cause to happen. See **Competent Intent.**

Intern – Student trainee, also refers to a physician's first year of work after medical school.

International Classification of Diseases – The ICD is designed to promote international comparability in the collection, processing, classification and presentation of mortality statistics. This includes providing a format for reporting causes of death on the death certificate. The reported conditions are then translated into medical codes through use of the classification structure and the selection and modification rules contained in the applicable revision of the ICD, published by the World Health Organization. These coding rules improve the usefulness of mortality statistics by giving preference to certain categories, by consolidating conditions and by systematically selecting a single cause of death from a reported sequence of conditions. The single selected cause for tabulation is called the underlying cause of death and the other reported causes are the non-underlying causes of death. The combination of underlying and non-underlying causes is the multiple causes of death. The ICD has been revised periodically to incorporate changes in the medical field. To date, there have been 10 revisions of the ICD.

Intraocular – Within the eye.

Intravenous – Within a vein.

Judgment – The court's final decision.

Jurisdiction – An agencies authority over an incident, investigation and/or prosecution.

Juvenile Court – See **Child Welfare Court**.

Kinship Care (Relative Placement) – Residential caregiving provided to children by nonparental relatives. Kinship care may be full-time or part-time, temporary or permanent and may be initiated by private family agreement or under the custodial supervision of a child welfare agency.

Laceration – A torn or jagged wound causing a splitting or tearing in the external skin surface in addition to the deep tissue.

Language Delay – A situation in which a child's language abilities are considerably poorer than the abilities of most children of the same age.

Late Effects – Refers to conditions or outcomes that may occur at any time after an acute injury, whether intentional or unintentional.

Lateral – Occurring on or pertaining to, the side.

Lesion – Any injury to any part of the body from any cause that results in damage or loss of structure or function of the body tissue involved. A lesion may be caused by poison, infection, dysfunction or violence and may be either intentional or unintentional.

Lethargy – A state marked by loss of energy, inactivity, sluggishness or excessive drowsiness.

Leukemia – A malignant disease of blood forming elements. Children suffering from leukemia may present petechiae or bleeding which should be considered in the differential diagnosis of children who bruise easily.

Listserv – Computerized one-to-many electronic mail system that allows individuals to share information with a group.

Local Child Death Review Team – A Child Death Review Team that operates within a specific area within a state, i.e., city, county, reservation or other geographical area. See **Multidisciplinary Team**.

Long Bones – Bones of the arms (ulna, radius, humerous) and legs (femur, tibia, fibula).

Malnutrition – A condition caused by inadequate nourishment.

Maltreatment – See **Child Abuse and Neglect**.

Mandated Agency – The agency designated by state law to receive and investigate reports of suspected child abuse and neglect. The specific agency varies from state to state.

Mandated Reporters – Persons designated by state law who are legally responsible for reporting suspected child abuse and neglect to the mandated agency within their state. Mandated reporters vary according to state law, but are primarily professionals, such as doctors, nurses, school personnel and social workers who have frequent contact with children and families.

Mandible – The bone of the lower jaw.

Manner of Death – The official, vital statistics classification, whether natural, suicide, homicide, accidental or undetermined. Also known as **Mode of Death.**

Manslaughter – See **Homicide.**

Master – A person appointed by a court in certain cases to hear testimony and make reports that, if approved by the court, become the decision of the court. In some states, masters may hear child welfare court cases. Also referred to as **referee** or **commissioner**.

Mechanism of Death – The physical reason for a death (e.g., head trauma caused brain swelling which caused decreased brain function which caused the heart and/or lungs to stop functioning).

Medial – Towards the middle or mid-line.

Medical Cause – Refers to death resulting from a natural cause other than SIDS.

Medical Examiner – An official whose duty it is to investigate sudden, suspicious or violent death to determine the cause. See **Coroner.**

Medical Neglect – Generally, the repeated failure of parents or caretakers to comply with recommendations from medical professionals for the treatment of a child's condition. Individual states may define the term differently.

Menkes Kinky Hair Syndrome – A rare, genetic disorder which blocks absorption of copper in the gastrointestinal system, causing brittle bones and eventual death. It is a differential diagnosis for child abuse.

Mesentery – Membranes which cover abdominal organs and attach the bowel to the abdominal wall. The mesentery may be injured in interabdominal trauma or inflames, as with peritonitis.

Metaphysis – The area of bone between the epiphyses (extremities) and diaphysis (shaft) which flares out at the end of long bones. It contains the growth zone of the bone.

Minor – See **Child.**

Misdemeanor – Criminal offenses that are less severe than felonies and generally punished by lesser fines or by jail terms which do not exceed a year.

Mode of Death - See **Manner of Death**

Mongolian Spot – A type of birthmark that appears most frequently on a child's lower back or buttocks. These dark pigmented areas usually fade by age five. They are sometimes confused with bruises.

Multidisciplinary Team –A group of professionals representing various disciplines who meet to coordinate their efforts in investigation, providing services and the prevention of child deaths and injury. See **Local Child Death Review Team**.

Munchausen Syndrome by Proxy – A pattern of abuse in which the perpetrator, usually a parent, will fabricate medical histories, inflict physical findings, alter laboratory specimens and induce disorders in a child to give the appearance that the child is ill.

Murder – See **Homicide.**

National Crime Information Center (NCIC) – Criminal justice information systems operated by the Federal Bureau of Investigation in Washington, D.C.

Natural Cause – Death resulting from inherent, existing conditions. Natural causes include congenital anomalies, disease, other medical causes and SIDS.

Neglect – See **Child Neglect**.

Negligence – In the law, doing something that a person of ordinary prudence would not do or the failure to do something that a person of ordinary prudence would do, under given circumstances.

Neonate – Infant under one month of age.

Neurologic Sequelae – A diseased condition of the nervous system resulting from previous disease. In abused children, the condition may result from previous abuse.

Occipital – Back of the head.

Ossification – The process during which immature or new bone or cartilage is converted into bone.

Osteogenesis Imperfecta – A genetic condition which causes bone to be brittle and prone to fracture. It is a differential diagnosis for child abuse.

Osteomyelitis – Inflammation of bone caused by a bacterial organism.

Paralysis – Complete or partial loss of functioning, usually involving motor function in a part of the body.

Paramedic – See **EMT-Paramedic**.

Parens Patriae – "Parent of the country." Refers to the role of the state as sovereign and the guardian of persons under legal disability. It is through parens patriae that the state investigates possible child abuse and neglect and places a child in foster care.

Passive – In psychology, not reacting visibly to something that might be expected to produce manifestations of an emotion or feeling.

Pathognomonic – Specifically distinctive or characteristic of a disease or pathologic condition; a sign or symptom on which a diagnosis can be made.

Pathologist - Physician with residency training in pathology. See **Forensic Pathologist** or **Pediatric Pathologist.**

Pediatrician – Physician who has completed residency training in pediatrics.

Pediatric Pathologist – Physician with special training in pediatrics and pathology. See **Board Certified.**

Perinatal – The period of time from around the twenty-eighth week of gestation through the first seven days after delivery.

Perineum – Region of the body between the anus and the genitals.

Periosteal Elevation (Hemorrhage) – The tearing away or lifting up of the bone's covering, from the hemorrhaging that occurs when a bone is broken or there has been bleeding under the periosteum. This is not necessarily indicative of child abuse as it can be due to leukemia or infiltrative disease such as tumors or inflammation. It may be present at birth from a difficult delivery.

Periosteum – The outer covering of bones that is essential for bone formation and healing.

Peritoneum – The lining of the abdomen.

Peritonitis – Inflammation of the membranous lining of the abdominal cavity.

Perjury – Knowingly and willfully giving false testimony under oath.

Permanency Plan – In child welfare, a plan for implementing the most permanent long-term living situation possible for a child, consistent with the child's best interest. This plan specifies where and with whom a foster care child shall live and the proposed legal relationship between the child and the permanent caretaker or caretakers.

Permanency Planning – The process by which a welfare agency with responsibility for the child in foster care develops a permanency plan for a child.

Perpetrator – In child welfare, a person(s) who committed an act that resulted in the death of a child.

Petechiae – See **Hemorrhage – Intradermal**.

Petition – In the law, a formal, written request to the court that it do something. The petition is a pleading

that begins a court case. It contains the facts and circumstances upon which a court is asked to provide certain relief as well as the relief being sought.

Physical Abuse – See **Child Abuse**.

Pia Mater – The fine vascular membrane that envelops the brain and spinal cord. It is located below the arachnoid and the dura mater.

Plaintiff – In a civil case, the person who files a lawsuit.

Pleadings – In the law, formal allegations of the claim and defenses raised by the parties to the court case.

Posterior – In human anatomy, the back surface of the body.

Postpartum Depression – Depression which may occur after childbirth.

Premature Infant – An infant born after thirty-seven weeks gestation but before full term and, arbitrarily, an infant weighing 2.2 - 2.5 pounds at birth. This definition varies.

Prenatal – Occurring before birth.

Preventable Death – A child's death is considered to be preventable if the community (through legislation, education, etc.) or an individual (through reasonable precaution, supervision or action) could have done that which could have changed the circumstances that led to the death.

Prevention – In public health, the keeping of something (such as an illness) from happening. There are three general levels of care designed for prevention:

- **Primary** – The first level of care, designed to prevent the occurrence of disease or injury and promote health.
- **Secondary** – The second level of care, based on the earliest possible identification of disease or injury so that it can be more readily treated or managed and adverse sequelae can be prevented.
- **Tertiary** – The third level of care, concerned with promotion of independent function and prevention of further disease or injury-related deterioration.

Probable Cause – In the law, a requisite element of a valid search and seizure or of an arrest, which consists of the existence of facts and circumstances within one's knowledge that are sufficient to warrant the belief that a crime has been committed (in the context of an arrest) or that property subject to seizure is at a designated location (in the context of a search and seizure). Whether probable cause exists depends on the independent judgment of a "detached magistrate."

Prosecution – The act of pursuing a lawsuit or criminal trial; also, the party initiating a criminal suit.

Proximal – Those parts of the body or portions of the bone, that are closest to the trunk or to the point of origin.

Psychosis – In psychology, a mental disorder causing gross impairment of a person's mental capacity, affecting response and capacity to recognize reality.

Public Law 96-272 – See **Child Welfare and Adoption Assistance Act.**

Purpura – See **Hemorrhage – Intradermal.**

Radiolucent – In medicine, a part of a body or object which permits the passage of x-rays without leaving a shadow on the film. Soft tissues are radiolucent; bones are not.

Rarefaction – Loss of density; on an x-ray, an area of bone which appears lighter than normal is in a state of rarefaction indicating a loss of calcium.

Rationalization – In psychology, attempting to prove that one's behavior is "rational" and justifiable and thus worthy of self and social approval.

Reaction Formation – In psychology, the substitution of behavior, thoughts or feelings which are diametrically opposed to the person's own unacceptable ones. For example, a parent feels guilty about lack of bonding with the child and instead overindulges the child.

Reasonable Effort – In child welfare, the ordinary diligence and care by a child welfare agency to identify child protection problems and provide services to solve those problems so as to prevent out-of-home placement or promote family reunification.

Reconsideration – In child welfare, the process of periodically reassessing and redeveloping the permanency and case plans.

Records Request Form –Forms for requesting records on individual cases.

Recurrent Otitis Media – Repeated inflammation of the middle ear. It is the leading cause of hearing loss in children.

Referee – See **Master.**

Regression – In psychology, retreating to an earlier developmental level involving less mature responses and, usually, a lower level of aspiration.

Regulation – For a governmental agency, directions for the operation of the agency, developed by the agency to implement its statutory responsibilities. Regulations have the force and effect of law when issued following notice to the public and an opportunity for the public comment.

Relative Placement – See **Kinship Care**.

Repression – In psychology, a defense mechanism in which the person is unable to remember disturbing feelings, thoughts or experiences.

Resident – In medicine, a post-intern trainee in an official training program (e.g., pediatrics).

Retinal Hemorrhage – Bleeding in the retina of the eye.

Reviewable Death – Death which has been reported as having met criteria for review by a Child Death Review Team, whether or not the review has yet been completed and reported. Criteria vary by team.

Rickets – Condition of delaying maturation of the bones caused by a Vitamin D deficiency. May be seen with severe malnutrition, hypoparathyroidism and renal disease.

Risk Assessment – A structured gathering and evaluation of information related to factors in a child's family, home environment, temperament and conditions, to determine the presence, level and type of risk(s) to the child's current and future safety and welfare. As relevant factors change, risk assessment must therefore be conducted over the life of a case.

Risk Factors – Refers to a person, thing, event, etc., that put an individual at an increased likelihood of incurring injury, disability or death.

Rubella – An infectious viral disease with particular effects on fetuses (possibly causing abnormalities) or newborn infants. One of the early manifestations may be petechiae or easy bruising. There also may be associated bone lesions that may be confused with child abuse.

Rupture – The break of an organ or other soft part.

Sacral Area – Lower part of the back.

Scapula – The flat, triangular bone in the back of the shoulder; the shoulder blade.

Scar – The dense, fibrous tissue that is left behind by the healing of injured tissue.

Sclera – The rough white outer layer of the eyeball.

Search Warrant – An order issued by a judge and directing certain law enforcement officers to conduct a search of specified premises for specified things or persons and to bring them before the court. Use of a search warrant is required by the Fourth and Fourteenth Amendment to the U.S. Constitution.

Secondary Infection – Infection by a microorganism following an infection by another microorganism.

Seizure – Involuntary muscular contraction and relaxation originating from the "short circuit" of the central nervous system. Seizures vary in pattern, length and intensity. Causes include fever, tumors, injuries or epilepsy.

Sequelae – The aftereffects of an injury or disease process. In child abuse, this term usually refers to the psychological or physical outcomes which result from being abused or neglected.

Serology – The study of blood serum for evidence of infection.

Sexual Abuse – See **Child Sexual Abuse.**

Sexually Transmitted Disease (Infection) (STD or STI) – Disease transmitted by sexual contact, including chlamydia, trichomonas, gonorrhea, syphilis, hepatitis B and HIV. The presence of a STD in a child is an indicator of possible sexual abuse. However, some STDs are passed on to the fetus during pregnancy or at birth.

Shaken Baby Syndrome – Characterization of head injuries to a young child caused by shaking without impact. Injury to an infant or child resulting from violent, repetitive shaking. Pathognomonic findings include intracranial hemorrhaging, retinal hemorrhaging and no cutaneous manifestations of injury. Survivors are frequently left with profound neurologic sequelae, e.g., blindness, deafness, mental retardation, cerebral palsy and seizures.

Shaken Impact Syndrome – Characterization of head injuries to a young child occurring with both shaking and impact. Different from Shaken Baby Syndrome, which does not include impact.

Shelter Hearing – See **Emergency Removal Hearing**.

Skeletal Series of X-rays – Defined series of x-rays designed to find most fractures. See **Baby Gram**.

Skeletal Survey – A series of x-rays taken of all the bones of the body.

Smothering – Specifically refers to asphyxiation of the nose and mouth usually by a hand or soft object. Mechanical asphyxia resulting from external pressure on the body preventing chest movement and breathing.

Social Isolation – The limited interaction and contact of many abusing or neglecting parents with relatives, neighbors, friends or community resources. Social isolation can perpetuate a basic lack of trust, which hinders both the identification and the treatment of child abuse and neglect.

Somatization – In psychology, a pathology in which a person becomes preoccupied with physical symptoms disproportionate to any actual physical disturbance. May be seen in victims of sexual abuse.

Splitting – In psychology, a defense mechanism in which a person views self and others as all good or all bad, failing to integrate the positive and the negative qualities of self and others into cohesive images. Often the person alternately idealizes and devalues the same person.

Spooning (Fingering) – A folk remedy from Southeast Asia for pain relief. The middle knuckle of the index finger or a spoon is firmly rubbed along the surface of the skin in any area of an ill person's

body, especially along the spine, behind the knees, in the bend of both arms and on the chest from just above the nipple to mid-clavicle. If a raised line appears, no further treatment is necessary.

Standard of Proof – An amount of probability necessary for court to render a decision regarding the evidence presented to it. There are three different standards of proof.

Beyond a Reasonable Doubt – The amount of probability required to find a criminal defendant guilty. The proof must be so conclusive and complete that the ordinary person could not reasonably deny it.

Clear and Convincing Evidence – An amount of probability less than beyond a reasonable doubt but more than probable cause. It is used in some civil cases, including termination of parental rights cases. The proof must produce a firm belief of truth to the trier of the fact.

Preponderance of Evidence – The amount of proof required in most civil cases, including child welfare cases (except for termination of parental rights proceedings). The proof must be more likely than not.

State Child Death Review Team – An appointed body of representatives that oversees the local child death review process, reports to the governor annually on the incidence of child fatalities and recommends prevention measures based on the data. See **Child Death Review Teams**.

Statute – A law passed by a legislative body.

Sternum – The bone that runs down the front part of the chest; the breastbone.

Stillborn – Potentially viable fetus born dead.

Strangulation – Asphyxia caused by external pressure applied to the neck either by the use of hands or a ligature (rope).

Subarachnoid Bleeding – Bleeding that occurs between the pia and the arachnoid membrane of the central nervous system.

Subcutaneous – Beneath the skin.

Subdural Hematoma – Bleeding between the internal lining of the skull and the brain.

Subgaleal – The inner lining of the scalp. A site of hemorrhage frequently secondary to hair pulling.

Subpoena – In the law, a command to appear at a certain time and place, on a certain date and give testimony on a certain matter.

Sudden Infant Death Syndrome (SIDS) – Sudden death of an infant that remains unexplained after a review of the medical history, a complete death scene investigation in which a thorough postmortem examination, including autopsy, fails to demonstrate an adequate cause. A diagnosis of exclusion can be made when no underlying cause of death can be identified. It is not caused by abuse or neglect.

Suffocation – Asphyxia caused by a general deprivation of oxygen either from obstruction of external airways or lack of breathable gas in the environment.

Suicide – Death of self-caused with intent. See **Intent.**

Summons – In the law, a document used to commence a civil action or special processing. A summons is issued by a court to the sheriff (or other designated official), requiring them to notify the person named that an action has been commenced against the person and that the person is required to appear on a day named and answer the complaint.

Syndrome – A group of signs and symptoms that occur together and are typical of a particular disorder or disease.

Termination of Parental Rights (TPR) – A legal process that severs the legal relationship between parents and the child and vests authority in the child welfare agency. The TPR order places the child in the guardianship of the child welfare agency and gives the agency the right to consent to adoption or long-term care short of adoption.

Testimony – Evidence given by a competent witness under oath or affirmation, as distinguished from evidence derived from written or other sources.

Thorax – Chest area, encompassing the heart, lungs and ribs.

Torsion – Twisting, as of a limb.

Traction – Drawing or pulling, as in setting a bone.

Trauma – An injury or wound brought about by an outside force. Trauma may be caused unintentionally or, as in physical abuse, intentionally. Trauma also refers to physiological discomfort or symptoms resulting from an emotional shock or painful experience.

Trend – In child death surveillance, refers to the changes occurring in the number and distribution of child deaths.

Undetermined Death – Death where the manner of death is not clear. See **Manner of death.**

Unsupervised Death – Death which data suggests that the decedent may not have had adequate supervision at the time of the fatal injury or death event. Defining variables include reports that the event was unwitnessed, that the caretaker was asleep at the time (except under normal sleeping hours) or that there was no adult caretaker present.

Unintentional Death – Refers to the act that resulted in death being one that was not deliberate, willful or planned.

Vascular – Pertaining to or containing blood vessels.

Venereal Disease – See **Sexually Transmitted Disease.**

Venue – Related to the locality of the court or courts which possess jurisdiction.

Vertical Team Prosecution – A prosecution in which every member of the prosecution team is the same throughout the trial.

Vesicle – Blisters containing fluid.

Viable Fetus – A fetus that would be able to live outside the uterus if born as defined by experts.

Victims of Crime Fund – Money available to serve crime victims through a federal and/or state program with local officials having responsibility for distribution of funds.

Visceral – Pertaining to the internal organs.

Vital Signs – Blood pressure, heart rate, respiratory rate and temperature.

Vitreous – The material that encloses the major portion of the eye, which is normally clear. With an eye injury there may be hemorrhaging and the area may turn red.

Welt – Minor damage to the skin or to the blood vessels directly underneath the skin caused by a blow or a cut. Does not involve bleeding.

Whiplash – See **Shaken Baby Syndrome.**

Witness – A person who has first-hand knowledge of the illness/injury/event leading to injury, disability or death. This excludes information obtained from other persons. A person inflicting injury on a child or identified as a perpetrator is not considered a witness. The witness may or may not be in charge or providing immediate care for the child and may or may not have custody of the child. First-hand knowledge usually includes seeing or hearing the illness/injury/event occur.

Wound Pattern – Wounds that are close together, similar size and shape and inflicted in the same area of the body.

Common Agency Acronyms

CPS Child Protective Services
CDRT Child Death Review Team
CFR Child Fatality Review
CR Central Registry

DHS Department of Health Services
DOH Department of Health
DOJ Department of Justice
DPH Department of Public Health
DSS Department of Social Services
DSW Department of Social Welfare
FIMR Fetal and Infant Mortality Review

Common Legal Acronyms

CAPTA Child Abuse Prevention and Treatment Act
CWAAA Child Welfare and Adoption Assistance Act (Public Law 96-272)
ICWA Indian Child Welfare Act
NCIC National Crime Information Center
TPR Termination of Parental Rights
VCF Victims Crime Fund

Chapter 18
Tools for Teams

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Planning for a New Child Death Review Team or Application for a New Team

PART 1: Your readiness for child death review

PART 2: Building your team & planning your reviews

Developed by the National Center for Child Death Review
at the Michigan Public Health Institute
2438 Woodlake Circle, Suite 240
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www.childdeathreview.org

PART ONE
Assessing Your Readiness for Child Death Review

1. Define the geographic area that the team will cover (local, regional, state etc.):

   ____

   ____

2. What is the total population in your community? ____________

   How many children are under age 18? ____________

   How many children are under age 10? ____________

   How many children are under age 5? ____________

3. What is the racial and ethnic makeup of your community?

Group	Percent
Caucasian	
African American	
American Indian	
Hispanic	
Pacific Islander	
Asian	
Other	

4. How many children, ages 0-18 died in the past calendar year of all causes?

Age	Number
< 1	
1-4	
5-9	
10-14	
15-18	

5. By what manner did the children die in the past year?

Manner	Number
Natural	
Accidental/Unintentional	
Homicide	
Suicide	
Undetermined	

6. By what causes did the children die in the past year?

Cause	Number
Perinatal Conditions	
SIDS	
Other Medical Causes	
Motor Vehicle	
Fires	
Drowning	
Suffocation	
Firearm	
Poisoning	
Other	
Undetermined	

7. What additional information do you have about causes of child deaths?

8. What agencies collect data on child deaths? How is the information accessed?

Agency	Type of Data
Medical Examiner/Coroner	
Public Health	
Social Services	
Prosecutor	
Law Enforcement	
Courts	
Community Advocate Groups	
Other	

9. Are you a Medical Examiner or Coroner jurisdiction? ___________________________

10. Who is the Medical Examiner or Coroner? ____________________________________

11. What special requirements or procedures do the Medical Examiner or Coroner follow for child deaths? Include both internal and external investigations. Attach any protocols or procedures.

12. Which law enforcement agencies operate in this jurisdiction?
State police ____
Sheriff ____
Police ____
College/University Police____
School Police____

13. What agencies have primary jurisdiction for child death investigations?

14. What special requirements or procedures (both external and internal) does this law enforcement agency follow for child deaths? Attach any protocols or procedures.

15. Which prosecutor/district attorney office(s) operate in this jurisdiction?

Are there special prosecutors dedicated to child deaths? Name:

16. What special requirements or procedures (both external and internal) does the prosecutor follow for child deaths? Attach any protocols or procedures.

17. Which Child Protective Services agencies operate in this jurisdiction and respond to child deaths?

18. What special requirements or procedures (both external and internal) does this CPS agency follow for child deaths? Attach any protocols or procedures.

19. Does any other agency investigate child deaths?________
If the answer is yes, which agencies?

20. If yes, what special requirements or procedures do these other agencies follow for child deaths?

21. Do any of the following types of reviews currently take place in your jurisdiction?

Check the box for all that apply and identify the person who chairs or administers the team and briefly describe.

Infant Mortality Review ☐
Name of Chair or Administrator: ____________________
Describe:

Domestic Violence ☐
Name of Chair or Administrator: ____________________
Describe:

Child Protection Team ☐
Name of Chair or Administrator: ____________________
Describe:

CPS Citizens Review Panel ☐
Name of Chair or Administrator: ____________________
Describe:

22. On a scale of 1 – 10 (poor-excellent), how would you describe interagency cooperation in your community? Describe:

23. What interagency collaborations currently exist in your community?

24. Does the Medical Examiner or Coroner have a procedure for cooperating with CPS (including exchanging information) when a child dies and vice versa? Yes ___ No ____
If yes, briefly describe the processes. Attach any protocols or procedures.

25. Does law enforcement have a procedure for cooperating with CPS (including exchanging information) when a child dies, and vice versa? Yes ___ No _____
If yes, briefly describe the processes. Attach any protocols or procedures.

26. Do you foresee any difficulties obtaining team agreement on the following issues (If yes, explain.)

	Yes	No
Obtaining full core team membership	☐	☐
Signing an interagency agreement on confidentiality	☐	☐
Sharing information between agencies	☐	☐
Attending a two day training	☐	☐
Submitting reports to the state program	☐	☐
Attending an annual meeting	☐	☐

If yes, explain:

Part Two
Building Your Team & Planning Your Reviews

1. Person taking the lead in planning the team: ______________________________
   Agency: ______________________________
   Address: ______________________________
   ____
   Phone: ____________________ Fax: ____________________
   E-Mail: ____________________
2. Collaborating Agencies:

AGENCY	Did they participate in the planning?	Have they committed to the review process?
a. Medical Examiner or Coroner Name: ____________ Title: ____________ Address: ____________ Phone/Email: ____________	☐ Yes ☐ No	☐ Yes ☐ No
b. Public Health Name: ____________ Title: ____________ Address: ____________ Phone/Email: ____________	☐ Yes ☐ No	☐ Yes ☐ No
c. Social Services Name: ____________ Title: ____________ Address: ____________ Phone/Email: ____________	☐ Yes ☐ No	☐ Yes ☐ No
d. Law Enforcement Name: ____________ Title: ____________ Address: ____________ Phone/Email: ____________	☐ Yes ☐ No	☐ Yes ☐ No
e. Prosecuting Attorney Name: ____________ Title: ____________ Address: ____________ Phone /Email: ____________	☐ Yes ☐ No	☐ Yes ☐ No
f. EMS Provider Name: ____________ Title: ____________ Address: ____________ Phone /Email: ____________	☐ Yes ☐ No	☐ Yes ☐ No

AGENCY	Did they participate in the planning?	Have they committed to the review process?
g. Others Name: ____________ Title: ____________ Address: ____________ Phone/Email: ____________	☐ Yes ☐ No	☐ Yes ☐ No
Name: ____________ Title: ____________ Address: ____________ Phone/Email: ____________	☐ Yes ☐ No	☐ Yes ☐ No
Name: ____________ Title: ____________ Address: ____________ Phone/Email: ____________	☐ Yes ☐ No	☐ Yes ☐ No
Name: ____________ Title: ____________ Address: ____________ Phone/Email: ____________	☐ Yes ☐ No	☐ Yes ☐ No
Name: ____________ Title: ____________ Address: ____________ Phone/Email: ____________	☐ Yes ☐ No	☐ Yes ☐ No
Name: ____________ Title: ____________ Address: ____________ Phone/Email: ____________	☐ Yes ☐ No	☐ Yes ☐ No
Name: ____________ Title: ____________ Address: ____________ Phone/Email: ____________	☐ Yes ☐ No	☐ Yes ☐ No
Name: ____________ Title: ____________ Address: ____________ Phone/Email: ____________	☐ Yes ☐ No	☐ Yes ☐ No
Name: ____________ Title: ____________ Address: ____________ Phone/Email: ____________	☐ Yes ☐ No	☐ Yes ☐ No

3. Knowing who you want to participate in planning the team is half the battle. The rest is getting those people to the planning table. What will be done to secure each participant in the planning process? Who will do it and when will it be done?

Person/Agency	Steps/Date	Assigned to

THE PLANNING MEETINGS: These questions will help you plan the first meeting of your child death review team planning group. There are two types of planning meeting activities: activities that educate participants about each other and on current practices in the community; and activities around planning how the team will operate. Both types of activities should be part of the initial planning meeting. Depending on the time available, accomplishing these activities may take more than one meeting.

4. What is the date and time of the initial planning meeting?

5. Where will the initial planning meeting be held?

6. Who will facilitate the planning meeting?

7. Who will provide administrative support for the planning meeting?

8. Which of the following will take place at the initial meeting?

Activity	Presenter/Facilitator	Materials
Identification of team purpose and objectives		
Description of Child Death Review		
Discussion of our child death data		
Discussion of our current procedures for responding to child deaths		
Discussion of team goals		
Discussion of team membership		
Discussion of review population		
Discussion of review procedures (case identification, who will coordinate, etc.)		
Discussion of confidentiality and access to information		
Discussion of reporting method		
Practice review(s)		
Development of time line for implementing team		

TEAM ORGANIZATION: The first topic should be the team's purpose. Everything else that the team decides upon: its activities, its members, the deaths it will review, etc. will all flow from the team's purpose or purposes.

9. What purpose(s) will the team have? Check all that the team will include.

Reviews of deaths	☐
Data collection and analysis	☐
System study	☐
Identification and implementation of changes to prevent future deaths	☐
Other (please identify)	☐

10. What activities will the team engage in? Check all that the team will include.

Serve as an immediate review team to help investigation	☐
Provide assistance and coordination to those investigating child deaths	☐
Otherwise evaluate individual deaths	☐
Identify and implement system changes	☐
Develop protocols for investigating or responding to child deaths	☐
Data collection and analysis	☐
Making recommendations and following up on action	☐
Advising government officials on changes to law, policy or practice	☐
Greater understanding of child deaths	☐
Other (please identify)	☐

11. What will be the team's geographic scope? Check only one.

City	☐
County	☐
Multi-County	☐
Judicial District	☐
Service District	☐
State	☐
Other	☐

Name the geographic area: ___________________

12. The members of a child death review team should be those who are necessary to carry out the team's purpose and complete the team's activities. Check all that the team will include.

Law Enforcement	☐	Division: __________________
Child Protective Services	☐	
Prosecutor/District Attorney	☐	
Medical Examiner or Coroner	☐	
Public Health Agency	☐	
Pediatrician or Pediatric Nurse Practitioner	☐	
Attorney for Child Protective Services Agency	☐	

Child Care Licensing	☐	Private Non-Profit	☐
Domestic Violence	☐	Court Appointed Special Advocate	☐
Education	☐	Protection and Advocacy Agency	☐
Emergency Medical Services	☐	Disabilities Expert	☐
Fire Department	☐	Substance Abuse Treatment Program	☐
Juvenile Justice	☐	Sudden Infant Death (SIDS) Program	☐
Local Hospital	☐	Vital Records	☐
Maternal and Child Health	☐	Prevention Partners	☐
Mental Health	☐	Others (identify)	☐
Child Abuse Prevention	☐		

13. **WHAT DEATHS WILL THE TEAM REVIEW**? This decision is based on what has been discussed in terms of team planning. Also needing consideration is the number of deaths that occur in the jurisdiction and how many deaths can be reviewed in one meeting. If it is determined that all deaths are to be reviewed, review procedures such as use of screenings and sub-committees that will allow the team to consider a wider number of cases may be in order. Check any and define.

A. Deaths of all children under a particular age? ______________________
What is the age? ____

B. Deaths from certain causes? ______________________________
What are the causes? ____
____

C. Deaths that are ME/Coroner cases? __________________________
What deaths are these? ____
____
____

D. Deaths of children/families known to a particular agency? ____________
Define "known." ____
____
____

14. What agency will sponsor the team or have lead authority?

Public Health	☐
Law Enforcement	☐
Social Services/CPS	☐
Prosecutor/District Attorney	☐
Medical Examiner/Coroner	☐
Child Abuse Prevention Center	☐
Private Non-profit	☐
Other (identify)	☐

15. How will the team identify the deaths?

Medical examiner/coroner provides a list ☐
Vital Records will provide death certificates ☐
County Clerk will provide a list ☐
Other ☐

16. How will the team be notified of the deaths?

17. How will the team review individual deaths?

Medical Examiner or others will screen cases for review ☐
Entire team will review all deaths ☐
Sub-committees review certain types of deaths ☐
Describe:

Other ☐
Describe:

CONFIDENTIALITY AND ACCESS TO INFORMATION

18. What provisions of law (statutes or ordinances, court rules, court orders or agency regulations) mandate that the team have access to information?

19. What provisions of law (statutes or ordinances, court rules, court orders, or agency regulations) or established practices will restrict team's access to case information?

20. Will the team use an interagency memorandum of agreement for the sharing of information?

21. Will the team develop any written materials to request/ensure access to records?

22. Complete the following table to address access to information on cases.

Information	Source	Mandates	Restrictions
Child Abuse/Neglect History			
Social Services Family History			
Scene Investigation			
Autopsy			
Medical Records			
Mental Health			
Substance Abuse			
Public Health Services			
Education			
Other			

23. If there are any restrictions on access to information, what approaches will be taken to secure access? Check all that apply and describe the approach.

Changes to the law ☐
Confidentiality agreements ☐
Court order ☐
Attorney General's opinion ☐
HIPAA finding ☐
Other___________________ ☐

ACCESS BY OTHERS TO THE TEAM'S INFORMATION

24. Teams vary by the information that they create and keep. What information will the team produce and/or retain? Check all that apply.

Member Notes ☐
Minutes ☐
Raw Data ☐
Aggregate Data ☐
CDR Case Report ☐
Other ☐ ____________________

25. For the information checked above, are there mandates that require sharing or restrict sharing of this information to non-team members?

Information	Mandates	Restrictions

26. Will the team require that access to information from the review be addressed by:

- Changes to the law? ☐
- Confidentiality agreements? ☐
- Court Order? ☐
- Attorney General's Opinion? ☐
- HIPAA Exemption Finding? ☐
- Other? ☐

27. Who will keep files of review information and where will the files be maintained?

28. How will review information be secured?

TEAM COORDINATOR AND TEAM CHAIR

Not all teams have chairs or coordinators, the individual whose paid job or agency assignment is to administer the team. But because a team coordinator can be a valuable asset, their participation should be considered.

The team coordinator has the important job of keeping the child death review team going. Leadership is the key to developing and maintaining a committed, motivated team. The team coordinator's duties may encompass orientation of new members, team development, team meeting responsibilities, prevention activities, and team continuity.

The chair may be a person who runs the review meetings but does not perform administrative duties for the review.

28. Who will act as team:

Coordinator? ______________________________

Chair of meetings? ______________________________

NOTES

Job Description for a Local Team Coordinator

Title: Local Child Death Review Team Coordinator

Purpose: To coordinate the (insert team name) child death review team; work with community leaders to maintain and enhance the review team, develop partnerships with child health and safety organizations; and implement CDR team recommendations in order to prevent child mortality and morbidity.

Duties and Responsibilities:

- Obtain and update mortality and morbidity data.
- Develop and implement a child death notification system so that the CDR team is aware of all deaths that occur in its jurisdiction or of residents of the jurisdiction that die elsewhere.
- Develop and maintain relationships with core member agencies of the CDR team; ensure that the team membership is adequate to effectively review cases.
- Schedule and plan all child death review team meetings including securing meeting site and sending meeting notices to team members.
- Collect case information and create written summaries for team meetings.
- Recruit and orient new team members to the process.
- Develop and maintain CDR team member confidentiality statements.
- Arrange for the chairing of/or chair all team meetings.
- Facilitate resolution of interagency disputes related to the child death review process.
- Ensure that the CDR team operates according to protocols as defined by the team and/or law.
- Assist the (insert team name) child death review team with a comprehensive approach to addressing child health and welfare issues, recognizing the inter-relatedness of multiple risk factors in prevention planning.
- Promote CDR team success in following through with recommendations and prevention initiatives and activities.
- Facilitate contacts with the media providing them information on causes of child deaths, including risk and protective factors.
- Complete and submit case reports to the state child death review office as appropriate and maintain a log of cases reviewed.
- Serve as a liaison to the state child death review office and other agencies as needed.
- Provide training and education for the (insert team name) child death review team, including orientation training for new teams and advanced training in specific issues relating to child health and safety for established teams.
- Prepare presentations and written materials as needed, including CDR program histories and descriptions, process tools for the team and annual reports that contain at a minimum review team findings.
- Meet with and give presentations to all groups interested in the CDR process and/or CDR findings relating to specific causes of death.

Education: Possession of a Bachelor's degree in relevant discipline is required.

Experience: Three to five years experience in the human service field.

Important Skills and Characteristics: Good knowledge of community health program development, and human service systems involved in child and adolescent health. Working knowledge of public health principles related to community health services. Demonstrated ability to work at the community level with diverse groups of people, with ability to build consensus across organizational lines. Excellent communication, written and organizational skills. Demonstrated ability to be self-motivated, a team player and work independently.

Job Description for a State Coordinator

Title: State Child Death Review Program Coordinator

Purpose: Provide administrative and project management for the (insert state) Child Death Review Program.

Duties and Responsibilities:

- Provide oversight for entire CDR Program including development, promotion and implementation.
- Coordinate project activities including analyzing project needs, developing and monitoring work plans and timelines; writing progress and evaluation reports.
- Organize, develop and maintain local child death review teams throughout the state.
- Advocate for the implementation of child death review findings and recommendations.
- Identify and review system problems related to the child health, safety and protection arena.
- Advocate for support of prevention programs.
- Assist policymakers in developing or amending laws; provide data as requested; prepare policy briefs when needed.
- Promote better communication among agencies at the state-level, between state and local levels and among the different local jurisdictions.
- Examine child death trends and issues.
- Advocate for the enhancement of the review process.
- Collect child death review case reports and child mortality data.
- Develop state child death review reports.
- Link local child death review teams with prevention resources and strategies.
- Maintain excellent working relationships with and serve as a liaison to state agencies.
- Develop and distribute technical assistance, training, resource and educational materials, planning and process guidelines, and other information to support the Child Death Review Program.
- Develop new relationships with and collaborate with community and statewide groups to enhance the Child Death Review Program.
- Promote and represent the (insert state) Child Death Review Program at local, state and national meetings and trainings.
- Oversee State Child Death Review Advisory Committees, including project communications, organization of meetings and telephone conferences, and writing and production of minutes, summaries, and reports.
- Coordinate with other state fatality review programs.

Education: Masters degree preferred, in the health or human services field, with specific training and education in child, adolescent and family health. Demonstrated knowledge base in statistics; epidemiology; community health services; and child safety, health and protection.

Experience: Three to five years minimum, and progressively more responsible, experience in the health or human services, with related program development; administration and supervision of personnel; evaluation; project development; budgeting, grant management, funding procurement and training. At least one year experience as a supervisor and one year experience as a program manager.

Important Skills and Characteristics: Excellent and demonstrated written and oral communications; strong interpersonal skills related to diverse populations in academic, public health and community settings. Excellent skills in public speaking. Ability to work productively in fast-paced environment with multiple, competing deadlines.

Agenda for First Planning Meeting

State or Community Name
Child Death Review Team Organizational Meeting
Date of Meeting
Location of Meeting

1. Welcome and introductions
2. Overview of purpose and history of child death review teams
3. Description of how a review team operates
4. How are children dying in our community? Presentation of child mortality data
5. Community response to a child's death: What actions occur when a child dies? What are the roles and responsibilities of agencies?
6. Benefits of implementing a review team
7. What will our team look like?
    a. Immediate or periodic review system?
    b. What types of cases will we review?
    c. How will we know when a child has died?
    d. When and where will we meet?
    e. What members should be involved?
    f. Who will coordinate the team?
    g. Who will facilitate the review meetings?
8. Discussion of confidentiality statements and interagency agreements to participate
9. Agenda items and materials for next meeting
10. Schedule next meeting
11. Adjourn

New Team Member Letter of Invitation

(Date)

Dear (Insert Name):

Child Death Review is a multidisciplinary process to help us better understand why children in our community die and to help us identify how we can prevent deaths. The child death review program in (state/community) has been in place since (year). Our team meets (frequency of team meetings) to review (type) deaths to children, ages (review age range). Team members share case information on child deaths that occur in the community with the goal of preventing other deaths. In order for this process to be successful, all agencies involved in the safety, health and protection of children should be part of the team. Therefore, we would like you to consider participating on the Child Death Review Team.

Included in this mailing are the team roster, an executive summary of last year's annual report based on review team findings and a team protocol book that covers all aspects of the review process. These materials should familiarize you with the review process in our community.

The death of a child is a tragic event. Reviewing the circumstances involved in every death is part of our job as professionals. Only then can we truly understand how to better protect our children and prevent future deaths from occurring.

Our next meeting is scheduled for (time and location of next meeting). I will contact you in a few days to discuss the review process and to answer any questions that you might have. Thank you for your time and interest in the child death review process.

Sincerely,

Team Coordinator's Name and Contact Information

Local Review Team Interagency Agreement

This cooperative agreement is made this _______day of _______between each of the following agencies:

____
for the Office of the Medical Examiner/Coroner

____
for the Child Protective Services Agency

____
for the Office of the Prosecuting Attorney

____
for the Sheriff's Department

____
for the State/Local Police Department

____
for the County/State Health Department

____
List Others as Needed

WHEREAS, the parties are vested with the authority to promote and protect the public health and safety and to provide services which will improve the well-being of children and their families.

WHEREAS, the parties agree that they are mutually served by the establishment of a multi-agency, multi-professional Child Death Review Team, and the outcomes of the reviews will be the identification of preventable child deaths and recommendations for interventions and prevention strategies.

WHEREAS, the objectives of a Child Death Review Team are agreed to be:

1. The accurate identification and uniform reporting of the cause and manner of every child death.

2 Improved communication and linkages among agencies and enhanced coordination of efforts.

3. Improved agency responses to child deaths in the investigation and delivery of services.

4. The design and implementation of cooperative, standardized protocols for the investigation of certain categories of child deaths.

5. The identification of needed changes in legislation, policy and practices, and expanded efforts in child health and safety to prevent child deaths.

WHEREAS, the parties agree that all members signing this agreement are essential to an effective review.

WHEREAS, the parties agree that the review process requires case specific sharing of records, and that confidentiality is inherent in many of the involved reports so that there will be clear measures taken to protect confidentiality, and no case review will occur without all present abiding by the confidentiality agreement, in accordance with ______________________ (applicable legislation).

NOW THEREFORE, it is agreed that all team members and others present at a review will sign a confidentiality agreement which prohibits any unauthorized dissemination of information beyond the purpose of the review process. The review team will not create any files with case specific identifying data. Case identification will only be utilized to enlist interagency cooperation in the investigation, delivery of services, and development of prevention initiatives. It is further understood that there may be an individual case which requires that a particular agency be asked to take the lead in addressing a systemic or quality of care issue based on the agency's clear connection with the issue at hand. It is further understood that the Office of the Prosecuting Attorney may use information obtained during the review to pursue prosecution if it appears that a crime may have been committed. It is also understood that team review data will be submitted to _________________________, where it will be maintained for the purpose of establishing a state central registry for child death data. The aggregate data will not include case-specific names. The registry will include standardized data from child death review teams, under the authority of the _________________________ ___________________________ (sponsoring agency of CDR).

Review Team Confidentiality Agreement

The purpose of a Child Death Review Team is to conduct a thorough examination of each child death in ____________ jurisdiction by the ___________ named Child Death Review Team.

In order to assure a coordinated response that fully addresses all systemic concerns surrounding child fatalities, all relevant data, including historical information concerning the deceased child and his or her family, must be shared at team reviews. Much of this information is protected from disclosure by law, especially medical and child abuse/neglect information. Therefore, team reviews are closed to the public, and confidential information cannot be lawfully discussed unless the public is excluded. In no case should any team member or designee disclose any information regarding team decisions outside the team, other than pursuant to team confidentiality guidelines. Failure to observe this procedure may violate various confidentiality statutes that contain penalties. Any agency team member may make a public statement about the general purpose or nature of the child death review process, as long as it is not identified with a specific case.

The undersigned agree to abide by the terms of this confidentiality agreement.

Name	Agency
________________________________	____________________________________
________________________________	____________________________________
________________________________	____________________________________
________________________________	____________________________________
________________________________	____________________________________
________________________________	____________________________________
________________________________	____________________________________
________________________________	____________________________________
________________________________	____________________________________
________________________________	____________________________________

Confidentiality Statement

The purpose of the Child Death Review Team is to conduct a thorough review of all preventable child deaths in ___________________ (jurisdiction) in order to better understand how and why children die and to take action to prevent other deaths.

In order to assure a coordinated response that fully addresses all systemic concerns surrounding child deaths, all relevant data should be shared and reviewed by the team, as permitted by law, including historical information concerning the deceased child, his or her family, and the circumstances surrounding the death. Much of this information is protected from public disclosure by law.

_____ (state your statute) stipulates in no case will any team member disclose any information regarding team discussion outside of the meeting other than pursuant to the mandated agency responsibilities of that individual. Failure to observe this procedure may violate various confidentiality statutes that contain penalty. Public statements about the general purpose of the child death review process may be made, as long as they are not identified with any specific case.

The undersigned agrees to abide by the terms of this confidentiality policy.

List names and signatures

Letter Requesting Assistance of the County Clerk

Dear County Clerk:

We have established a Child Death Review Team, under the auspices of the ___________________________________. Our team is a multidisciplinary, interagency group of professionals meeting regularly to review the deaths of children in the ___________________ (name of jurisdiction).

The purpose of the review is to improve our understanding of how and why children die and to develop recommendations to improve our response to child deaths and to develop prevention initiatives to keep children safe.

We need your assistance in identifying all of the children who die in _____________county. We understand that your office is mandated to submit all death certificates to the Office of the State Registrar. We are asking that you maintain a listing of all child deaths or make a duplicate copy of the death certificates on all child deaths, prior to sending the certificates on to the State. This will ensure that we are able to review all deaths in a timely manner. As the team coordinator, I will be contacting you regularly to obtain these names.

I will be contacting you in the next few days to work out an arrangement with you. We are looking forward to renewing our commitment to the health, safety and protection of our children.

Sincerely,

Team Coordinator's Name and Contact Information

Request for Medical Records

Some teams may operate under legislation that gives them access to medical records for cases being reviewed. The following form may assist in obtaining those records.

MEMORANDUM

CONFIDENTIAL

Date: ______________________

To: ______________________

From: ______________________

______________________(applicable legislation) states that providers of medical care shall provide medical information regarding a child whose death is being reviewed by a Child Death Review Team. Pursuant to this Act, the ___________Child Death Review Team requests the medical records on the following deceased children who we believe have been seen at your facility.

Name Date of Birth Date of Death Approximate Date(s) of Evaluation

____

____

____

____

____

If you have any questions, please call ____________________________________.

Thank you for your assistance.

Request for Cross-Jurisdictional Assistance

Dear Child Death Review Coordinator (or Investigator):

It has come to the attention of our Child Death Review Team that we may share interest in obtaining information related to the death of a child. We would appreciate your assistance in the following manner:

☐ The child is a resident of our county, but died in your county. Our team would like you to provide us with information on the circumstances of the death, including:

- ___ Autopsy
- ___ Death Scene Investigation
- ___ EMS Run report
- ___ Crash Report
- ___ Fire Report
- ___ Child Death Review Team Report

☐ The child died in our county, but is a resident of your county. Our team reviewed the death. If your team would like access to our review findings, we would be happy to provide it to you upon request.

☐ The child died in our county, but is a resident of your county. As such, your team will likely be reviewing the death, pursuant to state law ____. We would also like to review this death, to better understand the circumstances and how our community can ensure that similar deaths may be prevented. We would like you to provide us with your Child Death Review Team findings.

Attached is the information that we have on the child's death. Thank you for your attention. You may contact me at _________________________.

Sincerely,

Your Name

Information on the Child:

County of Death __________________ Name of Child _________________________________

Mother _____________________________ Father_____________________________________

Resident Street Address____

City, State, Zip ____

Date of Death____________________ Age at Death ____Yrs ____Days ____Hrs ____Min

Date of Birth ____________________ Race_____ Sex____ Autopsy ______Yes _____No

Medical Examiner/Coroner ______________________________ Phone: __________________

Lead Investigator/Agency: _____________________________ Phone: __________________

Cause of Death ____

Other key information regarding circumstances of death, please describe in detail:

Child Death Review Team Meeting Agenda

State or Community Name
Child Death Review Team Meeting Agenda
Date of Meeting
Location of Meeting

1. Welcome and introduction of members
2. Updates on state/national child death review programs and issues
3. Reminder of team purpose and confidentiality requirements
4. Completion/follow-up of reviews from last meeting
5. New cases for review
    a. Share, question and clarify case information.
    b. Discuss the investigation.
    c. Discuss services.
    d. Identify risk factors.
    e. Recommend system improvements.
    f. Identify prevention opportunities and plan actions to initiate.
6. Progress report on recommendations made from previous review meetings
7. Date and time of next meeting

Meeting Summary Sheet

This sheet should be prepared 2-3 weeks prior to a review meeting and distributed to all team members so they may conduct a proper search of their records for pertinent case information.

Child Death Review Team
Cases for Review _________(Date of Meeting)

Review # ☐

Name of Child ____

Mother ________________________________ Father___________________________________

Street Address____

City, State, Zip____

Date of Death_______________ Age at Death ____Yrs ____Days ____Hrs ______Min

Date of Birth ________________ Race_____ Sex______ Autopsy _____Yes ____No

Doctor's Name ______________________________ Place of Death_______________________

Cause of Death ____

Special Considerations____

CONFIDENTIAL

Review # ☐

Name of Child ____

Mother ________________________________ Father___________________________________

Street Address____

City, State, Zip____

Date of Death_______________ Age at Death ____Yrs ____Days ____Hrs ______Min

Date of Birth ________________ Race_____ Sex______ Autopsy _____Yes ____No

Doctor's Name ______________________________ Place of Death_______________________

Cause of Death ____

Special Considerations____

Review # ☐

Name of Child ____

Mother ________________________________ Father___________________________________

Street Address____

City, State, Zip____

Date of Death_______________ Age at Death ____Yrs ____Days ____Hrs ______Min

Date of Birth ________________ Race_____ Sex______ Autopsy _____Yes ____No

Doctor's Name ______________________________ Place of Death_______________________

Cause of Death ____

Special Considerations____

Child Death Review Team Meeting Tracking Table

State or Community Name
Child Death Review Team
2004 Reviews and Recommendations

Date of Review	Child's Name	Age	Cause of Death	Team Recommendation(s)	Follow up	Action Taken
01/16/2004	John Smith	17 yrs	Motor vehicle crash	State needs to enact primary seatbelt enforcement legislation.	Contacted state legislators.	Team wrote a letter supporting this legislation. Each team member wrote his or her representative. Contacted state program office to encourage other review teams to advocate for this bill.
01/16/2004	Jane Doe	12 yrs	Asthma	Children and families need education on asthma treatment and recognizing severity of attacks.	Created task force to review current info provided to patients.	Task force has met twice. Reviewing data on asthma deaths, protocols for treatment and management plans.
02/20/2004	Jill Doe	15 yrs	Suicide	Area schools lack plans, resources for students in crisis.	Team rep from Intermediate School District gathered data, resource information to present to area schools.	Two schools are writing protocols for identifying and referring students who need help; new relationships with local resources have been formed; select staff will attend training to support new protocols.
03/19/2004	Jim Doe	4 mos	Suffocation	Safe sleep campaign still not reaching all populations. Need to better target those most at risk.	Contacted local churches, shelters, day care centers to discuss issue. Representatives plan to attend next meeting for brainstorming session.	

Advisory Board Description of Purpose & Function

Purpose: In accordance with Public Act (or agency rules) to support the name of your program by providing guidance, expertise, and consultation in analyzing and understanding the causes, trends, and system responses to child fatalities, and to make recommendations in law, policy and practice to prevent child deaths in jurisdiction.

Function: The committee will meet to:

- Advise the governor, legislature, state agencies and the public on changes in law, policy and practice to prevent deaths to children and improve the overall health and safety of jurisdiction's children.
- Recommend systems improvements in policy and practice for state and local agencies in order to improve their effectiveness in identifying, investigating, responding to and preventing child fatalities.
- Provide support and expert consultation to local child death review teams.
- Recommend improvements in protocols and procedures for the (name of your program).
- Review jurisdiction's child mortality data and local child death review team reports to identify causes, risk factors and trends in child fatalities.
- Provide an annual report on child fatalities, to include mortality data, State Advisory Board recommendations and an overview of the (name of your program).

Administration and Support to the Team: The ______ Agency will have administrative responsibility for the team. A chair(s) will be designated by the Director of _____ to provide leadership for the team. This person(s) will have broad state-level experience in child health, safety and protection and demonstrated leadership abilities. The _________ will provide staff support and manage the operations of the program.

Meeting Schedule: The committee will meet quarterly.

Composition of the Committee: The Director of the Agency will appoint representatives from: (List agencies).

Additional members could include persons from: (List agencies).

State Advisory Board Agenda

(Insert state) Child Death Review Team Meeting Agenda
Date of Meeting
Location of Meeting

1. Welcome and introduction of members

2. Review mandate, goals and objectives of state advisory team

3. Program updates

   a. County teams
   b. Annual report
   c. Budget information
   d. New research publications
   e. Pending legislation relevant to child health, safety and protection
   f. News from other state program and the National Center for Child Death Review

4. Teen driving deaths
   a. Division of Motor Vehicles presentation on graduated licensing state requirements
   b. Department of Education presentation on drivers education curriculum
   c. Child Death Review Program findings on teen driving deaths
   d. Discussion of recommendations to prevent future deaths

5. Date and time of next meeting

Child Death Review Annual Report Outline

1. Executive Summary including recommendations and the Child Death Review process
    - Conducting a local review
    - Review outcomes
    - State support
    - The State Child Death Advisory Board
    - Recommendations for policymakers to improve the CDR process

2. Summary of Child Mortality Data, including Numbers and Rates for all Deaths.

3. Child Death Review Team Findings for All Deaths
    - By key indicators, including age, gender, race and ethnicity, income, preventability, level of supervision, and other critical indicators of wellbeing or risk.

4. Summary of Child Mortality Data including Numbers and Rates, by Specific Manner and Cause and Summary of Child Death Review Findings by Specific Manner and Cause
    - For every section include:
        - Mortality data by year and trends over ten years if possible
        - A general description of the cause of death, relative to national data, key risk factors, known proven interventions to prevent the deaths, and resources available for more information
        - Breakdowns by age, race, ethnicity and gender
        - Key risk factors identified through the review process and the numbers and rates of each
        - Actions taken as a result of the reviews locally or at the state level
        - Recommendations for state and local leaders
        - Recommendations for parents and caregivers

    - Grouping could follow this sequence:
        - Natural Deaths
            - Overview of natural child deaths, ages 0-18
            - Natural infant deaths excluding SIDS, ages 0-1
            - Sudden Infant Death Syndrome
            - All causes of natural child deaths, ages 1-18
        - Accidents (Unintentional Injuries)
            - Overview of accidental child deaths, ages 0-18
            - Accidental - motor vehicle
            - Accidental - suffocation and strangulation
            - Accidental - fire and burn
            - Accidental - drowning
            - Accidental - firearm
            - Accidental - other causes

Homicides
- Overview of child homicides, ages 0-18
- Homicide - firearm and weapon
- Homicide - child abuse and neglect
- Homicide - other causes

Suicide
- Overview of child suicides, ages 0-18
- Suicide – firearm and weapon
- Suicide – suffocation/strangulation
- Suicide – other causes

Undetermined
- Overview of undetermined child deaths, ages 0-18

5. Appendices
   - List of figures and tables
   - Number of cases reviewed and reported by teams.
   - Total number of deaths among state residents, ages 0-18, by county of residence and age group
   - Total number of deaths among state residents, ages 0-18, by county of residence and year of death
   - Local Child Death Review Team coordinators

CDR Legislation Checklist

Use this list to evaluate your current or planned CDR program legislation. This list can help you identify possible elements you not included in your bill.

- **Purpose –** In developing the purpose of the team it will be important to consider whether establishment of teams will be mandated or permitted by the legislation enacted.
  - ❑ Prevention
  - ❑ Identification of fatalities resulting from abuse and neglect
  - ❑ Improvements in agencies' function
  - ❑ Education of Public and of Professionals Working with Children
  - ❑ Other

- **Funding –** This is one of the most difficult issues in developing or expanding teams. One issue to consider is funding through the Children's Justice Act, which is administered by the U.S. Department of Justice. Such funds are often used to establish or support child death review teams.
  - ❑ State
  - ❑ Local
  - ❑ Private
  - ❑ Staffing and support resources for CDR

- **Membership –** Teams should consider racial, ethnic and cultural representation, which will reflect the community in which the team or teams operate.
  - ❑ Composition specialties represented may include:
    - Coroner/Medical Examiner (consider training and background when selecting one and/or the other)
    - Law Enforcement
    - Public Health/Injury Prevention
    - Mental Health
    - Social Services
    - Child Advocacy (non-governmental)
    - Public Education
    - Child Health (e.g., pediatrician)
    - Criminal Justice
    - Tribal Representative or Military Representative if relevant
    - Emergency Medicine/First Responders
  - ❑ Appointed/designated
  - ❑ Role related to public office (e.g., state's attorney)
  - ❑ Mandated (e.g., professions or groups that must be represented)
  - ❑ Training provided to members (local or state)
  - ❑ Compensation (reimbursement, per diem)
  - ❑ Structure (e.g., Is there a hierarchy, voting, etc.)
  - ❑ Term of service

- **Case Review Process** – Specificity with respect to the process of case review will vary from state to state. Below are some of the factors to consider as components of the case review process. Whether these elements should or need to be statutorily mandated will need to be considered and will depend upon the existing or desired process in the jurisdiction.
  - Frequency of meetings (quarterly, monthly, ad hoc, other)
  - "Trigger mechanism" (criteria for review, referral source, age of child, cause of death, jurisdiction)
  - Autopsy requirements
  - Protocol development
  - Standard definitions
  - Mandatory or permissive case review
  - Level of activity -- state, regional, and/or local
  - Evaluation of team function
  - Criteria for Scene Investigation/Preservation

- **Authority/Impact** – Teams can serve various functions and the legislation that enables team development may also be helpful in spelling out what authority the teams, through the review process may have.
  - Legislative (evaluation of laws, recommendations, enactments)
  - Public health (including development and implementation of preventive programs)
  - Contribution to epidemiological research/data
  - Individual case influence
  - Where is CDR housed – This is an important political and budgetary consideration.
  - Evaluation of agency function

- **Data Collection and Dissemination** – In order to conduct a comprehensive review, teams need access to records and reports that may be relevant to the fatality. This becomes increasingly important with respect to intrastate coordination among the local teams.
  - What is collected? (data from other agencies, law enforcement reports, medical records, interviews)
  - Dissemination of data (annual report, frequency of reporting, media outlets, public forums)
  - Database
  - Standardized reporting forms
  - Training to agencies and/or professionals (not other CDR teams)
  - Missing data (process for follow-up)

- **Data Sharing** – Legislation needs to contemplate facilitating access to a range of information particularly between border states and within and between agencies while still maintaining and abiding by existing rules and regulations addressing privacy and confidentiality. Additionally, to enhance and encourage the free flow of information among team participants; issues such as immunity, subpoenability of members or records and discoverability of team documents should be addressed in legislation as well as the issue of confidentiality of team deliberations and discussions.
  - Uniformity, coordination and sharing of data (intra-agency, interagency, among state, regional and local teams, regional/interstate)
  - Legislative requirements and prohibitions (punitive measures for confidentiality violations)
  - Privacy and confidentiality (identifiers; open/closed meetings)
  - Immunity

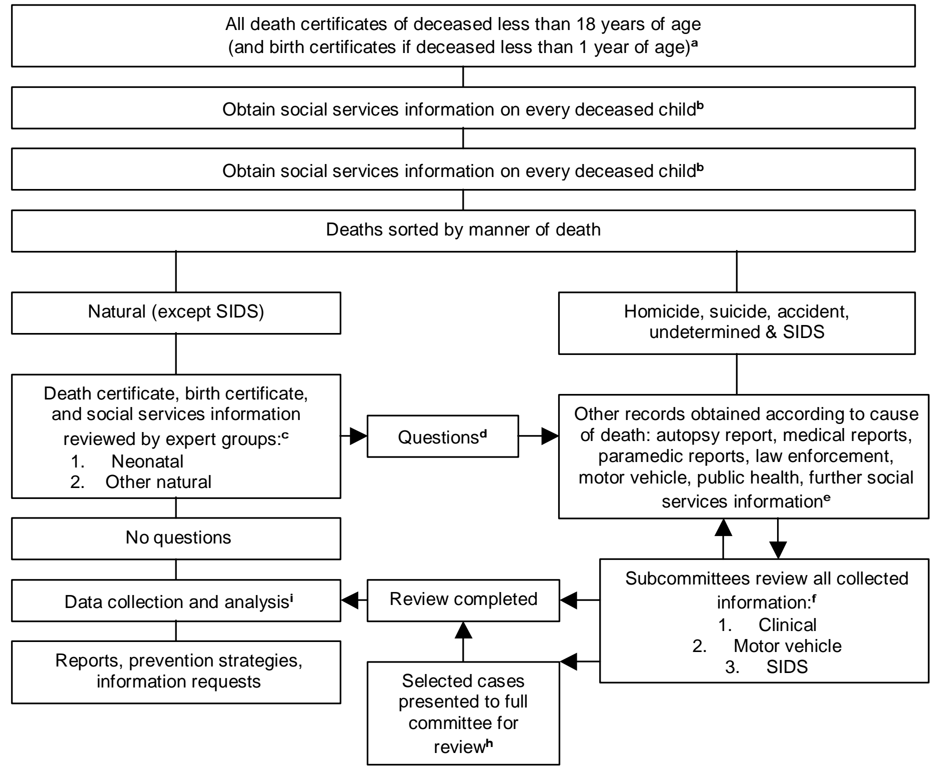
Prevention Matrix

Selecting a prevention activity can be difficult. The following model can assist your Child Death Review team in strategizing various approaches to preventing child injuries and deaths. To lead your prevention discussion, take each activity suggested by your team and weigh the suggestions listed in the following table. Encourage your team to come up with as many ideas as possible.

	Activity 1	**Activity 2**	**Activity 3**
Effectiveness			
Ease of implementation			
Cost			
Sustainability			
Community acceptance			
Political reality			
Unintended Consequences			

- **Effectiveness**: Will this activity be effective in reducing injury or death to children? Why or why not?
- **Ease of implementation**: Is this activity feasible? How much effort is needed to implement this activity? What steps would be involved?
- **Cost:** How much would this activity cost and how would it be funded? Would it be too expensive?
- **Sustainability**: How long could this intervention last? Who will oversee the intervention in the long term?
- **Community acceptance:** Is this activity unpopular in the community? Does the community understand the problem the CDR team is attempting to address? If not, should the team attempt to inform the community?
- **Political acceptability**: Are there any political issues that this activity would face?
- **Unintended consequences**: If this activity is implemented, what consequences or risks may develop as a result?

After going through this process with each activity, teams should select the activity that is most effective, feasible, affordable, sustainable and politically acceptable with the least amount of unintended consequences.



Notes:
Colorado Child Fatality Review Process

a. Birth and death certificates are obtained through the Colorado Dept of Public Health and Environment, Division of Health Statistics and Vital Records.

b. Social services information is obtained by searching two statewide databases: 1) Child Welfare Services Tracking (CWEST), 2) Central Registry, which has information on all founded cases of abuse or neglect. These are searched by child's name, any known AKAs, siblings' names and parents' names.

c. "Neonatal" expert group reviews all natural child deaths occurring at less than 28 days of age. "Other Natural" expert group reviews all other natural manner deaths (except SIDS).

d. If the expert groups have questions about any death that has been signed out as natural manner (except SIDS), the case is passed to the clinical subcommittee for more in-depth review. The questions are:
- Inadequate or inaccurate death certificate?
- Inadequate death investigation?
- Access to/adequacy of medical care?
- Preventable death?

e. Records (autopsy, medical, paramedic, law enforcement, motor vehicle, public health and further social services info) are obtained as necessary and available for review by clinical / other subcommittees.

f. "Clinical" subcommittee reviews all homicide, suicide, accident (except motor vehicle-related) and undetermined manner deaths, as well as any natural, motor vehicle or SIDS deaths referred back from expert and other clinical groups. "Motor Vehicle" subcommittee reviews all motor vehicle-related deaths. "SIDS" subcommittee reviews all SIDS deaths.

g. On occasion, the clinical subcommittee review raises more questions and further information is requested.

h. Cases selected for presentation to the full Child Fatality Review Committee are: all cases of neglect or abuse; cases which highlight system failures or policy issues (the committee may recommend strategies for avoiding such failures in the future); some cases which suggest preventive strategies; cases which suggest new death patterns; and cases for which the clinical subcommittee requests the broader professional expertise of the full committee.

i. Data is collected and analyzed through the data subcommittee and the Colorado Department of Public Health and Environment. Preventable deaths precipitate collection of additional data.

Missouri's Local Review Process

Any child, birth through age 17, who dies will be reported to the coroner/medical examiner

The coroner/medical examiner conducts a death scene investigation, notifies the Child abuse hotline and completes Data Form 1. The coroner/medical examiner, along with a certified child-death pathologist will determine the need for an autopsy

If an autopsy is needed, a certified child-death pathologist performs it. Results are brought to the child fatality review panel by the coroner/medical examiner, if reviewable criteria are met.

If the death is not reviewable, Data Form 1 is completed by the coroner/medical examiner. This persons sends the Data Form 1 to the chairperson of the child fatality review panel for co-signature. The chairperson sends the Data Form 1 to the state STAT within 48 hours.

State STAT reviews for accuracy and completeness; signs and sends Data Form 1 to STAT which links it to the Department of Health and Senior Services birth and death data.

If the death is reviewable, the coroner/medical examiner sends the Data Form 1 to the chairperson of the child fatality review panel for co-signature. This person sends the form to STAT within 48 hours. The person refers the death to the child fatality review panel.

The chairperson schedules the panel meeting as soon as possible. The panel reviews the circumstances surrounding the death and takes appropriate actions. The Data Form 2 is completed, co-signed by the chairperson and sent to STAT within 60 days. Within ten days of completion of the review, filing of criminal charges or the determination of criminal charges not being filed, the final report must be sent to STAT.

STAT links Data Forms 1 and 2 to the Department of Health and Senior Services birth and death data. Panel members pursue the mandates of their respective agencies.

Guides to Effective Child Death Reviews

To help teams take action to prevent child deaths

Developed by
The National MCH Center for Child Death Review

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(Title V Social Security Act) Health Resources and Services Administration
Department of Health and Human Services

Additional copies may be downloaded at www.childdeathreview.org

Guides to Effective Reviews

The goal of Child Death Review is to understand why children die and to take action to prevent other deaths.

Using the Guides

These guides can be used as you review specific causes of child deaths. Use the guides to help determine what records should be brought to your meeting, what risk factors to evaluate, the types of services your team should ensure are provided, and evidence-based prevention activities your team may consider.

Effective review team meetings require team members to:

- Come prepared with information on the deaths to be reviewed
- Share their information openly and honestly
- Seek solutions instead of blame

At each case review, members should seek to answer:

- Is the investigation complete, or should we recommend further investigation? If so, what more do we need to know? Do we need to discuss it at our next meeting?
- Are there services we should provide to family members, other children and other persons in the community as a result of this death?
- Could this death have been prevented and if so, what risk factors were involved in this child's death?
- What changes in behaviors, technologies, agency systems and/or laws could minimize these risk factors and prevent another death?
- What are our best recommendations for helping to make these changes?
- Who should take the lead in implementing our recommendations?
- Is our review of this case complete or do we need to discuss it at our next meeting?

Effective Reviews – Natural Deaths to Infants

Facts

- Natural deaths to infants comprise the largest group of child deaths. These include deaths due to congenital anomalies, infants born prematurely and of low birth weight, respiratory complications, infections and other medical conditions.
- Infant death rates are calculated differently than other child death rates. They are the number of deaths per 1,000 live births.
- The greatest numbers of natural deaths are infants who die within the first 24 – 48 hours of life. Black infants are more than twice as likely to die in their first year than white infants.
- Many infant deaths can be prevented through improvements to maternal prenatal health.
- Prematurity refers to infants born at less than 37 weeks gestation, and low birth weight refers to infants weighing less than five pounds, five ounces at birth.

Records Needed

- Public Health birth records
- Health records for well and sick visits and immunizations
- Death certificates
- Prenatal care records
- Hospital birth records
- Emergency Department records
- Any support services utilized, including WIC and Family Planning
- Police reports
- Prior CPS reports on caregivers
- Maternal home interview, if available
- Home visitation reports

Risk Factors

- Prior pre-term delivery.
- Previous infant or fetal loss.
- Inadequate prenatal care (late entry, missed appointments).
- Medical conditions of the mother.
  - Maternal age (under 20, over 35)
  - Infections, including sexually transmitted (STI)
  - Hypertension
  - Diabetes
  - Poor nutritional status
  - Obesity
  - Short inter-pregnancy interval
- Poverty.
- Substance, alcohol or tobacco use.
- Stressors and/or lack of social support.
- Less than 12th grade education.
- Unintended pregnancy.
- Unmarried or lack of male involvement in pregnancy.
- Physical and/or emotional abuse of mother.

Services to Consider

- Bereavement services.
- Specialized burial services for stillborn or fetal deaths.
- Preconception and pregnancy planning for families that have lost infants.
- Specialized services for surviving siblings.
- Genetic counseling for certain congenital anomalies.

Improvements to Agency Practices

- Much of prevention is closely related to agency practices surrounding maternal health. Many practices are considered prevention and described in the next section.

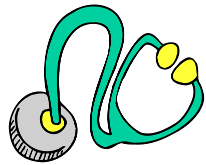
Effective Prevention Services/Actions

- Ensure that all women have available preconception care and counseling and prenatal care that is acceptable, accessible and appropriate.
- Ensure that all women have postpartum care options available that include contraception, pregnancy planning and preconception care.
- Improve local provider knowledge of preconception health care issues.
- Improve emergency response and transport systems.
- Foster maternal and infant support services to improve the social/psychological environment for women and families at risk.
- Encourage the comprehensive assessment of risks due to STIs, substance abuse including alcohol, smoking, domestic violence, depression, social support, housing, employment, transportation, etc. by all local providers and perhaps as a local hospital delivery policy.
- Develop and distribute community resource directories to make consumers and providers aware of where to go for help and services.
- Provide mentoring, support, outreach and advocacy at the community level utilizing paraprofessionals, indigenous health workers and faith-based initiatives.
- Develop systems to provide transportation and childcare to women seeking prenatal care.
- Coordination of care between programs and parts of the health care system.
- Forums to raise awareness of consumers, providers and policy makers of infant mortality issues.
- Local community/business/health care partnerships to broaden the number of stakeholders.
- Enhanced community education to include unplanned/unwanted pregnancy prevention, including teen pregnancy prevention services and early detection of signs and symptoms of pre-term labor.

For More Information

- National Fetal and Infant Mortality Review Program
  www.acog.com
- March of Dimes
  www.modimes.org

Effective Reviews - Natural Deaths Ages 1 - 18



Facts

- Death from natural causes is the second leading cause of mortality to children over one year of age, following unintentional injuries.
- Cancer, congenital anomalies and cardiac conditions are the top three causes of natural death.
- Fatalities from illnesses such as asthma, infectious diseases and some screenable genetic disorders, under certain circumstances, can and should be prevented.
- Failure to seek medical care for ill children can be fatal in some instances.

Records Needed

- Public Health birth records
- Pediatric records for well and sick visits
- Death certificates
- Hospital birth records
- Emergency Department records
- Public Health immunization records
- Names, ages and genders of other children in home
- Police reports
- CPS reports on caregivers and child
- Home visitation reports
- ISD records, if applicable

Risk Factors

- Children with chronic health conditions or congenital anomalies.
- Exposure to environmental hazards, especially of vulnerable children.
- Non-compliance with prescribed treatment regimens.
- Parental or caregiver failures to seek adequate medical attention.

Services to Consider

- Bereavement services.
- Specialized services for surviving siblings.
- Crisis responses for friends of decedent, including in schools.

Improvements to Agency Practices

- Were services in place for chronically ill children?
- Were referrals made and followed up for repeat health care visits and other care?
- Were efforts made to obtain full complement of available public services for eligible families?
- Was investigation coordinated with CPS and other agencies?
- Was death referred to medical examiner if medical neglect was suspected?

Effective Prevention Actions

- Provide coordinated wrap-around services for chronically ill children.
- Develop community education campaigns surrounding chronic health problems in children, such as asthma.
- Ensure that schools are provided sufficient information and training for children with chronic health problems.
- Conduct assessments and seek removal of suspected environmental health hazards.

For More Information

- American Academy of Pediatrics
  www.aap.org
- American Lung Association
  www.lungusa.org
- Easter Seal Society
  www.easter-seals.org
- March of Dimes
  www.modimes.org

Effective Reviews – Asthma

Facts
- Asthma affects approximately five million children a year in the U.S. The asthma death rate for ages 19 years and younger increased by 78% between 1980 and 1993, many believe due to environmental conditions.
- Asthma is one of the most common chronic diseases of childhood.
- An estimated 4 million children under 18 years old have had an asthma attack in the past 12 months.
- Asthma fatalities can usually be prevented.
- The asthma death rate for ages 19 years and younger increased by 78% between 1980 and 1993, many believe due to environmental conditions.
- Failure to seek medical care for asthmatic children can be fatal.
- Even though asthma cannot be cured, it can almost always be controlled.

Records Needed
- Death certificates
- Pediatric records for well and sick visits, including info on medications prescribed, asthma management plan, pulmonary function testing, specialty referrals
- Emergency Department/EMS records
- Any support services, such as school asthma management programs
- CPS reports on caregivers and child

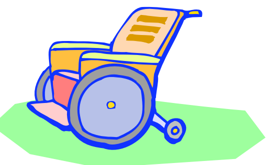
Risk Factors
- Lack of steroid inhalers or peak flow meters.
- African-American and low-income children; children with allergies.
- Children living in crowded conditions, which leads to increased exposure to allergens and infections.
- Exposure to environmental hazards such as tobacco smoke, air pollution, strong odors, aerosols and paint fumes.
- Non-compliance with prescribed treatment regimens.
- Parental or caregiver failures to recognize seriousness of attacks and seek adequate medical attention.

Services to Consider
- Bereavement services for family and friends.
- Crisis responses for friends of decedent, including in schools.

Improvements to Agency Practices
- Were referrals made and followed up on for health care visits for poorly controlled asthma and other care?
- Were efforts made to obtain full complement of available public services for schools and eligible families?
- Was investigation coordinated with CPS and other agencies?
- Was death referred to medical examiner if medical neglect was suspected?
- If the child was in foster care, were there asthma triggers present in the foster home?

Effective Prevention Actions
- Develop community education campaigns regarding childhood asthma.
- Ensure that schools are provided sufficient information and training to respond to students' asthma attacks.
- Conduct assessments and seek removal of suspected environmental health hazards.
- Educate health care providers on the need to prescribe corticosteroids, the need for timely referrals to specialists and the need to limit refills for rescue medications without a physician visit or attention.
- Educate parents and children on the severity of asthma and its dangers.
- Develop system for pharmacies to notify practitioners of excessive bronchodilator use by their patients.

For More Information
- American Academy of Pediatrics
  www.aap.org
- American Lung Association
  www.lungusa.org
- Centers for Disease Control and Prevention
  www.cdc.gov
- Allergy/Asthma Network Mothers of Asthmatics
  www.aanma.org



Effective Reviews – Children with Disabilities

Facts

- Based on underlying cause only, developmental disabilities are the 5th leading cause of non-traumatic death for children 1-14 years and 3rd leading cause for children 15-19 years.
- Nine percent of all children have disabilities.
- Child abuse is estimated to cause approximately 25% of all developmental disabilities in children.
- Children with disabilities are at the greatest risk of burn-related deaths and injury.
- Children with disabilities are abused at approximately twice the rate of children without disabilities.
- The most common form of homicidal event against children with cerebral palsy is starvation.
- Immobility is the single best predictor of mortality risk of children with disabilities, followed by feeding ability.
- Function, rather than diagnostic category, is most predictive of early mortality.
- Aspiration, constipation, dehydration and epileptic seizures are the four major health issues that can cause death in people with developmental disabilities. The 1st three can go unrecognized until major illness or death.
- Children with disabilities may not be able to express discomfort or indicate they don't feel well.
- It can be difficult to differentiate the disability from other signs of abuse.

Records Needed

- Autopsy reports
- Birth records if under age one
- Emergency Department records
- Police reports
- Prior CPS reports on caregivers
- Any support services utilized
- Medical records and medication records
- School records

Risk Factors

- Reduced mobility.
- Feeding difficulty.
- Feeding tube.
- Use of restraints.
- Quality of supervision / multiple supervisors.
- Competency of supervisor to manage disability.
- Poorly controlled seizures.
- Prematurity and extreme prematurity.
- Complex, uncommon medical issues.
- Parents not trained to recognize symptoms.
- Lack of medical continuity/follow-up by caretakers.
- Lack of suitable childcare.
- Unrecognized disability.

Services to Consider

- Bereavement services for parents and other family members.
- Burial payments for families needing financial assistance.

Improvements to Agency/School Practices

- Do professionals know how to appropriately manage and respond to disability?
- Are parents adequately educated to care for and manage disability and health safely, including use of medical equipment, and recognizing signs of distress and what reaction is needed?
- Is there a team approach to identify and respond to risk factors of children with disabilities?
- Are there appropriate autopsy protocols for children with disabilities?
- Do schools have effective information and training about disability, and adhere to best practices and use Positive Behavioral Services?
- Do newborns with disabilities leaving hospitals have care plans, service coordinators and follow-up plans?
- Were parents of children with disabilities in poverty referred to Medicaid, EPSDT and other free health insurance for children?
- Does child have access to effective medical care for complexity of disability?
- Did parents have sufficient support, including respite care?

Effective Prevention Actions

- Support parents adequately to provide safe, effective care.
- Collaborate among disability agencies and child abuse protection agencies.
- Educate caregivers, schools and other professionals to recognize health danger signs.
- Teach children with disabilities fire safety and survival skills and develop emergency plans for them.
- Train parents of children with disabilities on subjects of neglect and sexual abuse.
- Ban or closely regulate use of restraints for children with disabilities by schools, families and service agencies.
- Identify trends and direct training needs; recommend development and/or modification of provider policies; modify state policies to address systemic issues that are identified during review.
- Develop medical homes for children with disabilities using coordination of care model.

For More Information

- Easter Seal Society
  www.easterseals.com
- March of Dimes
  www.modimes.org

Effective Reviews - Sudden Infant Death Syndrome

Facts
- Sudden Infant Death Syndrome (SIDS) is the sudden death of an infant under one year of age, which remains unexplained after a comprehensive investigation. This must include an autopsy, examination of the death scene and review of the baby's health history.
- SIDS is a diagnosis of exclusion and can only be made if there is no other possible cause of death. If the death scene indicates there was a possibility of suffocation, SIDS should not be listed as the cause of death.
- Most SIDS occurs to babies between two and four months old, during winter months. African American and American Indian SIDS rates are two to three times higher than the white SIDS rate.
- The mechanism causing SIDS is still unknown, although it is believed that SIDS occurs when an infant is at a vulnerable age, is exposed to environmental risk factors and has a neural defect that prevents the child from responding to oxygen depletion.
- Although it is not known why placing babies on their backs to sleep reduces SIDS, the National Back to Sleep campaign has reduced the SIDS rate by more than half since 1994.

Records Needed at Review
- Autopsy reports
- Scene investigation reports and recreation photos
- Prenatal, birth and health records
- Interviews with family members
- Child Care Licensing investigative reports
- EMS run reports
- Emergency Department reports
- Prior CPS history on infant, caregivers and person supervising infant at time of death
- Criminal background checks on person supervising the infant at time of death
- Reports of home visits from public health or other services
- Any information on prior deaths of children in family
- Downloaded information from apnea monitors, if applicable

Risk Factors
- Infants sleeping on their stomachs.
- Soft infant sleep surfaces and loose bedding.
- Maternal smoking during pregnancy.
- Second-hand smoke exposure.
- Overheating.
- Prematurity or low birthweight.
- Place and position where child was sleeping or playing.
- Type of bedding, blankets and other objects near infant.
- Faulty design of cribs or beds.
- Number of and ages of persons sleeping with infant.
- Obesity, fatigue, or drug or alcohol use by persons supervising or sleeping with infant.
- Quality of supervision at time of death.
- Family's ability to provide safe sleep or play environment for infant.

Services
- Bereavement services for parents and other family members.
- Referral to SIDS alliance for professional and peer support.
- Provision of cribs or other beds for children still in home.
- Safety assessment by CPS if neglect was suspected.
- Burial payments for families needing financial assistance.
- Provide links to services such as family planning.
- Critical Incident Stress Debriefing for persons responding to scene.

Improvements to Agency Practices
- Are investigations coordinated with medical examiners, law enforcement and CPS?
- Are autopsy protocols in place, which include a process for sending scene investigation materials to the pathologist performing the autopsy?
- Are comprehensive scene investigations conducted at the place of death, as soon as possible, including scene reenactments and interviews?
- Are referrals made for bereavement services?
- Are high-risk families with newborns and young infants provided prevention services?
- Is a process in place to contact the Consumer Product Safety Commission when faulty products could be involved in causing a death?

Effective Prevention Actions
- Education at childbirth classes and in hospitals to expectant and new parents on safe infant sleep environments.
- In-hospital assessments by nurses with parents to assess a baby's sleep environment when it goes home.
- Crib distribution programs for families.
- Smoking cessation education and support for pregnant and parenting women and other caregivers.
- Working with hospitals and providers to make sure that every infant that leaves the hospital has a primary care provider established.
- The "Back to Sleep" campaign.
- Specific messages targeted to families and childcare providers who traditionally practice stomach sleep positions.
- Education to health care providers on giving guidance on SIDS risk reduction to parents and caregivers.
- Licensing requirements for child care providers on safe sleep environments and infant sleep positions.

For more information
- The National SIDS Resource Center http://www.sidscenter.org/
- The American Academy of Pediatrics http://www.aap.org/
- Consumer Product Safety Commission http://www.cpsc.gov/

Effective Reviews - Suffocation

Facts

- Suffocation is caused by either:
  - *Overlay:* a person who is sleeping with a child rolls onto the child and unintentionally smothers the child.
  - *Positional asphyxia*: a child's face becomes trapped in soft bedding or wedged or trapped in a small space such as between a mattress and a wall or couch cushions.
  - *Covering of face or chest:* an object covers a child's face or compresses the chest, such as plastic bags, heavy blankets or furniture.
  - *Choking:* a child chokes on an object such as a piece of food or small toy.
  - *Confinement*: a child is trapped in an airtight place such as an unused refrigerator or toy chest.
  - *Strangulation:* a rope, cord, hands or other objects strangle a child.
- Infants and toddlers are most often the victims.
- The majority of suffocations occur to children while sleeping in unsafe environments.
- It is difficult to distinguish an unintentional suffocation from SIDS or a homicide in young children. Autopsies and scene investigations are essential.
- Rates of infant suffocations are increasing as investigators better distinguish suffocation from SIDS.

Records Needed at Review

- Autopsy reports
- Scene investigation reports and photos
- Interviews with family members
- Child Care Licensing investigative reports, if occurred in child care setting
- EMS run reports
- Emergency Department reports
- Prior CPS history on child, caregivers and person supervising child at time of death
- Child's health history
- Criminal background checks on person supervising child at time of death
- Reports of home visits from public health or other services
- Any information on prior deaths of children in family
- Any information on prior reports that child had difficulty breathing
- Downloaded information from apnea monitors, if applicable

Risk Factors

- Place where child was sleeping or playing.
- Position of child when found.
- Type of bedding, blankets and other objects near child.
- Faulty design of cribs, beds or other hazards.
- Number of and ages of persons sleeping with child.
- Obesity, fatigue, or drug or alcohol use by persons supervising or sleeping with child.
- Quality of supervision at time of death.
- Child's ability to gain access to objects causing choking or confinement.
- If hanging, child's developmental age consistent with activity causing strangulation.
- Family's ability to provide safe sleep or play environment for child.
- Prior child deaths or repeated reports of apnea episodes by caregiver.

Services

- Bereavement and crisis services for family members and friends.
- Provision of cribs or other beds for children still in home.
- Safety assessment by CPS if neglect was suspected.
- Burial payments for families needing financial assistance.
- Critical Incident Stress Debriefing for persons responding to scene.

Improvements to Agency Practices

- Are investigations coordinated with medical examiners, law enforcement and CPS?
- Are autopsy protocols in place?
- Are comprehensive scene investigations conducted at place of death, as soon as possible, including scene reenactments and interviews?
- Are referrals made for bereavement and crisis services?
- Are high-risk families with newborns and young infants provided prevention services?
- Is CPS notified in cases of suspicious deaths?
- Is a process in place to contact Consumer Product Safety Commission if death involved consumer product?

Effective Prevention Actions

- Education at childbirth classes and in hospitals to expectant and new parents on safe infant sleep environments.
- In-hospital assessments by nurses with parents to assess babies' sleep environments.
- Culturally competent public education campaigns and coordination with the "Back to Sleep" campaign.
- Crib distribution programs for needy families.
- Education to professionals on risks of infant suffocation.
- Notification to CPSC and continued product safety recalls on choking and strangulation hazards.
- Licensing requirements for child care providers on safe sleep environments and infant sleep positions.

For More Information

- The National SIDS Resource Center http://www.sidscenter.org/
- The American Academy of Pediatrics http://www.aap.org
- Consumer Product Safety Commission http://www.cpsc.gov/

Effective Reviews – Fires and Burns

Facts
- Most fire-related deaths to children occur in house fires, and the cause of death is most often asphyxia due to smoke inhalation, not burns.
- Toddlers, especially African American and American Indian males, are most often the victims.
- The vast majority of fire deaths occur in low-income neighborhoods.
- Children playing with matches or lighters start most of the fires that kill children.
- Young children tend to hide from the fire, making it difficult for family members or rescue personnel to locate them.
- Functioning smoke alarms will almost always prevent fire fatalities.
- The risk of death in a fire increases significantly when the supervising adult is intoxicated.

Records Needed at Review
- Autopsy reports
- Scene investigation reports and photos
- Fire marshal reports that include source of fire and presence of smoke detectors
- EMS run reports
- Emergency Department reports
- Information on zoning or code inspections and violations
- Prior CPS history on child, caregivers and persons supervising child at time of death
- Names, ages and genders of other children in home
- Criminal background checks on persons supervising child at time of death
- Reports of home visits from public health or other services
- Any information on prior deaths of children in family

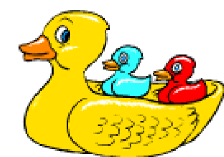
Risk Factors
- Lack of working smoke alarms in the home.
- Quality of supervision at time of death.
- Drug or alcohol use by supervising adults.
- Child's ability to gain access to lighters, matches or other incendiary devices.
- Members of household falling asleep while smoking or leaving candles burning.
- Victim's lack of exposure to fire safety education.
- Lack of a fire escape plan.
- Use of alternative heating sources, substandard appliances or outdated wiring.
- Failure of property owner to maintain code requirements.
- Timeliness of fire rescue response.

Services
- Bereavement and crisis services for family members and friends.
- Provision of emergency shelter for surviving family members.
- Safety assessment by CPS if neglect was suspected.
- Burial payments for families needing financial assistance.
- Critical Incident Stress Debriefing for persons responding to scene.

Improvements to Agency Practices
- Are investigations coordinated with medical examiner, police, fire marshal and CPS?
- Are referrals made for bereavement and crisis services?
- Are high-risk families with young children provided prevention services?
- Do well-baby or other routine health visits include information about smoke alarms?
- Is there a process in place to contact Consumer Product Safety Commission when faulty products lead to death?
- Do mental health providers routinely screen and provide treatment for child fire-setters?

Effective Prevention Actions
- Smoke alarm distribution programs that are targeted in low-income neighborhoods, providing non-removable, lithium batteries.
- Legislation requiring installation of detectors in new and existing housing, especially when combined with multifaceted community education and detector give-aways.
- *Risk Watch* or similar programs in schools, preschools and child care settings to teach fire safety and home fire escape.
- Utilization of mobile "Smoke Houses" by fire departments to teach children how fires start, how fast they can spread, and how best to escape a burning house.
- Codes requiring hard-wired detectors in new housing stock.
- Passage and enforcement of local ordinances regarding the inspection of rental units for fire safety, especially for the presence of working smoke detectors.

For More Information
- Harborview Injury Prevention and Research Center
  http://depts.washington.edu/hiprc/
- United States Fire Administration
  http://www.usfa.fema.gov/safety/
- National Fire Protection Association
  http://www.nfpa.org/Education/index.asp
- Safe Kids Worldwide
  www.safekids.org



Effective Reviews - Drowning

Facts
- Most drowning deaths to children occur when there is a lapse in adult supervision.
- Toddlers, especially males, are most at risk of drowning.
- Babies most often drown in bathtubs; toddlers in pools; older children and teenagers in open bodies of water.
- Infants can drown in water less than five inches deep, in less than five minutes.
- When adequate supervision is combined with approved personal flotation devices, drowning occurrences are rare.
- Most toddlers who drown in pools enter the water unseen by others.

Records Needed at Review
- Autopsy reports
- Scene investigation reports
- EMS run reports
- Prior CPS history on child, caregivers and persons supervising child at time of death
- Names, ages and genders of other children in home
- Information on zoning and code inspections and violations regarding pools or ponds

Risk Factors
- Lack of adequate adult supervision.
- Drug or alcohol use by supervising adults.
- Child's ability to gain access to pools.
- Whether or not child was able to swim.
- Whether a personal floatation device was appropriate and used.

Services
- Bereavement and crisis services for family members and friends.
- Safety assessment by CPS if neglect was suspected.
- Burial payments for families needing financial assistance.
- Critical Incident Stress Debriefing for persons responding to scene.

Improvements to Agency Practices
- Are investigations coordinated with medical examiner, police and CPS?
- Are referrals made for bereavement and crisis services?
- Are high-risk families with young children provided prevention services, including parenting skills and safety education?
- Do well-baby visits include information about bathtub safety for infants?
- Is there local enforcement of building codes for pool fencing?
- Was there adequate emergency response and equipment for a water rescue?

Effective Prevention Actions
- Strong support and local enforcement of building codes regarding proper pool and pond enclosures.
- Placement of signage near bodies of water to warn of possible water dangers such as strong currents and drop-offs.
- Public awareness campaigns and water safety classes for parents of young children, emphasizing constant adult supervision and use of personal floatation devices.
- Children's swim and water safety classes, especially for children over age four.
- Parent education at childbirth classes and well-baby visits on bathtub safety for infants.

For More Information
- The National Children's Center for Rural and Agricultural Health and Safety
  http://research.marshfieldclinic.org/children/Resources/Drowning/drowning.htm
- National Center for Injury Prevention and Control (Centers for Disease Control and Prevention)
  http://www.cdc.gov/ncipc/factsheets/drown.htm
- Harborview Injury Prevention and Research Center
  http://depts.washington.edu/hiprc/
- US Consumer Product Safety Commission
  http://www.cpsc.gov/cpscpub/pubs/chdrown.html
- Safe Kids Worldwide
  www.safekids.org

Effective Reviews - Child Abuse and Neglect

Facts

- Abusive Head Trauma: Most child abuse deaths are the result of injuries to the head due to violent shaking, slamming or striking.
- Blunt force injury to the abdomen: The second most common cause of child abuse fatality is from punches or kicks to the abdomen leading to internal bleeding.
- Other likely causes: Smothering, drowning and immersion into hot water.
- One-time event: Although children who die from physical abuse have often been abused over time, a one-time event often causes a death.
- Common "triggers": Caretakers who abuse their children usually cite crying, bedwetting, fussy eating and disobedience as the reason they lost their patience.
- Young children are most vulnerable: Children under 6 years of age account for four-fifths of all maltreatment deaths; infants account for roughly half of these deaths.
- Fathers and mothers' boyfriends are the most common perpetrators of abuse fatalities.
- Mothers are more often at fault in neglect deaths.
- Fatal abuse is interrelated with poverty, domestic violence and substance abuse.
- The majority of children and their perpetrators had no prior contact with CPS at the time of the death.
- It is very difficult to investigate, identify and prosecute fatal child abuse.

Records Needed at Review

- Autopsy reports
- Scene investigation reports and photos
- Interviews with family members
- Names, ages and genders of other children in home
- Child Care Licensing investigative reports
- EMS run reports
- Emergency Department reports
- Prior CPS history on child, caregivers and person supervising child at time of death
- Child's health history
- Criminal background checks on person supervising child at time of death
- Home visits records from public health or other services
- Any information on prior deaths of children in family
- Any pertinent out-of-state history

Risk Factors

- Younger children, especially under the age of five.
- Parents or caregivers who are under the age of 30.
- Low income, single-parent families experiencing major stresses.
- Children left with male caregivers who lack emotional attachment to the child.
- Children with emotional and health problems.
- Lack of suitable childcare.
- Substance abuse among caregivers.
- Parents and caregivers with unrealistic expectations of child development and behavior.

Services

- Involving CPS in assessing the removal of remaining children from the home.
- Bereavement services for parents and other family members.
- Burial payments for families needing financial assistance.
- Critical Incident Stress Debriefing for persons responding to scene.

Improvements to Agency Practices

- Are investigations coordinated with medical examiners, law enforcement and CPS?
- Are autopsy protocols in place?
- Are comprehensive scene investigations conducted at place of death, as soon as possible, including scene reenactments and interviews?
- Are referrals made for bereavement services?
- Are high-risk families with newborns and young infants provided prevention services?
- Did mandatory reporters comply with requirement(s) of child protection laws?
- Were prior inflicted injuries identified and reported?
- Did CPS conduct a full investigation and make appropriate referrals and recommendations?

Effective Prevention Actions

- Training hospital emergency room staff to improve their ability to identify child abuse fatalities and improve reporting to the appropriate agencies.
- Providing an advisory on the mandated reporting of child abuse and neglect to local human service agencies, hospitals and physicians.
- Case management, referral and follow-up of infants sent home with serious health or developmental problems.
- Media campaigns to enlighten and inform the general public on known fatality-producing behaviors, i.e., violently shaking a child out of frustration.
- Crisis Nurseries which serve as havens for parents "on the edge" where they can leave their children for a specified period of time, at no charge.
- Intensive home visiting services to parents of at-risk infants and toddlers.
- Education programs for parents such as the Parent Effectiveness Training (P.E.T.), the Parent Nurturing Program and Systematic Training for Effective Parenting (S.T.E.P.).

For More Information

- American Professional Society on the Abuse of Children http://apsac.org
- National Clearinghouse on Child Abuse and Neglect http://nccanch.acf.hhs.gov/
- Prevent Child Abuse http://preventchildabuse.com
- Prevent Child Abuse America http://www.preventchildabuse.org

Effective Reviews - Motor Vehicle Deaths

Facts

- Motor vehicle deaths include those involving cars, trucks, SUVs, bicycles, trains, snowmobiles, motorcycles, buses, tractors and all-terrain vehicles.
- Victims include drivers, passengers and pedestrians.
- Young people ages 15-20 years make up 6.7% of the total driving population in this country but are involved in 14% of all fatal crashes. Most crashes involve recklessness, speeding or inattention.
- Sixteen-year-olds driving with one teen passenger are 39% more likely to get killed than those driving alone, increasing to 86% with two and 182% with three or more teen passengers.
- Studies show that more than 80% of all infant and toddler car safety seats are not properly fastened in vehicles.
- Children weighing 40-80 pounds (ages 4-9) should be seated in booster safety seats, but most are not.
- Helmets can prevent the majority of bicycle-related fatalities.

Records Needed at Review

- Autopsy reports
- Scene investigation reports and photos
- Interviews with witnesses
- EMS run reports
- State Uniform Crash Reports with road and weather conditions at time of crash
- Emergency Department reports
- Blood alcohol and/or drug concentrations of driver and victim
- Previous violations such as drunk driving or speeding
- Any out-of-state history
- Graduated licensing laws and violations
- Information on crashes at same site
- Lab analysis of safety belt, safety seat, booster seat, helmet or other equipment damage

Risk Factors

Children Under 16

- Riding in the front seat of vehicles.
- Not using or improper use of child seats and safety belts.
- Not wearing adequate safety equipment, especially bicycle helmets.
- Unskilled drivers of recreational vehicles, such as ATVs and snowmobiles.
- Riding in the bed of a pickup truck.
- Small children playing in and around vehicles.
- Crossing streets without supervision.

Children Over 16

- Exceeding safe speeds for driving conditions.
- Riding as a passenger in a vehicle with a new driver.
- Riding in a vehicle with three or more passengers.
- Driving between 12 midnight and 6:00 a.m.
- Not using appropriate restraints.
- Alcohol use by drivers or passengers.
- Riding in the bed of a pickup truck.

Services

- Bereavement and crisis services for family and friends.
- Critical Incident Stress Debriefing for persons responding to scene.

Improvements to Agency Practices

- Are investigations coordinated with medical examiners, local and state law enforcement?
- Are comprehensive scene investigations conducted at place of death, as soon as possible, including type of restraint needed and type of restraint used?
- Was the primary cause of the incident determined?

Effective Prevention Actions

Children Under 16

- Lower Anchors and Tethers for Children (LATCH): USDOT requires all new child safety seats meet stricter head protection standards.
- Education to increase booster safety seat usage for children between 40 and 80 pounds.
- Child Safety Seat Inspection Programs: Innovative programs sponsored by the DOT, DaimlerChrysler, Ford and General Motors that train dealers and others to provide on-site safety seat inspection and training.
- Free or low-cost car safety seat distribution.
- Bicycle Helmet Laws and offer free or reduced-cost helmets to children.
- Truck bed law prohibiting children from riding in truck beds and KIDS AREN'T CARGO is an education campaign discouraging truck bed riding.
- Re-engineer roads and improve signage.

Children Over 16

- Graduated Licensing Laws: Including supervised practice; crash and conviction free requirements for a minimum of six months; limits on number of teen passengers; nighttime driving restrictions and mandatory seat belt use for all occupants.
- Teen Driver Monitoring Programs: Street Watch and SAV-TEEN marks teen cars and allow anyone observing poor driving habits to report them to law enforcement. Law enforcement either visits the teen's home or reports the incident to the parents or owner of the car.
- Driver's Education: Customize local programs to emphasize most common risk factors, e.g., off-road recovery on gravel roads in rural communities.
- Safety Belts: Education to increase adolescent seat belt use and primary seat belt enforcement laws.
- Re-engineer roads and improve signage.

For More Information

- U.S. Department of Transportation
  National Highway Traffic Safety Administration
  www.nhtsa.dot.gov
- Safe Kids Worldwide
  www.safekids.org
- Ford Motor Company – Boost America!
  www.boostamerica.org
- DaimlerChrysler – Fit for a Kidwww.fit4akid.org

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Effective Reviews - Suicides

Facts
- Suicide is the third leading cause of death for adolescents, following motor vehicles and firearm homicides. More young people die from suicide than from cancer, heart disease, AIDS, birth defects, stroke, pneumonia, influenza and chronic lung disease combined.
- The methods used most often to complete suicide include firearms, hanging, and poisoning.
- The risk for suicide is highest among young white males. Adolescent males of all races are four times more likely to complete suicide than females. Adolescent females are twice as likely as adolescent males to attempt suicide. There appears to be an increase in rates for ages 12-14.
- Males complete suicide more often because they most often use firearms.
- Depression, coupled with significant precipitating events, leads to most suicides in young persons. Some of these precipitating events may seem insignificant to adults, but pose serious risks to vulnerable teens.
- The school setting has been identified as a critical place to recognize warning signs of suicide and to implement primary and secondary prevention activities.
- Cluster suicides, those completed by other teens following a friend's suicide, are not uncommon. Any teen suicide should trigger watches on other vulnerable teens.

Records Needed
- Autopsy reports, including toxicology screens
- Scene investigation reports and photos
- Suicide note(s)
- Ballistics information on firearms
- Computer downloads
- Interviews with family and friends
- EMS run reports
- Emergency Dept reports, including prior hospitalization
- Prior CPS history on child, caregivers and person supervising child at time of death
- Child's mental health history if available
- School records and/or school representative at meeting
- Names, ages and genders of other children in home
- History of prior suicide attempts
- Substance/alcohol abuse history
- Any information on recent significant life events, including trouble with the law or at school
- If a firearm was used in the suicide, information on the storage of the firearm

Risk Factors
- Long term or serious depression.
- Previous suicide attempt.
- Mood disorders and mental illness.
- Substance abuse.
- Childhood maltreatment.
- Parental separation or divorce.
- Inappropriate access to firearms.
- Interpersonal conflicts or losses without social support.
- Previous suicide by a relative or close friend.
- Other significant struggles such as bullying or issues of sexuality.

Services
- Bereavement services for parents/other family members.
- Burial payments for families needing financial assistance.
- Critical Incident Stress Debriefing for persons responding to scene.
- School crisis response teams.

Improvements to Agency Practices
- Are investigations coordinated with medical examiners, law enforcement and Children's Protective Services?
- Are autopsy protocols in place for suicide deaths? Are toxicology screens done routinely?
- Are comprehensive scene investigations conducted at the place of death, as soon as possible, including interviews?
- Are referrals made for bereavement services?
- Are friends of the victims closely monitored for warning signs of suicide in schools by teachers, administrators, janitors, bus drivers, etc?

Effective Prevention Actions
- The Yellow Ribbon Suicide Prevention Campaign helps youth identify places to get help when they or their friends are troubled.
- School gatekeeper training to help school staff identify and refer students at risk and respond to suicide or other crises in the school.
- Community gatekeeper/suicide risk assessment training for community members who interact with teens.
- General suicide education targeted to teens to help them understand warning signs and supportive resources.
- Screening programs, including those in schools, to identify students with problems that could be related to suicide, depression and impulsive or aggressive behaviors.
- Peer support programs to foster positive peer relationships and competency in social skills among high-risk adolescents and young adults.
- Crisis centers and hotlines.
- Restriction of access to lethal means of suicide, including removal of firearms in homes of high-risk teens.
- Interventions after a suicide that focus on friends and relatives of persons who have completed suicide, to help prevent or contain suicide clusters and to help adolescents and young adults cope effectively with the feelings of loss that follow the sudden death or suicide of a peer.
- Development of assessment tools for evaluating suicide risk for students who are expelled from school or arrested for minor offenses.

For More Information
- Youth Suicide Prevention Program http://www.yspp.org/
- National Yellow Ribbon Program www.yellowribbon.org
- National Strategy for Suicide Prevention www.mentalhealth.org/suicideprevention
- Suicide Prevention Resource Center www.sprc.org

Effective Reviews - Teen Homicides

Facts

- Youth homicides represent the greatest proportion of all firearm deaths. Each day in the U.S., firearms kill an average of 10 children and teens, even though the number of teens killed by firearms in the U.S. has dropped by 35% in the past four years.
- In 2000, the *Youth Risk Behavior Surveillance Survey* reported that almost one-fifth of the 10th and 12th graders reported that they had carried a firearm within the previous 30 days for self-defense or to settle disputes.
- Youth homicide is mostly a serious problem in large urban areas, especially among black males. Homicides are the number one cause of death for black and Hispanic teens.
- When socio-economic status is held constant, differences in homicide rates by race become insignificant.
- Homicides are usually committed by casual acquaintances of the same gender, race and age, using inexpensive, easily acquired handguns.
- Drug dealing and gang involvement are often the cause of disputes leading to homicides.
- Majority of homicides occur in small pockets of large cities.

Records Needed

- Scene investigation reports
- Police and crime lab reports
- CPS histories on family, child and perpetrators
- Names, ages and genders of other children in home
- Ballistics information on firearms
- Prior crime records in neighborhood
- Juvenile and criminal records of teen and perpetrators
- Interviews with witnesses
- Information from gang squad

Risk Factors

- Easy availability of and access to firearms.
- Youth living in neighborhoods with high rates of poverty, social isolation and family violence.
- Youth active in drug and gang activity.
- Early school failure, delinquency and violence.
- Youth with little or no adult supervision.
- Prior witnessing of violence.

Services to Consider

- Bereavement services.
- Neighborhood-based crisis intervention.
- Witness protection services.

Improvements to Agency Practices

- Are comprehensive investigations conducted on all youth homicides?
- Are crime surveillance efforts targeted to neighborhoods with high rates of teen violence?
- Do schools have policies in place to address threats made to students?
- Are witnesses to violence provided appropriate services?

Effective Prevention Actions

- Intensive, early intervention services for high-risk parents.
- Targeted activities in neighborhoods with high homicide rates, including:
  - Enhanced police presence and gun deterrence in hot spots.
  - Involvement of political leaders.
  - Widespread mobilization of neighbors and community members.
  - After-school recreation programs.
  - Neighborhood Watch.
- Interdiction of illegal guns and focused prosecution of gun offenders.
- Dropout prevention programs and alternative education opportunities.
- Mentoring, therapy and bullying prevention support programs.
- Multi-systemic therapy for troubled youth.

For more information

- Johns Hopkins Center for Gun Policy and Research www.jhsph.edu/gunpolicy/
- Department of Justice http://www.usdoj.gov/youthviolence.htm