



Section One: Child Death Review

An Introduction for Team Members

National Center Program Manual

TABLE OF CONTENTS

Introduction 4

CDR Purpose, Principles, and Objectives 6

The Core Functions of CDR 14

Criteria for Excellence in CDR 15

Team Member Roles..... 17

Conclusion..... 21

Section One: Child Death Review

An Introduction for Team Members

Introduction

Every year in the United States, almost 37,000 children die before their 18th birthday. The death of a single child is a profound loss to a family and community, bringing unjust suffering and the pain of unfulfilled promises. Understandably, when a community is affected by a child's death, it wants answers and a deep understanding of how and why the child died. These answers can help communities have a clearer understanding of underlying risk factors and inequities that they may not identify otherwise.

Child Death Review (CDR) enables states and communities to generate that deep understanding, identify underlying risk and protective factors, and create meaningful change and safer, more equitable communities.

There are more than 1,350 CDR teams in all 50 states, the District of Columbia, Guam, and within some Tribes. Though they sometimes go by different names, have different case definitions, or operate out of different agencies, these programs share their commitment to learn from the tragedies they face and help protect children in the future.

This manual provides the information and tools needed to establish, manage, conduct and evaluate effective case review teams and systems. Teams are encouraged to adapt the foundational content of this manual to what will best serve their state or local context.



In addition to Section One – *Child Death Review: An Introduction for Team Members*, the following sections will be available:

- Effective Child Death Review Meetings*
- The Child Death Review Coordinator: Managing and Organizing a Team*
- Building and Maintaining a Local or State-Level Review Team*
- Effective Child Death Review State Advisory Boards*
- Acting on Review Findings*

REVIEW TEAM OPERATIONS

Review teams can operate at the state, regional, county, or city level. For the purposes of this manual, if relevant, there will be distinctions between state review and local review.



CDR Purpose, Principles, and Objectives

This section outlines the foundational elements that underlie the CDR process—its purpose, principles and objectives; its core functions; criteria for excellence; and the role of team members.

The purpose of CDR is that a comprehensive and multidisciplinary review of child deaths will lead to a better understanding of how and why children die. These findings are used to catalyze action to prevent other deaths, ultimately improving the health and safety of communities, families, and children.

The CDR process affords communities the opportunity to acknowledge the ways in which personal, community, or systems-level biases affect members of the community and explore and understand health disparities—preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by disadvantaged populations.¹

1 Centers for Disease Control and Prevention. *Health Disparities Among Youth*. November 24, 2020. <https://www.cdc.gov/healthyyouth/disparities/index.htm>.

There are seven key operating principles of CDR. These principles should govern the structure, purpose, and goals of all CDR teams.

1

The death of a child is a community responsibility.

2

A child's death is a sentinel event that should urge communities to identify other children at risk for illness, injury, maltreatment, or death.

3

A death review requires multidisciplinary participation from the community.

4

A review of case information should be comprehensive and broad with an understanding of implicit bias and health equity.

5

A review should lead to an understanding of risk and protective factors.

6

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.

7

Individual case reviews should also be balanced with accumulated data on non-fatal injuries and poor health outcomes to better understand and respond to trends that will impact larger population groups.

In order to meet the needs of the multidisciplinary CDR team members, objectives are multi-faceted. These objectives touch on the many layers of fatality review, ranging from investigation of deaths, to systems improvement, to prevention.



Ensure the Accurate Identification and Uniform Reporting of the Cause and Manner of Every Child Death

- *Reviews ensure team members are informed of all deaths which can lead to additional investigation, provision of services to the family, community, and/or professionals, and prevention.*
- *More complete information can help clarify how and why the child died.*



Improve Communication and Linkages Among Local and State Agencies in Order to Enhance Coordination

- *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.*
- *Sharing information to better understand agency responsibilities and limitations deepens a community understanding of how systems work together.*



Improve Agency Responses in the Investigation of Child Deaths

- *Reviews promote early and efficient notification of child deaths, facilitating timely investigations, provision of services, and identification of systems gaps.*
- *Sharing information from completed investigations can improve consistency and promote standardized investigations.*







Improve Agency Response to Protect Siblings and Other Children in the Homes of Deceased Children

- *Reviews can alert other agencies, such as social services, that other children may be at risk of harm.*
- *Reviews can identify gaps in policies that may have prevented earlier notification to these agencies.*



Improve Criminal Investigations

- *Reviews can provide new case information to aid in better identifying intentional injuries to children.*
- *Reviews can provide a forum for professional education on current findings and trends related to child homicides.*



Improve Delivery of Services to Children, Families, Providers, and Community Members

- *Reviews can identify services the community, family, and/or professionals need following a child death.*
- *Reviews can facilitate interagency referral protocols to ensure timely service delivery.*



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.*



Identify Significant Risk Factors and Trends in Child Deaths

- Reviews bring a broad social-ecological perspective (URL: <https://bit.ly/3iEmbrK>) to the deaths, thus medical, social, behavioral, and environmental risks are identified and addressed.



Identify and Advocate for Needed Changes in Legislation, Policy, and Practices and Expanded Efforts in Child Health and Safety to Prevent Child Deaths

- Every review should identify key findings (URL: <https://bit.ly/2GvFruw>) that articulate objective, modifiable risk and protective factors.
- Reviews are intended to be a catalyst for community action.
- Teams are not expected to always take the lead but should identify who will be responsible and accountable for the proposed action.



Increase Public Awareness and Advocacy for the Issues Affecting Health and Safety

- Review findings on the risks and systems gaps involved in the deaths of children are presented to key stakeholders and opportunities can be identified for education and advocacy.
- Disseminate positive, protective findings from case reviews to appropriate agencies and the community.



The Core Functions of CDR

Although the purpose and objectives of CDR 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 the following three core functions:

1

A CDR team that conducts individual case reviews of deaths by:

- Accessing information*
 - Reviewing deaths from a broad, multidisciplinary perspective*
 - Identifying findings*
 - Catalyzing prevention*
-

2

A state-level advisory team that reviews CDR findings and other mortality data and trends to make and act on prevention recommendations by:

- Reviewing data*
 - Writing recommendations*
-

3

Program staff that is managing and supporting CDR teams by:










- Identifying, developing, and sustaining state and/or local CDR teams*
- Providing training and technical assistance to CDR teams*
- Supporting data collection*
- Linking CDR teams to prevention resources*
- Collaborating with key stakeholders to identify and resolve barriers CDR teams encounter*

Criteria for Excellence in CDR

The following list of criteria was generated by a group of CDR experts from teams and programs throughout the U.S. who came together to develop a guidance.

[Child Maltreatment Fatality Reviews \(URL: <https://bit.ly/3jmDiyO>\):](https://bit.ly/3jmDiyO)

Learning Together to Improve Systems that Protect Children and Prevent Maltreatment

-  *Reviews should be family-centered and child-focused, while at the same time presenting learning opportunities for participating agencies.*
-  *Reviews should seek to understand and address implicit bias and health equity within the team and community.*
-  *Reviews should include the telling of the child's life story—not just the death event—and include information from a broad ecological perspective.*
-  *Reviews should be objective, forward-thinking, and not punitive towards communities, agencies, or families.*
-  *When possible, the review facilitator should be independent from an involved agency.*
-  *Reviews should have a multi-system focus, including broad team membership, case information from many sources, and findings and recommendations that address a broad array of systems.*
-  *Case discussions should follow a consistent pattern, though the content of the discussions may vary. Deliberations should have a standard format, while maintaining a balance between agency-level viewpoints.*
-  *The focus of the reviews should be on risk and protective factors, systems issues, recommendations, and plans of action.*
-  *The expectation of every review is that it will lead to action. The actions will engage a broader set of partners than those participating in the review.*



What CDR is **NOT**

Child death review should not be viewed as an opportunity for different agencies or community groups to gather and discuss blame related to an individual child death or shame each other regarding their actions related to a death. It is not meant to be a peer review or second guessing of family members, individual staff performance, or agency actions. Although agency actions may be discussed during a review, it is critically important that team members use their understanding of the circumstances leading to a child death to focus on the future: what can be done differently and better in the future to protect children and keep them safe and healthy. This principle may be difficult for some teams to adhere to, but it should always be front and center of any discussion.

[View the Principles, Purpose, & Objectives Worksheet \(URL: https://bit.ly/31FTtkl\)](https://bit.ly/31FTtkl)

CDR adds tremendous value to local, state, and national efforts by:

- Facilitating a coordinated conversation about the death of a child in order to identify urgent risks and needs.*
 - Building relationships across disciplines that allows for professional interweaving of perspectives on child health and safety.*
 - Creating an opportunity for professional debriefing.*
 - Driving quality improvement in systems.*
 - Collecting data to identify risk and protective factors.*
-

Team Member Roles

A CDR team is effective when it has the right multidisciplinary membership.

These include:

- *Community or state agencies with responsibilities for the investigation and/or prevention of child deaths.*
- *Broad representation of the community or state agencies responsible for protecting the health and welfare of children.*
- *Broad representation of the populations most at risk and impacted by child deaths.*

PARTICIPATION ON A TEAM

Participation on a team may be required by legislation or may be selected based on unique needs/expertise. Members may be asked to participate as a full member or an ad hoc member who participates on a case-specific basis because of their unique knowledge.



Team Member **Expectations**

All team members should come to every CDR meeting prepared to share what their agency knows about the child, family, and/or community. Team members should also be prepared to discuss their agency initiatives related to how the child died as well as any systems improvements implemented since the death of the child.

Team members must be willing to have open, honest, and cooperative relationships and dialogue. Team members must also be willing to advocate for change in order to prevent future deaths.

Most CDR teams will have at least representatives from the following agencies or professions:

- | | |
|--|--|
| <input type="checkbox"/> <i>Law Enforcement</i> | <input type="checkbox"/> <i>Public Health</i> |
| <input type="checkbox"/> <i>Child Protective Services</i> | <input type="checkbox"/> <i>Pediatrician or Other Family Health Provider</i> |
| <input type="checkbox"/> <i>Prosecutor/District Attorney</i> | <input type="checkbox"/> <i>Emergency Medical Services</i> |
| <input type="checkbox"/> <i>Medical Examiner/Coroner</i> | |
-

The following list of criteria was generated by CDR experts from teams throughout the United States as potential CDR team members.

- | | |
|--|---|
| <input type="checkbox"/> <i>Attorney for Child Protective Services</i> | <input type="checkbox"/> <i>Housing Authority</i> |
| <input type="checkbox"/> <i>Child Care Licensing Investigator</i> | <input type="checkbox"/> <i>Home Visiting/ Outreach Programs</i> |
| <input type="checkbox"/> <i>Domestic Violence Expert</i> | <input type="checkbox"/> <i>Court-Appointed Special Advocate</i> |
| <input type="checkbox"/> <i>Education</i> | <input type="checkbox"/> <i>Disabilities Protection and Advocacy Agency</i> |
| <input type="checkbox"/> <i>Fire Department</i> | <input type="checkbox"/> <i>Safe Sleep and/or Sudden Unexpected Infant Death Program</i> |
| <input type="checkbox"/> <i>Juvenile Justice</i> | <input type="checkbox"/> <i>Substance Abuse Treatment or Prevention Program</i> |
| <input type="checkbox"/> <i>Local Hospital</i> | <input type="checkbox"/> <i>Vital Statistics</i> |
| <input type="checkbox"/> <i>Maternal and Child Health</i> | <input type="checkbox"/> <i>Prevention Partners</i> |
| <input type="checkbox"/> <i>Mental Health</i> | <input type="checkbox"/> <i>Other Members as Required or as Appropriate on a Case-by-Case Basis</i> |
| <input type="checkbox"/> <i>Child Abuse Prevention Organization</i> | |
| <input type="checkbox"/> <i>Non-Profit Community Group</i> | |



Regardless of the participant's role, they should consider the following questions to help the team be most effective:

- What information do you have about the actions taken by your agency regarding the child/family or contacts between the child/family and the agency?*
- What specialized knowledge or expertise do you have that the team can use in its work?*
- What help can you give the team to accomplish its goals?*
- What connections between agencies and other providers can be built through your participation on the team?*

Conclusion

The concepts outlined in this chapter—the purpose, operating principles, objectives, criteria for excellence, and member roles—provide a scaffolding with which to build a dynamic and effective CDR program that becomes an invaluable community asset. Distinct in its ability to engage diverse stakeholders for the purpose of childhood fatality prevention, CDR equips its partner agencies and broader community with a proven process to respond to and help prevent child fatalities.

Tools to Help You With This Section:

- [Video: Child Death Review 101](https://bit.ly/3npT7lo) (URL: <https://bit.ly/3npT7lo>)
- [Team Worksheet: Principles, Mission, Objectives](https://bit.ly/31FTtkl) (URL: <https://bit.ly/31FTtkl>)
- [CDR Team Member Roles](https://bit.ly/3nGyFDb) (URL: <https://bit.ly/3nGyFDb>)
- [New Team Member Letter of Invitation](https://bit.ly/30I0oJP) (URL: <https://bit.ly/30I0oJP>)



This guidance was made possible in part by Cooperative Agreement Numbers UG7MC28482 from the US Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB) as part of an award totaling \$944,745 annually with 0 percent financed with non-governmental sources. Its contents are solely the responsibility of the authors and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

Copyright © October 2020 MPHI



www.ncfrp.org



Section Two: Child Death Review

Effective Child Death Review Meetings

National Center Program Manual

TABLE OF CONTENTS

- Introduction 4
- Using a Health Equity Framework in Fatality Review..... 6
- Prior to the Meeting..... 10
- The Review Discussion Agenda..... 11
- The Steps in an Effective Review Discussion of a Child’s Death 12
 - Share, Question, and Clarify All Case Information*..... 12
 - Discuss Systems Improvements* 20
 - Summarize Findings*..... 20
 - Identify Prevention Recommendations* 20
- Conclusion..... 25

Section Two: Child Death Review

Effective Child Death Review Meetings

Introduction

Every year in the United States, almost 37,000 children die before their 18th birthday. The death of a single child is a profound loss to a family and community, bringing unjust suffering and the pain of unfulfilled promises. Understandably, when a community is affected by a child's death, it wants answers and a deep understanding of how and why the child died. These answers can help communities have a clearer understanding of underlying risk factors and inequities that they may not identify otherwise.

Child Death Review (CDR) enables states and communities to generate that deep understanding, identify underlying risk and protective factors, and create meaningful change and safer communities.

There are more than 1,350 CDR teams in all 50 states, the District of Columbia, Guam, and within some Tribes. Though they sometimes go by different names, have different case definitions, or operate out of different agencies, these programs share their commitment to learn from the tragedies they face and help protect children in the future.

This manual provides the information and tools needed to establish, manage, conduct and evaluate effective case review teams and systems. Teams are encouraged to adapt the foundational content of this manual to what will best serve their state or local context.



In addition to Section Two – *Effective Child Death Review Meetings*, the following sections will be available:

- Child Death Review: An Introduction for Team Members*
- The Child Death Review Coordinator: Managing and Organizing a Team*
- Building and Maintaining a Local or State-Level Review Team*
- Effective Child Death Review State Advisory Boards*
- Acting on Review Findings*

REVIEW TEAM OPERATIONS

Review teams can operate at the state, regional, county, or city level. For the purposes of this manual, if relevant, there will be distinctions between state review and local review.

Using a Health Equity Framework in Fatality Review

This section describes the importance of a foundational orientation around health equity when conducting fatality review, how to infuse that approach into case reviews, how to prepare for a case review meeting, the steps involved in an effective review, systems to examine, and how to move from initial case review to recommendations.

Health equity is the ethical and human rights principle that motivates us to eliminate health disparities; health disparities--worse health in excluded or marginalized groups--are how we measure progress toward health equity.¹

Child deaths are not distributed equally across the population. Long-standing systemic inequities, racism, and historic and ongoing oppression drive disparities broadly, including disparities in child fatalities. Case review should never become a context in which to place blame on community agencies and individual providers, and teams should never place blame on families or parents for the loss of their children.



Health equity is achieved when every person has the opportunity to **attain his or her full health potential** and no one is disadvantaged from achieving this potential because of social position or other socially determined circumstances. Health inequities are reflected in differences in length of life; quality of life; rates of disease, disability, and death; severity of disease, and access to treatment.²

It is incumbent on CDR teams to help achieve equity by thoroughly seeking out root causes for behavior and outcomes. Instead of focusing on the individual level risk factors of personal behavior, the team should focus on systems-level factors that individuals may respond to in unhealthy ways. Systems-level factors impact the most people, are frequently oppressive, and their improvement promises to increase health and wellbeing broadly. A non-judgmental, inquiring approach seeks to ask: What drives the behavior we observed? And what was its root cause? And what is behind even that?

The further upstream the team looks, the less they will see individual behavioral risk factors. The risk associated with physical and social environments, and economic and service delivery contexts are often driven by policy and resource distribution, advantaging some and disadvantaging others.

1 Centers for Disease Control and Prevention. <https://www.cdc.gov/chronicdisease/healthequity/index.htm>. Accessed November 2020.

2 Centers for Disease Control and Prevention. *Health Equity*. March 11, 2021. URL: <https://www.cdc.gov/chronicdisease/healthequity/index.htm>.



There is a [Health Equity Toolkit](https://bit.ly/2H4iTRr) (URL: <https://bit.ly/2H4iTRr>) and a [Using Health Equity in Fatality Review training video](https://bit.ly/3IJ9n5y) (URL: <https://bit.ly/3IJ9n5y>) available for CDR teams. Much of what is presented here and in these resources, applies to every decision CDR leaders and team members make, from engaging partners, to facilitation of the case review, to writing recommendations. To summarize the toolkit's introduction³:

Fatality review methodologies offer unique strategies for analyses of individual and community factors that significantly affect health disparities. Many of these community factors are not discoverable through analyses of vital statistics and other population-based data. One such example is fatality review's capacity to examine racism: how it impacts health and creates health disparities. Racism is a pervasive problem throughout our culture and one that is difficult to identify when looking only at medical data. Fatality review processes hinge on in-depth exploration and identification of factors that contribute to poor maternal and child health outcomes, putting them in a unique position to provide great insight into the problems families face in seeking and obtaining healthcare, as well as significant information about health equity and disparities. During fatality review processes, teams use a variety of tools to identify and examine factors that contribute to fetal, infant, and child death.

³ The National Center for Fatality Review and Prevention. National Center Guidance Report: Improving Racial Equity in Fatality Review, pg. 6.

Specific ways a health equity approach can be incorporated into fatality review include:

1

Invite persons to serve on the team that represent the child populations being reviewed.

Instead of approaching this as an extra step, consider it one of the best ways to ensure that the work the team is doing, the data they're collecting, and the recommendations they're making will be relevant, effective, and welcomed by the community.

2

Clarify values and assumptions that team members may have in order to foster shared principles.

Team members should clearly understand the values and assumptions of the program, what health equity is, how it is defined, and why and how the CDR program works to eliminate disparities and advance health equity. For examples of values and assumptions related to health equity, see page 39 of [Delaware's Health Equity Guide for Public Health Practitioners and Partners](https://bit.ly/3i5GkZE) (URL: <https://bit.ly/3i5GkZE>).

3

Challenge assumptions during reviews.

It is important for facilitators and team members to be aware that the CDR meeting is a time when participants can hold themselves accountable for inaccurate or biased assumptions. It is important both for individual team members to reflect on whether their judgments are founded in a full understanding of the root causes of both behavior and poor outcomes, and for team members to be able to respectfully question if the case review is being infiltrated by biases or unfair assumptions.

The CDR meeting can often be re-focused toward equity by posing simple questions like:

- What type of recommendations can result from viewing this case with a social responsibility lens versus a personal responsibility lens?
- How are they different?
- What systems-level change can occur with recommendations for individual-level behavior change?
- What systems-level change can occur with recommendations focused on social responsibility?

4

Provide training on equity.

Intensive, multi-day equity training for CDR teams is recommended, but more accessible resources, including digital ones, are available for leaders to provide to teams to support their understanding of their own implicit biases, how disparities are driven by social determinants of health, steps toward achieving health equity, and why it matters. A deep dive into health inequities and social determinants is important for entire working groups to experience together. It is an opportunity to team build, create further consensus on complex social issues, and operate more efficiently with concepts of equity.

5

Provide a context for data.

Ensure that data highlighting disparities is consistently shared with context that speaks to issues of health equity. [Colorado's Child Fatality Prevention System](https://bit.ly/2GVK94X) (URL: <https://bit.ly/2GVK94X>) uses the following language before presenting their data. By adding contextual language, it clarifies the role of systemic oppression in how and why children die and encourages audiences not to blame certain communities for the poorer outcomes they experience.

Some families lose infants, children and youth to the types of deaths reviewed by fatality review teams not as the result of the actions or behaviors of those who died, or their parents or caregivers. Social factors such as where they live, how much money or education they have and how they are treated because of their racial or ethnic backgrounds can also contribute to a child's death. Segregation impacts access to high-quality education, employment opportunities, healthy foods and health care. Combined, the economic injustices associated with residential, educational, and occupational segregation have lasting health impacts that include adverse birth outcomes, infant mortality, high rates of homicide and gun violence and increased motor vehicle deaths.



Prior to the Meeting:

- Ensure all deaths have been identified.
- Provide enough information to team members to enable them to search their own agency records for information. A [Meeting Summary Sheet](https://bit.ly/2SSGO9e) (URL: <https://bit.ly/2SSGO9e>) should be sent to members before the meeting. It includes relevant information such as the name of the children and family members in the cases, dates of birth and death, the cause of death, and special considerations in the case.
- Invite ad hoc members and additional experts, based on cases being reviewed.
- Confirm each team member has received CDR training, including their role, responsibility, and an orientation to health equity. Ensure each team member has adequate time to search their agency records and is prepared to share relevant information during the review team meeting.
- Make sure all participating agencies have agreed to move forward with the review.



There are different approaches used by teams to conduct CDR reviews. **Whatever approach is used should be systematic and consistent.** The following basic steps should be followed in order to maximize the results from CDR.

The Review Discussion Agenda

The primary purpose of CDR meetings will be to conduct case reviews. But there are other items that should be addressed at every meeting.

A typical [Child Death Review Team Meeting Agenda](https://bit.ly/3727k8w) (URL: <https://bit.ly/3727k8w>) for a meeting includes:



Welcome and introduction of members



Updates on state/national child death review programs and issues



Reminder of team purpose and signing of confidentiality documents



Completion/follow-up of reviews from last meeting



New cases for review:

Share, question, and clarify case information

Discuss the investigation

Discuss services

Identify findings

Recommend system improvements

Identify prevention opportunities and plan actions to initiate based on the findings



Progress report on recommendations made from previous review meetings



Date and time of next meeting

The Steps in an Effective Review Discussion of a Child's Death

The individual case discussions should be done in an organized, systematic format. This will ensure that you have allowed for all important information to be shared among agencies and that you focus on identifying key risk factors and findings that will help you decide on prevention actions and system improvement changes.

STEP 1: Share, Question, and Clarify All Case Information

The goal of this step is to understand all the circumstances leading to or involved with the death. Team members should know before the meeting which cases will be reviewed, so they can bring all case-relevant information to the meeting. The [Meeting Summary Sheet](https://bit.ly/3kxQ9zH) (URL: <https://bit.ly/3kxQ9zH>) should be sent by the team coordinator to all team members several days, or even a few weeks, before the meeting. Case reviews are only effective if team members come prepared.



At the review, agency representatives take turns sharing the information they have about the child, the family, and the circumstances of the death. The [Cause of Death Guides for Effective Child Death Reviews](https://bit.ly/33Xfw7Z) (URL: <https://bit.ly/33Xfw7Z>) are a set of tools to help identify the specific records necessary for complete reviews based on the type of death being reviewed.

Case confidentiality is paramount. Teams take different approaches to this, relying heavily on lead agency policy and state laws. It is appropriate to offer a verbal reminder of the need for up-to-date confidentiality documents at the start of each meeting. Often, teams do not share written case material or only distribute review materials in the case review meeting, destroying it afterward.

Share

It is important to share information in a logical order. Commonly, the investigating agency or the agency responsible for the autopsy shares their records first.

One suggestion for the order of this information sharing process is:

- | | | | |
|---|-----------------------------|---|----------------------|
| 1 | Medical Examiner or Coroner | 5 | Social Services |
| 2 | EMS/Fire | 6 | Public Health |
| 3 | Law Enforcement | 7 | Prosecuting Attorney |
| 4 | Health Care Providers | 8 | Other |
-

Question

To be most effective, team members should hold questions until all team members have shared information. Consider setting this expectation at the beginning and encouraging team members to take notes as questions arise. Team members can follow up with questions once everyone has shared.

It is important to reiterate that the questions are not meant to determine if a person or agency involved in the case/investigation made any mistakes. They are meant to determine if all pertinent questions the team needs to know about the circumstances of the death have been answered. It is important to ask open-ended, non-judgmental questions. See the following page for categories.



INVESTIGATION

In reviewing deaths, it is important to have a clear understanding of what investigations were completed. By creating a clear picture of the investigations, the team can help identify systems gaps and successes.

- ① Who is the lead investigative agency?
- ② Was there a death scene investigation?
- ③ Was the death scene re-created? Were photos taken?
- ④ Were other investigations conducted?
- ⑤ What were the key findings of the investigation(s)?
- ⑥ Does the team feel the investigation was adequate?
- ⑦ Is the investigation complete?
- ⑧ What more do we need to know?
- ⑨ Does the team have suggestions to improve the investigative system?















SERVICE DELIVERY

In reviewing deaths, it is important to identify the timeline of service delivery to the family before the death, during the event causing death, and following the death. Siblings or any other family members may need additional follow-up. Additionally, professionals, community members and others may need additional resources following the death to support health and safety.

-  Were there any services 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?
-  Were quality services and community resources readily available, accessible, culturally and linguistically appropriate, and responsive to the family and community?
-  Who will take the lead in following up on these service provisions?
-  Does the team have suggestions to improve service-delivery systems?

Clarify

The last step is to clarify misinformation or conflicting accounts. One common way to accomplish this is to identify risk factors that may have impacted the child, family, and/or community.

Identifying the risk and protective factors involved in a child's death during the review can lead to findings the team believes could reduce those same risk factors for other children, thereby preventing future deaths. 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:

- | | | | |
|---------------------------------|-------------------------------------|---|--|
| <input type="checkbox"/> Health | <input type="checkbox"/> Economic | <input type="checkbox"/> Environmental | <input type="checkbox"/> System-level
(Agency Policies
and Procedures) |
| <input type="checkbox"/> Social | <input type="checkbox"/> Behavioral | <input type="checkbox"/> Product Safety | |

This is not an exhaustive listing but is meant to provide broad categories. The team can discuss why they believe the risk factors involved may or may not fit into one or more of these categories or identify another category. *Teams should try to examine the death from as broad an ecological perspective as possible.*

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

If after all members present have shared their case information, the team still feels there are gaps in understanding of any aspects of the death, it may be best to table the discussion until the next meeting. Then information unable 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. Assign a specific team member to obtain the needed information 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.



AT EACH CASE REVIEW, MEMBERS SHOULD ANSWER THESE QUESTIONS:

- *Do we have enough information to proceed with case review and discussion? If not, what additional information is needed? Is it possible to obtain this information?*
- *Are there services that should be provided to family members, other children or other persons in the community as a result of this death? Are these services culturally appropriate and available in the community?*
- *What risk and protective factors were involved in this death? Could this death have been prevented?*
- *What findings do we have that relate to changes in behaviors, technologies, agency systems and/or laws that could minimize these risk factors and prevent another death?*
- *What are agencies doing to prevent future deaths that are like this death?*
- *Do we need to discuss this case at our next meeting?*

STEP 2: Discuss Systems Improvements

Once all the facts of the case have been shared, clarified 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.

STEP 3: Summarize Findings

Once a case has been fully discussed, it is important for the team leader to summarize all the findings. *Findings are objective observations of risk and protective factors in the case.* These can include needed systems or practice improvements, and strengths exhibited by participating agencies, the family, or community. These findings are necessary in order to craft actionable, effective prevention recommendations. If a team contributes to the National Fatality Review-Case Reporting System, their findings should be documented in Section L. More detail is provided in the [Findings Guidance](https://bit.ly/377rm1w) (URL: <https://bit.ly/377rm1w>).

STEP 4: Identify Prevention Recommendations

The final step is to author prevention recommendations and document prevention activities. In order to develop effective, actionable recommendations, the team must review findings. Though some teams may do so more frequently, review teams should review all their data and findings every 12-18 months, identifying the prominent, leading risk factors across their causes of death. By doing this on a regular basis, CDR teams will maximize their impact, addressing risk factors that drive fatalities from multiple causes.

Recommendations can be written in the [SMARTIE method](https://bit.ly/33Yn5LW) (URL: <https://bit.ly/33Yn5LW>), developed by The Management Center, focusing on the following features:



Strategic: Answers to “who, what, where, when, which, and why” are described.



Measurable: A tangible plan for measuring impact is determined. It is important to ensure that the measures in the plan are accessible.



Ambitious: Decide how important this activity is to your end goal and if it is possible.



Realistic: Can this work be done with the resources available? It is also important to assess political and social will in deciding if an activity is realistic.



Time-Bound: Identify a timeline and a due date. It is important to identify a final due date but also dates to measure progress.



Inclusive: Engage the most impacted population in all aspects of the work. It is vital to ensure there is a meaningful way to include everyone.



Equitable: Identify how to ensure principles of social justice and health equity are used to address systematic inequity and oppression.

Findings and recommendations from CDR provide important context and guidance to help design relevant prevention programs, policies, interventions, and safe environments for infants, children, and youth.

The review team does not 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 many places to send such recommendations and the team should be aware of these options in their area:

Key Individuals:

Community and state leaders should be aware of findings and recommendations based on fatality reviews to help them understand the full scope of the risk and protective factors that impact their constituents. Some leaders to consider include mayors, county commissioners, governors, and state and federal legislators. District attorneys, school superintendents, county sheriffs, and prominent community or faith leaders are well-positioned to advance recommendations.

Agencies:

Programs that sit in local and state-level public health and human services agencies have a role in preventing fatalities. These programs may include safe-sleep, suicide prevention, infant mortality reduction, injury prevention, family preservation, and child welfare.

New Coalitions:

CDR teams may work together with partners to establish new workgroups such as a childhood injury prevention coalition or infant mortality reduction task force. Their efforts to excavate inequities in the community may catalyze a coalition of community partners focused on advancing equity across the community to improve outcomes.



Existing Groups:

State advisory boards for CDR and local Safe Kids Coalitions commonly advance CDR recommendations. Local or state policymakers, including city councils and state legislatures, should be provided any reports or recommendations that rise out of CDR reviews to help ensure that local and state policy advances safety, health, and equity. Committee chairs for legislative committees focused on health or safety are a good place to start in identifying the most relevant arm of the legislature. Professional associations, such as chapters of the American School Counselor Association or National Sheriff's Association are also promising prevention partners.

**CDR TEAM
FOLLOW-UP**

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



In summary, attributes of a successful CDR team include team members who:

- Approach CDR with a prevention focus.
- Commit to uncovering and addressing health equity.
- Consistently come to team meetings prepared to share information and have transparent, respectful conversations.
- Focus on improving agency policies, practices, services, and prevention.
- Obtain and use both mortality and morbidity data to obtain a fuller picture of an individual death and trends in child safety and injury.
- Identify modifiable risk and protective factors and translate those into findings.
- Collect and enter quality case-level data that is used for reports to policy makers and the public.
- Collaborate with key partners to create actionable recommendations based on proven or best practices.
- Enlist prevention partners, make sure the right people get the recommendations, and then hold them accountable.
- Address secondary trauma on the team.
- Celebrate successes.

Conclusion

Child death review teams can conduct effective meetings by considering ahead of time how to structure a meeting, establishing consistent, structured processes for disseminating information and conducting case reviews, approaching the identification of findings and writing of recommendations from a purposeful and informed place, and by focusing on advancing health equity throughout the case review process. A health equity approach can be incorporated in the fatality review process by inviting members to serve on the team that represent the populations of children being reviewed, challenging assumptions during reviews, providing training on equity, and providing a context for the data that are presented. Effective meetings provide impactful, quality data that can inform communities of underlying vulnerabilities and risk and help them catalyze change to help save children's lives.

Tools to Further Help You With This Section:

- [Video: Effective Review Team Meetings](https://bit.ly/2lItvvZ) (URL: <https://bit.ly/2lItvvZ>)
- [Video: Sample SUID Review Meeting from Tidewater Region, Virginia](https://bit.ly/2HXXgmk) (URL: <https://bit.ly/2HXXgmk>)
- [Child Death Review Team Meeting Agenda](https://bit.ly/3IKR7sh) (URL: <https://bit.ly/3IKR7sh>)
- [Team Meeting Case Tracking Table](https://bit.ly/3iZmb5R) (URL: <https://bit.ly/3iZmb5R>)
- [Cases for Review Summary Sheet](https://bit.ly/3j0cDYv) (URL: <https://bit.ly/3j0cDYv>)
- [Case Findings Summary Sheet](https://bit.ly/31PEmFr) (URL: <https://bit.ly/31PEmFr>)
- [The Cause of Death Guides for Effective Child Death Reviews](https://bit.ly/350TCzU) (URL: <https://bit.ly/350TCzU>)
- [Improving Racial Equity in Fatality Review](https://bit.ly/2STesMj) (URL: <https://bit.ly/2STesMj>)
- [Guidance for Review of Zika-Related Fatalities](https://bit.ly/3k5omGE) (URL: <https://bit.ly/3k5omGE>)
- [Guidance for Reviewing Deaths of Infants/Children with Disabilities and/or Special Health Care Needs](https://bit.ly/2lqakRH) (URL: <https://bit.ly/2lqakRH>)





Tools to Further Help You With This Section – Continued:

- [Effective Reviews: Child Deaths on Farms](https://bit.ly/3nNhyQ2) (URL: <https://bit.ly/3nNhyQ2>) with a [PowerPoint Presentation: Guide to Effective Review of Farm-Related Child Deaths](https://bit.ly/33YC3BC) (URL: <https://bit.ly/33YC3BC>)
- [Reviewing Deaths of Children in Disasters and Mass Fatality Events](https://bit.ly/3k08lld) (URL: <https://bit.ly/3k08lld>)
- [PowerPoint Presentation: Review of Infant Deaths Due to Congenital Anomalies](https://bit.ly/2GXl7CE) (URL: <https://bit.ly/2GXl7CE>)
- [PowerPoint Presentation: Improving Child Abuse and Neglect Fatality Reviews](https://bit.ly/3jUfbsl) (URL: <https://bit.ly/3jUfbsl>)
- [Planning for Remote Fatality Reviews](https://bit.ly/2SWyCVG) (URL: <https://bit.ly/2SWyCVG>)
- [Improving the Coordination of Fatality Review Programs with American Indian and Alaska Native Communities](https://bit.ly/34ve4ds) (URL: <https://bit.ly/34ve4ds>)
- [Guidance for CDR and FIMR teams on Addressing Vicarious Trauma](https://bit.ly/3oxzui8) (URL: <https://bit.ly/3oxzui8>)



This guidance was made possible in part by Cooperative Agreement Numbers UG7MC28482 from the US Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB) as part of an award totaling \$944,745 annually with 0 percent financed with non-governmental sources. Its contents are solely the responsibility of the authors and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

Copyright © October 2020 MPH I



www.ncfrp.org



Section Three: Child Death Review

**The CDR Team Coordinator: Organizing and Managing
a Child Death Review Team**

National Center Program Manual

TABLE OF CONTENTS

- Introduction 4
- The Role of the CDR Team Coordinator 5
- Models and Authority for CDR..... 7
- Steps to Organize a Review Team 10
- Factors that Contribute to Success..... 19
- Information Necessary for Reviews..... 26
- Confidentiality 28
- Effective Team Meetings..... 31
- CDR and Ethics..... 32
- Taking Care of Team Members..... 40
- Working with the Media 41
- Coordinating with Other Review Teams..... 45
- Data Collection..... 48
- Conclusion..... 49

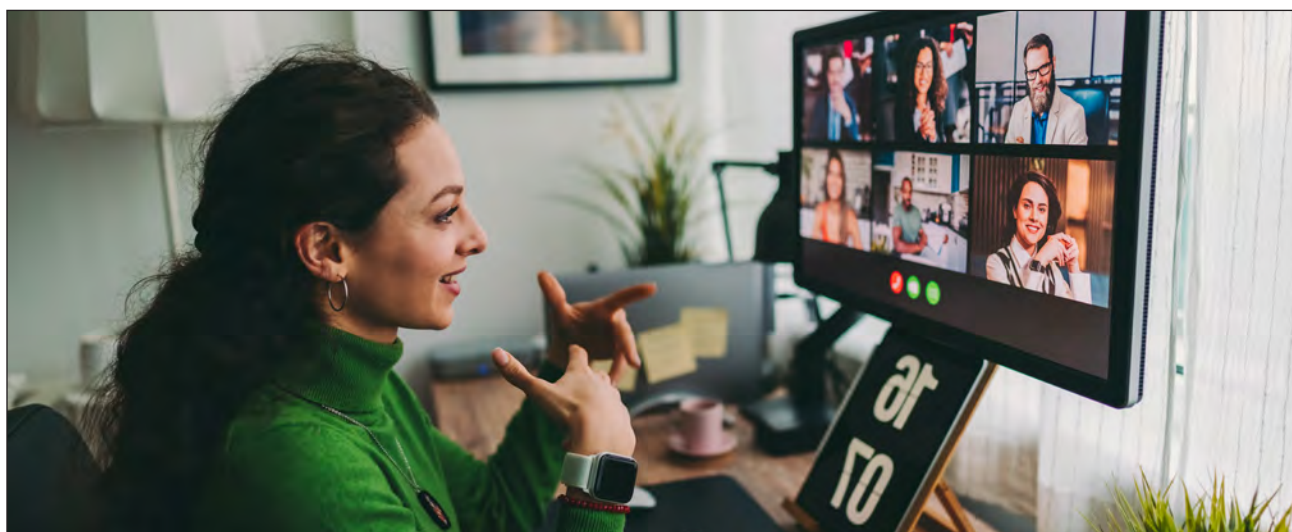
Section Three: Child Death Review

The CDR Team Coordinator: Organizing and Managing a Child Death Review Team

Introduction

This section is written for team coordinators leading child death review (CDR) at the state or local level.

This section describes the role of the coordinator, the steps to establish a team that will review child death cases, and ways in which the coordinator can ensure the review team process is efficient and effective.



The Role of the CDR Team Coordinator

Depending on the jurisdiction, the team coordinator may be designated through legislation, by an agency head, or be a person who volunteers to organize and coordinate a team.

In some states, all local CDR team coordinators are from the same type of agency, such as the county health department or the district attorney's office. In other states, this role is not defined in law or policy, and agency leads may vary. Often, state legislation stipulates that one state agency must assume the leadership role in establishing and managing the review program or conducting actual case reviews. In absence of legislation, a state or local agency with interest in supporting the CDR process and a commitment to preventing all causes of death may be the best candidate to facilitate the process. For example, the state or local Title V maternal child health or injury prevention program within the state health department may be a logical choice. Regardless, the role of the CDR team coordinator is often an additional responsibility to one's job. While not all coordinators can find this role defined in their job descriptions, the CDR coordinator is very much the glue that holds the entire process together.



The team coordinator does not have to do all
the core functions for the team to be successful.

Some teams are very effective in dividing responsibilities. For example, the CDR coordinator may be 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. 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.

CDR Coordinators' responsibilities typically include:

- Recruit and train new team members.*
- Determine meeting dates and locations and send team members meeting notices.*
- Compile the summary sheet of child deaths to be reviewed and distribute it to team members two to three weeks before the meeting.*
- Ensure that new members receive an orientation to the CDR team before their first meeting.*
- Ensure that all new CDR team members and ad hoc members sign a confidentiality agreement.*
- Encourage sharing information for effective case reviews, including drafting a case summary or abstract before the reviews.*
- Chair the team meetings and facilitate dialogue that helps the CDR team achieve its prevention goals.*
- Resolve disputes and work to ensure effective discussions and group dynamics.*
- Complete and submit data reports through the process designated for their state.*
- Ensure that the CDR team operates according to protocols as defined by the team or law.*
- Track findings from reviews so the findings can impact prevention recommendations.*
- Facilitate contacts with the media.*
- Maintain contact with the state CDR program office.*
- Ensure that the team members have opportunities to debrief and address secondary trauma from the discussions.*



Models and Authority for CDR

In 2020, every state in the United States and the District of Columbia had a designated person that served as the lead for CDR. These state leads may or may not provide direct training and technical assistance to state and local review team coordinators, but coordinators should work in tandem with them as they build and manage their teams.

Local reviews may take place within a defined jurisdiction. 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, such as community health department regions.

Because there are variations in the types of deaths that are reviewed, establishing or setting case selection criteria is needed. **When setting case selection criteria, consider:**

- 1 *Age of the child*
- 2 *Manner and cause of death*
- 3 *Place of death*
- 4 *Place of residence*
- 5 *The timeframe from death to review*

Often the variation in cases reviewed depends on the primary purpose of the review program and whether the review is at the local or state level.

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 most common models of CDR programs include:

- Local and state-level reviews and local response to findings.
- State and local review of cases; state and local response to findings.
- State-only review of cases; state-level response to findings.
- Local-only review of cases; local response to findings.

Leadership

Local and state-level reviews and local response to findings	State and local review of cases; state and local response to findings	State-only review of cases; state-level response to findings	Local-only review of cases; local response to findings
State agency provides oversight and coordination to network of local teams, including protocols, guidelines, training, and technical assistance.	Local reviews may operate without state mandates or guidelines; agency leads vary by local jurisdiction.	Team consists of state-level agency representatives, led by one agency.	Local teams operate independent of state-level oversight, though some states may bring local teams together for training.

Reviews

Local and state-level reviews and local response to findings	State and local review of cases; state and local response to findings	State-only review of cases; state-level response to findings	Local-only review of cases; local response to findings
Conducted at the local and state levels. May or may not be required.	Local teams review all or most cases, while a state-level team reviews a representative sample of cases.	No local reviews take place. Some states provide a case summary, prepared by an abstractor, for the review team to consider. In other states, agency representatives bring records to the review.	Conducted by city or county-level teams.

Findings and Recommendations

Local and state-level reviews and local response to findings	State and local review of cases; state and local response to findings	State-only review of cases; state-level response to findings	Local-only review of cases; local response to findings
Focused on local policy and practice; prevention implemented locally.	State may review local findings.	State prepares report on findings and makes recommendations focused on agency policy/practice.	Some teams issue reports on their findings, focused on local-level intervention.

Funding

Local and state-level reviews and local response to findings	State and local review of cases; state and local response to findings	State-only review of cases; state-level response to findings	Local-only review of cases; local response to findings
Local teams may or may not be funded for case reviews.	Local teams rarely receive state funding.	State programs are often funded by state agencies or federal grants to support reviews, data collection, and reporting.	Local teams rarely receive state funding.

Important Considerations

Local and state-level reviews and local response to findings	State and local review of cases; state and local response to findings	State-only review of cases; state-level response to findings	Local-only review of cases; local response to findings
<p>Case selection criteria vary. Often, state-level subcommittees examine specific types of cases.</p> <p>Reviews are mostly retrospective, often taking place 60-90 days after a death.</p> <p>This model works best when a full-time CDR coordinator is hired to support teams and connect state/local efforts.</p>	<p>Clear case selection definitions for teams.</p> <p>Local findings need to be elevated to the state.</p>	<p>The state committee may also serve at the state Child Abuse Prevention and Treatment Act (CAPTA) Citizens' Review Panel (CRP).</p> <p>A variation of this model may see an agency have internal reviews with their representatives; especially agencies tasked with care and custody of children.</p> <p>Vital that all state-level reviews are coordinated and overlaps are intentionally planned for.</p>	<p>In the absence of a state coordinator, it is vital for all the local teams in a state to form a resource-sharing network to support each other's work.</p> <p>Local teams without state oversight should be aware of the state's legislation, promulgated rules, or policies related to case review and records access.</p> <p>While one agency should lead, shared ownership of the process is important.</p>



Steps to Organize a Review Team

Establishing a review team requires planning and coordination with numerous agencies. Usually, one agency takes the lead in planning for a team. As mentioned in the table on [pages 8-9](#), a state may or may not have a mandated agency lead for local or state level review teams.



ORGANIZING A REVIEW TEAM

- 1 Designate a team organizer.
- 2 Contact the state program coordinator.
- 3 Study CDR program materials.
- 4 Assess community 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 and morbidity data.
- 8 Schedule an organizational meeting.
- 9 Conduct an organizational meeting.
- 10 Follow-up before the first review meeting.



1

Designate a Team Organizer

Review teams are created through 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 agencies, and child advocates.

States may legislate who the lead should be, and interested persons should contact this person/agency. In other cases, team membership is also laid out in legislation. It is essential to acknowledge that a team organizer does not have to be the person who ends up coordinating the team or facilitates the team meetings.

2

Contact the State Program Coordinator

The local review team organizer should contact the state or regional CDR 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 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 available through resources the National Center has a section on its website. A good place to start is [tools for teams](https://www.ncfrp.org/cdr/tools-for-cdr-teams/) (URL: <https://www.ncfrp.org/cdr/tools-for-cdr-teams/>). Supplemental information regarding the roles of other professionals, how their agencies function and their role in CDR should also be studied.



4

Assess Community Readiness to Establish a Team

Prior to the first meeting, assessing the community's need and readiness for CDR should be conducted. An assessment tool template, [Planning for a New CDR Team](https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/Tools-Planningtool.pdf) (URL: <https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/Tools-Planningtool.pdf>), can be adapted for the team. The tool can also help identify partnerships and secure commitments to participate.

5

Collect Mortality and Morbidity Data

To help plan the scope of the review programs, it is necessary to understand how and why children in the state or community die. Contact the state or community public health agency or state CDR program to assist in gathering mortality and morbidity data over a specific length of time. Consider obtaining child mortality data online through the [CDC's WONDER website](https://wonder.cdc.gov/) (URL: <https://wonder.cdc.gov/>). Consider asking for help from a public health partner to compile the data.

6

Contact an Existing Review Team

The team organizer should contact the CDR team coordinator of a team currently operating successfully and request to attend a review meeting. Observing an existing review team will illustrate how teams operate and provide direction on recruiting potential team members. Locating a team in a similar jurisdiction may be helpful, and it may be helpful to observe more than one CDR team. The state CDR program can help facilitate introductions and may have suggestions for which teams to visit.

Contact the Core Local Agencies that May Serve on the Team

The team organizer should contact the directors of core member agencies to discuss establishing a CDR team. Team organizer should become familiar with potential agency roles and the need for their participation on the team.



See Section Two for a Full Description of Team Membership.

In recruiting team members, request the highest possible level of agency staff to 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 wellness. 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](https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/Tools-Letterofinvite.pdf) (URL: <https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/Tools-Letterofinvite.pdf>) is available and can be adapted for different jurisdictions and agency leads.

Schedule an Organizational Meeting

Most organizational issues should be addressed before your first case review. After all core agencies have been contacted, the team organizer should schedule an organizational meeting. Meetings should only be held if most of those invited can attend. Request that the state CDR program coordinator attend the first meeting to provide guidance.

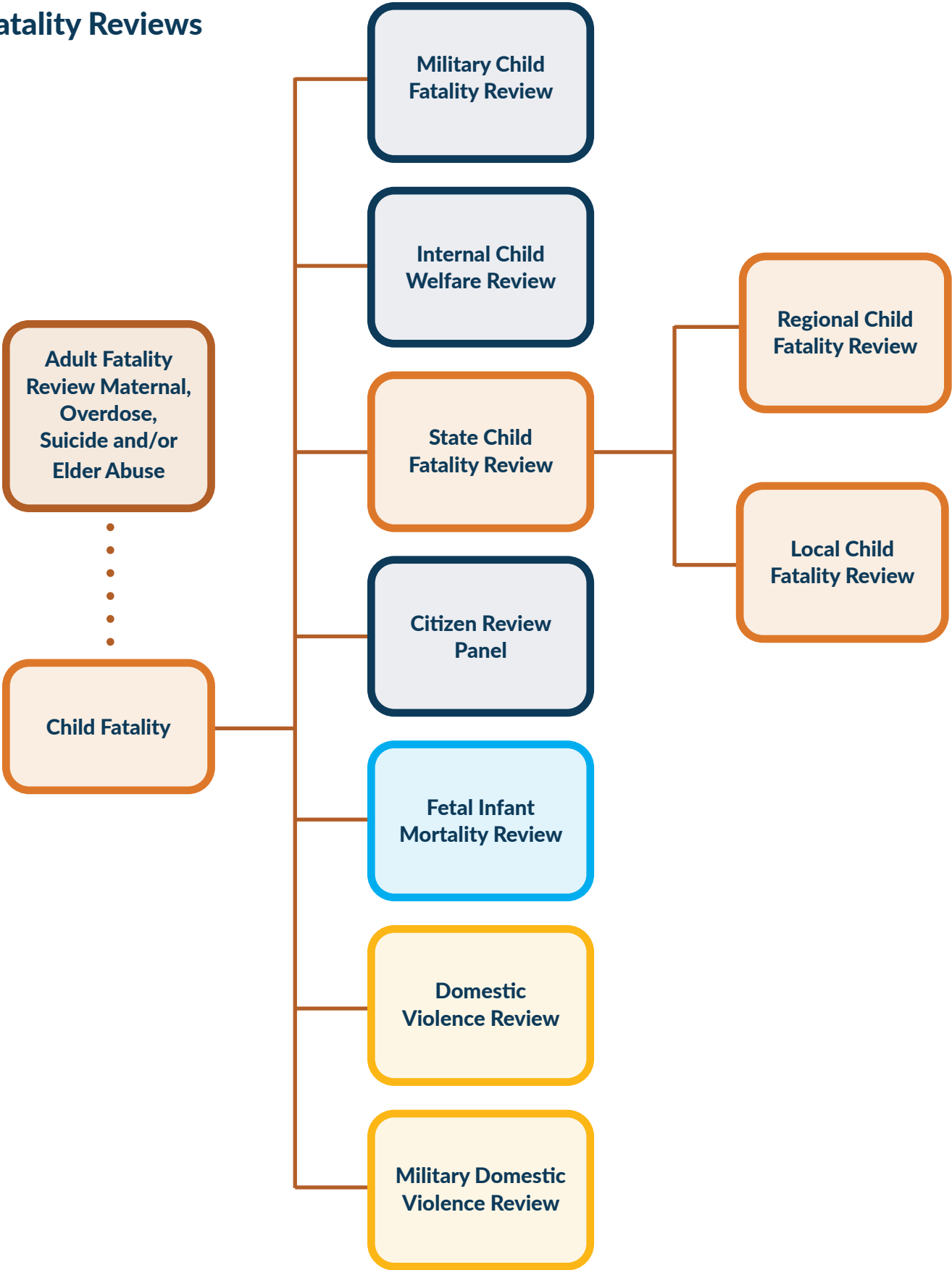
Conduct an Organizational Meeting

An [example agenda](https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/Tools-1stplanningmtgagenda.pdf) (URL: <https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/Tools-1stplanningmtgagenda.pdf>) for the first planning meeting is available. Several organizational meetings may be necessary before the team is ready to begin reviewing deaths.

The agenda can include:

- Introduce potential members:** Ask team members to introduce themselves, their agency, the agency's response when a child dies, and their goals for participating in CDR.
- Provide an overview of the purpose and history of child death review in the state:** The purpose of CDR is to review individual child deaths to understand how systems work in the community to identify risk and protective factors with the ultimate goal of preventing future deaths.
- Describe how a child death review team operates:** Share and discuss state statutes, administrative rules, or policies that may impact how the team may or should be operationalized.
- Present child mortality statistics for the jurisdiction:** Share the child mortality statistics for the county or region obtained from the state child death review program, health department, or planning tool.
- Discuss current response to child deaths:** Develop a road map of actions taken by agencies in the community from the time a 911 call comes in or a child arrives at the hospital to when a child dies. This is an effective way to help member agencies understand their different roles and the systems that respond to child death. For some, it may be the first time they learn about another agency's roles. Doing this early will save a lot of time when having case discussions.
- Describe the current resources available in the community related to death investigation, services, child health, and safety:** Ask team members to share resources, policies, and practices related to how agencies respond to a death.
- Describe other review processes that may be occurring in the community or state:** Identify other review processes that might be in your community. [See the web of reviews for common fatality reviews on page 16.](#)

Web of Common Fatality Reviews





- 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 answers are not clear, indicate that the program will check with other coordinators, find out what is working, and report back to the group.
- Discuss the benefits of both immediate response and retrospective reviews and decide on the process(es) the team will follow:** The team must have a voice in setting the parameters of the CDR team to ensure success.
- 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 obtaining death certificates before they are sent from the county to the state registrar's office. A [sample letter](https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/Tools-countyclerk.pdf) (URL: <https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/Tools-countyclerk.pdf>) requesting records from the county clerk is available.
- Establish a meeting schedule:** Teams should schedule regular meeting times. Attendance will be higher if a regular time and place are 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 before conducting CDR reviews so that official working relationships may be established and so that members agree to the confidentiality provisions for your team. Discuss possible legal and institutional barriers to these agreements and develop solutions.

See examples below:

- [Local Review Team Interagency Agreement](https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/Tools-Interagencyagreement.pdf) (URL: <https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/Tools-Interagencyagreement.pdf>)
- [Review Team Confidentiality Agreement](https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/Tools-Reviewteamconfagree.pdf) (URL: <https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/Tools-Reviewteamconfagree.pdf>)

- Agree on materials to compile and distribute to team members at the first review meeting:** Materials should include basic information about CDR 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 National Fatality Review-Case Reporting System (NFR-CRS) Case Report Tool if your team uses it:** These are usually available from your state program office or by emailing the National Center at info@ncfrp.org. A PDF version of NFR-CRS is available on the [NFR-CRS website](https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/CDR_CRS_v5-1.pdf) (URL: https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/CDR_CRS_v5-1.pdf).
- Select a team coordinator or chairperson:** Select these person(s) if not already mandated by legislation. The team coordinator and chair/meeting facilitator 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/meeting facilitator should be a person with excellent leadership skills and a person highly respected in your community.
- Conduct a practice review using an old case or a made-up case:** Follow all team procedures and agreements. Following the review, tweak any procedures and agreements.

10

Follow-up before 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.



Factors that Contribute to Success

Several factors help lay the groundwork for a successful program. They fall into categories of program infrastructure, like funding, leadership, and home agencies; preparation, like organizational preparation, inter-agency agreements, and team-member buy-in; and processes, like training, access to relevant records, and actual case reviews.

Factors that Contribute to Successful Creation of a CDR Team

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 CDR is often a bottom-up process, agreement to participate is often top-down. When a state entity makes CDR a priority to its functioning, the institutionalization can help ensure its future existence.
Legislation	Enabling, protecting, or information-sharing legislation relating to CDR is passed at the state level.	It gives a legal basis for conducting reviews, sharing sensitive information, and protecting confidentiality; and this may legitimize the process for some.
Financial Support	Funds to cover community consultants for technical assistance and support are appropriated by the participating agency(ies).	The expertise and dedicated time of CDR program staff facilitates the formation and sustainability of teams, especially in the face of member turnover.
Housing of Program	State or local CDR program and staff are housed in a neutral location, with a committed 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 the multidisciplinary audience at one time; can answer pertinent questions in open, discussion-style format. It gives representatives from rural areas the opportunity to network, possibly forming regional teams.
Organizational Meeting	The team convenes their first meeting as organizational only; no reviews are done.	Provides an opportunity for team members to get acquainted and set process parameters before attempting reviews.
Interagency Agreement	Agency directors sign a joint agreement to participate in the CDR process.	Solidifies multi-agency commitment and the idea of shared ownership in the process. Can ensure participation of field staff.

Factors that Contribute to Successful Creation of a CDR Team – continued

Factor	Example	Why This Contributes to Success
Confidentiality Statements	All members sign confidentiality statements regularly before sharing information.	Further assures those still wary of liability associated with CDR. Provides a safe environment, encourages members/agencies to share sensitive information.
Training	Statewide training is 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 a networking opportunity, sharing experiences.
Retrospective Practice Reviews	The team chooses deaths from the recent past as the first set of reviews.	Raises members' comfort level with the process, without the pressure of discussing ongoing investigations, etc.
Buy-in of Core Members	Agency representatives required by law or agency policy to participate are committed to CDR; attend all meetings.	Sets tone for other members to follow; raises the perceived importance of process; more credible, relevant information will be shared.
Additional Membership	The team coordinator invites individuals who were involved in each of the cases reviewed or subject matter experts to those meetings.	It gives the team a clearer picture of events, adds to the completeness of information on the report form, facilitates prevention discussions.
Access to Records	Adequate records on each death are made available to the team for review.	It makes it easier for teams to identify risk factors, move from findings to recommendations to action. Increases usefulness of aggregate CDR data.
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 a feeling of productivity and accomplishment.

Case Selection

A primary goal of CDR teams is to reduce the number of preventable child fatalities by conducting systematic, multidisciplinary reviews of child deaths. Due to limited time and resources, some jurisdictions cannot review every child death. Several factors will influence case selection.

Consider the following when determining which cases to review:

- | | | | |
|---|--|---|-----------------------------------|
| 1 | <i>Total numbers of deaths in the jurisdiction</i> | 5 | <i>Access to case information</i> |
| 2 | <i>Ages of children</i> | 6 | <i>Place of death</i> |
| 3 | <i>Cause and manner of deaths</i> | 7 | <i>Cases under litigation</i> |

Selection by the Number of Deaths in Your Jurisdiction

Selecting what types of deaths to review may depend on the geographic area and the actual number of deaths the teams can review. Jurisdictions with small populations or low numbers of child deaths may be able to review all child deaths. If the team has scheduled meetings but no cases to review, the team can use the meeting time to discuss prevention. Large areas will have to develop a process to review as many deaths as is feasible. If the team is unable to review all deaths, evaluate preventability when prioritizing cases.

Best Practice

When at all possible, review all deaths for children who are residents of the jurisdictions and deaths of non-residents who die within the jurisdiction.

Selection by Age

Generally, states define a child as younger than age 18. Although decisions may depend on the expected caseload, reviewing deaths in all age categories up to or through age 18 is recommended. **As of 2020, all but one state in the U.S. reported their review programs encouraged reviews to at least age 17.** Some teams even choose to review young adults through their early 20's. Most deaths in these older age groups are preventable and are commonly due to motor vehicle crashes, homicide, and suicide.

Best Practice

Review all deaths to children younger than age 19.

Selection by Manner and Cause

Many state CDR laws allow for or require that, at a minimum, child abuse death 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.

Thirty-five states review medical deaths in CDR, including those due to asthma, cancer, infectious diseases, and cardiac events, as there are elements of preventability in many natural deaths. The team should develop an approach to reviewing them. For example, many deaths due to perinatal conditions such as prematurity and low birth weight 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, including geographic clusters of deaths due to cancer, or whether health care services were available and appropriate.

Best Practice

Review all deaths, regardless of cause and manner of death. If this is not feasible, review all deaths in which the child was not expected to die within six months.



Selection Based on Access to Information

The team may have strict limits on its ability to access case information which may determine the ability to conduct an effective review. For example, the team may not be able to access prenatal medical records, limiting the ability to review deaths due to perinatal conditions.

★ *Best Practice*

Access as much information about each case as possible. Invite critical partners to the review, even if you cannot access information from their agency.

Selection by Place of Death

Decide whether the team will review the fatalities of residents or all children, regardless of residence, who die. You may also need to consider whether you will conduct effective reviews of residents who die in other counties or states because of the complexities in obtaining meaningful information. Communities that are major trauma or neonatal centers 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 the local community. In this situation, the team may choose not to review these deaths.

Out-of-state fatalities can be challenging as it can be difficult to access information from other states. Every team is encouraged to develop cooperative relationships with other jurisdictions. The first step is to contact the CDR coordinator from neighboring states the teams are likely to request records from in the future. View the [list of CDR coordinators](https://www.ncfrp.org/cdr-map/) (URL: <https://www.ncfrp.org/cdr-map/>).

Best Practice

Review all deaths occurring in the jurisdiction and out-of-jurisdiction deaths to residents whenever possible.

Selection of Cases under Litigation

Because of state regulations, some states are only allowed to review cases that are not 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.

Best Practice

Consult with appropriate legal parties and team members to decide how to handle cases where litigation is still pending.

Information Necessary for Reviews

Reviews are most effective when team members bring their case-specific information relevant to the circumstances of the child's life and death.

Team members individually share this information at the review. The information shared at the meeting may fall into several categories.

Below are three examples:

EXAMPLE 1: Case-specific information

Facts about the life and 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.

EXAMPLE 2: Data on other deaths or similar injuries

These data may show trends that will help the team advocate for necessary changes in state policies or procedures.

EXAMPLE 3: Information on local and state resources

This includes services, programs, and policies relevant to preventing this type of death or information on the delivery of services.

In reviewing this information, the team will ultimately ask whether the death could have been prevented. It is helpful to consider what could have been changed that would have prevented the death and what changes are necessary to prevent future, similar, deaths.



Case Information Needed for a Quality Review

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

- Death investigation reports, including scene reports, interviews, and 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 welfare 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.*

Depending on how the child died, additional information and sources may need to be identified. Teams should take a broad, whole-child approach when considering what relevant records may shed light on the case.

Access to Information

CDR teams provide a forum for the sharing of information essential to the improvement of a community. A review team needs to share information about the child to understand the context in which the child lived and died.

Team members may provide the coordinator with information before a review or bring their own records to the review. All team members should take the lead in presenting their own agencies' information.



Confidentiality

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 must be addressed to ensure smooth team operations, those concerns do not have to impede the review process.

There are two separate but related confidentiality concerns related to the CDR process:

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

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

- The team cannot do its work without having access to information about the child, the family, the professional systems, 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 is interested in knowing how and why children are dying and what can be done to prevent those deaths.*

Team access to and sharing of comprehensive information for effective case reviews

There are many ways to approach access to information for case reviews. Teams should enter into agreements between members to ensure information sharing, regardless of the team has legislation. If the jurisdiction has CDR legislation, review it for information around confidentiality.

The HIPAA laws related to the sharing of medical information can be challenging to navigate. View [Summary of the HIPAA Privacy Rule](https://www.hhs.gov/hipaa/for-professionals/privacy/laws-regulations/index.html) (URL: <https://www.hhs.gov/hipaa/for-professionals/privacy/laws-regulations/index.html>), including permitted uses of personal health information.

CDR team members should sign a confidentiality agreement before sharing information in a review meeting. 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 annually, have recent signatures, and remind members about their responsibilities of maintaining confidentiality. View a [sample confidentiality agreement](https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/Tools-Reviewteamconfagree.pdf) (URL: <https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/Tools-Reviewteamconfagree.pdf>).



Others' access to the review discussion and findings

The team needs to consider what information can be shared for prevention purposes. Some teams are mandated to use de-identified information to inform prevention activities. Case-specific information is often kept confidential.

State and federal public information acts, including the Freedom of Information Act, or FOIA, are 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. Legislation enabling CDR may also hold the review meetings exempt from these laws. Some teams may hold their case reviews in private and then open their general discussion on prevention to the public.

Assurances of Document Storage and Security

Develop written statements describing exactly how all information, records, and documents for CDR cases will be stored, e.g., locked files in locked offices or online on local servers. Consider including policies regarding who has access to these files and how the team's information will be turned into aggregate data for broader distribution.



Effective Team Meetings

The following is explicitly written for team coordinators and facilitators.

Effective Team Facilitation: Effective facilitation requires thoughtful preparation, respectful leadership, and meaningful reflection. As a facilitator, be open to trying something new and listening to team members' constructive feedback. Observe effective meetings in other contexts and consider using similar techniques. Review team meetings will be improved when facilitators approach meeting planning, implementation, and follow-up in a thoughtful, structured way. Effective facilitation can help teams overcome barriers around team membership, ensure more effective team discussions, meet the varied needs of team members, and help the team maintain its focus on prevention. Careful planning allows the facilitator to anticipate barriers to effective review and be prepared. View the [Fatality Review Facilitation Guide](https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/Fatality_Review_Facilitation_Guide.pdf) (URL: https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/Fatality_Review_Facilitation_Guide.pdf) for additional guidance on facilitation and methods for involving the team in decision making.



See [Section Two](#) for a full description of an effective team meeting.



CDR and Ethics

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.

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 established written standards reflected in their profession's code of ethics. It is not uncommon for CDR teams to face ethical dilemmas throughout their process of conducting reviews.

Examples of Ethical Dilemmas

It is not always clear what teams and their 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.



TEAM MEMBERSHIP



Scenario 1:

Situation: The team plans to conduct a case review of a ten-year-old pedestrian that an intoxicated driver killed. This driver is the cousin of a CDR team member.

Dilemma: Should the team ask this person to recuse himself from the meeting?

Recommended Action: Ask the team member to recuse themselves for this review. Consider the team member's ability to remain unbiased in the review of future deaths involving intoxicated drivers.



Scenario 2:

Situation: A small county reviews 4-5 deaths a year and is planning to review an unexpected infant death at the next meeting. The father of the infant contacts you asking to attend the review meeting.

Dilemma: Should parents be informed the team is reviewing their child's death? Upon request, should parents be invited to attend meetings? Should parents be provided with findings resulting from the review?

Recommended Action: Family members should not attend review meetings. However, family members may be powerful partners in prevention if allowed by legislation.





CASE SELECTION



Scenario 1:

Situation: The team plans to review two deaths due to fires at the next meeting but does not have a member who has expertise in fire investigation or prevention. The team is split as to whether to add a team member who has expertise.

Dilemma: Should the team review a case in which it lacks expertise?

Recommended Action: The team should include someone with expertise if at all possible. This can be someone who just comes to the meeting where that type of expertise is needed. If the team cannot find an expert, consult a state or national expert. The state CDR coordinator or the National Center can help make connections.



Scenario 2:

Situation: A team member is a supervisor with direct experience working on a case being reviewed. The supervisor knows that the agency did not follow protocol.

Dilemma: Should the team member share this information with the team?

Recommended Action: Yes, once the internal investigation is completed.





SHARING INFORMATION



Scenario 1:

Situation: You have direct case knowledge about a case you worked on less than a year ago. The infant died at ten months due to a treatable infectious disease.

Dilemma: Do you present information at the review?

Recommended Action: Information from records should be made available to the CDR team. However, individual participation should be optional.



Scenario 2:

Situation: The county prosecutor is waiting for information on a potential child neglect death that will be discussed.

Dilemma: Should the prosecutor attend the meeting?

Recommended Action: The prosecutor should review state statutes for information about how information from CDR meetings and discussions can be shared. The prosecutor should also review team agreements and ensure to follow them.





USE OF INFORMATION



Scenario 1:

Situation: During a homicide review, conflicting opinions are shared by team members.

Dilemma: Should someone on your team inform the prosecutor of the information?

Recommended Action: The team should review all legislation and team agreements before sharing any information.



Scenario 2:

Situation: The press in a small county would like to write a story to promote safety and has asked the CDR team to share general findings. The team is concerned that everyone would know which death is being discussed.

Dilemma: Should the team share data and findings with the press?

Recommended Action: When numbers are small, data can be presented in the frame of national risk factors so that no identifiable information is shared.

Taking Care of Team Members

Persons who participate in CDR are at risk of suffering vicarious trauma. Vicarious trauma (VT) is defined as experiencing or feeling something by hearing the details of someone else's trauma instead of experiencing it firsthand. Vicarious trauma occurs because of elevated levels of exhaustion from the cumulative, repeated, pervasive, long-term stress of exposure to others' traumatic experiences. Several terms are often used interchangeably with VT (secondary trauma, compassion fatigue, burnout), and definitions of these conditions vary in the literature. The signs and symptoms of vicarious trauma may occur in several physical and psychosocial ways. Not everyone responds to repeated exposure to stories of trauma in the same way. The risk of suffering vicarious trauma is variable and fluctuates across time and among individuals.

It is essential that the coordinator acknowledges the risk of vicarious trauma for team members and openly addresses it with them. The National Center has developed a [Guidance for CDR and FIMR Teams on Addressing Vicarious Trauma](https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/GuidanceVicariousTrauma.pdf) (URL: <https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/GuidanceVicariousTrauma.pdf>). It describes the effects of VT and offers suggestions for minimizing VT's impact on the team. Coordinators are encouraged to review the entire guidance for more detailed information.





Working with the Media

The work of CDR involves sensitive issues, many of which are of great interest to the public and the media. Additionally, teams are likely to be promoting prevention programs that require the media's attention to increase public awareness. The team needs to have a media strategy.

This strategy should include:

- Responding to requests from the media*
- Working with the media to promote prevention*
- Using social media*

Responding to Requests from the Media

It is suggested that teams 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 it is also a responsibility of the entire community.*
- The review team supports the public's right to know what it does without discussing individual cases.*
- 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 public to reach its goals.*



CRITICAL FACTORS IN DEVELOPING THE TEAM'S POLICY

Chain of command for release of information: Identity in the policy who should respond to each media request. Agencies should be allowed to respond directly to media inquiries that seek to gain knowledge about their agency.

Procedures: Outline the basic steps to be followed when information is requested. Remember that a “one size fits all” procedure does not work. The team will need different procedures for different types of information requests.

Confidentiality: Applicable statutes and the team’s confidentiality policy should set the limits around information sharing. The media policy should restate its confidentiality policy and the statutory mandates under which it is established.

The 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.

The spokesperson should be:

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

Working with the Media to Promote Prevention

The media can be very effective in promoting the findings and recommendations. Many of the member agencies will have media experts who should be consulted in developing a media strategy.

The team will need to identify the social media venues and other available media outlets within the community and key contacts within each outlet or medium to be proactive. The team should have a clear vision of what messages to disseminate, who the target audience is, and what media platforms will be used.

Tips for Effective Use of Social Media¹

Schedule social media content in advance:

Scheduling saves time on a day-to-day basis and helps develop a content calendar. Efforts are more organized and deliberate. Content calendars and planned content serve as a backbone for consistent sharing—and from there, you can supplement with further engagement with your audience.

Post interactive content to encourage engagement:

This includes things such as Running Twitter polls, hosting Q&A sessions on Instagram, posting Facebook surveys, or asking your target audience to share their stories through a regular status update. Include hashtags to increase your reach.

Use visuals to drive website traffic:

People are three times more likely to engage with tweets containing photos and videos.

Respond Quickly:

Dedicate a staff person to responding to social media to respond and engage with viewers quickly.

Learn popular and new social media platforms:

Stay on top of emerging social media platforms but be wary of those that require payment.

1 Borrowed from "Social Media for non-profits: how to make an impact with little budget." <https://www.sendible.com/insights/social-media-for-nonprofits>

Coordinating with Other Review Teams

Today in the United States, in addition to CDR, there are active networks of maternal mortality reviews (MMR), fetal and infant mortality reviews (FIMR), specialized child maltreatment reviews through citizens review panels (CRP), domestic violence fatality reviews (DVFR), suicide reviews, vulnerable adult, overdose fatality, and elder abuse fatality reviews. The unifying feature of these different types of fatality reviews is that they are wide-angle, multidisciplinary case studies conducted in a climate that promotes open discovery of information.



Because many of these reviews share similar purposes and include the same agencies as CDR, **it is crucial to identify how CDR can coordinate with these other reviews.**

Deaths across the life span often have intertwined risk factors. Coordination can help review teams share information and findings, thereby understanding the links between fetal, infant, child, maternal, spousal/partner, and elder deaths. Some teams currently conduct joint meetings to share information. For example, in a situation where a family has died due to domestic violence, CDR and domestic violence review teams can meet for one review.

Coordination can also minimize duplication of efforts and create economies of scale. Some programs utilize one coordinator to manage several review programs, identify cases for reviews, or collect case information. Some programs use one data analyst to manage data collection, analysis, and reporting for all reviews.

Coordinated fatality review findings and recommendations are more likely to be acted upon. In several states, the different review programs and teams are beginning to issue one report instead of several, giving greater power to their recommendations. Visit the National Center's website for examples.



Many national meetings have been held to identify and create best practices for enhancing collaboration between reviews.

Specific recommendations resulting from these meetings and the guidances include:

1

Consolidate the management and administration of review programs:

- Assign one agency to coordinate/administer all teams.
- Consolidate staff resources and money.
- Conduct joint training.

2

Improve communication during the case review processes:

- Get to know each other's review processes and team members.
- Educate each other about review approaches and underlying philosophies.
- Establish formal liaisons between review teams and have members serve on multiple teams.
- Work together to identify common case findings and processes for case reviews.
- Cluster reviews by types of deaths, hold joint reviews, or collaborate on reviews where there are areas of overlap.



3

Standardize or link data collected from reviews:

- Develop unified data collection instruments that standardize questions and data elements for all types of deaths and reviews.
- Consolidate or link databases.
- Compile and aggregate raw data across reviews into a centralized data clearinghouse.
- Share data with other teams.

4

Coordinate recommendations, reports, and interventions to prevent deaths:

- Develop unified data collection instruments that standardize questions and data elements for all types of deaths and reviews.
- Consolidate or link databases.
- Compile and aggregate raw data across reviews into a centralized data clearinghouse.
- Share data with other teams.

For additional information on collaborating across reviews, view the [National Center's Collaborating Across Review Systems Training video](https://mediasite.mihealth.org/Mediasite/Play/9d44e60d358a48289240fba409d422e21d?catalog=db105963a5d-642c9b6237f5de124c02a21) (URL: <https://mediasite.mihealth.org/Mediasite/Play/9d44e60d358a48289240fba409d422e21d?catalog=db105963a5d-642c9b6237f5de124c02a21>).

Data Collection

The individual case review of a child's death should catalyze local and state action to prevent other deaths. It is important to systematically collect data and report on the review findings over time to help develop prevention and change systems. Compare review findings with child mortality to help develop prevention and change systems.

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 and 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.*
- State and local teams use the reports to demonstrate the effectiveness of their reviews and advocate for funding and support for CDR programs.*
- National groups use state and local CDR findings to inform national policy and practice.*

Forty-seven states use the National Fatality Review-Case Reporting System (NFR-CRS), facilitating standardized, comprehensive, multidisciplinary data on every case. NFR-CRS allows jurisdictions to immediately access their data, run pre-programmed standardized reports, and export data for analysis. To learn more, visit the [NFR-CRS webpage](https://www.ncfrp.org/data/nfr-crs/) (URL: <https://www.ncfrp.org/data/nfr-crs/>).



Conclusion

Team coordinators play a vital role in every aspect of a CDR team—from getting it off the ground to ensuring that it is effective and sustainable over time. They are point people who organize the team, address conflict and ethical concerns, and work with the media. They also help keep the team on track and focused on its goals. The coordinator’s vision that connects individual components of the fatality review process—high-quality death investigations, records access, and strong community collaboration—to the overarching goal of reducing fatalities is a powerful motivator to both the team and the community to support prevention efforts.

Nearly 1400 communities across the United States, U.S. Territories, some Tribal jurisdictions, and the District of Columbia benefit from coordinators who undertake the role and responsibility of leading case review teams. Their commitment, courage, and ingenuity inspire the National Center’s work to ensure they have the resources they need to do their work effectively. The final resources included in this section of the manual have been developed to support coordinators in their efforts to establish and lead CDR.

Tools to Support Coordinators

To support the efforts of the CDR coordinator, here is a summary of selected resources. In addition to the resources below, the National Center encourages coordinators to examine the [Tools for Teams section](https://www.ncfrp.org/cdr/tools-for-cdr-teams/) (URL: <https://www.ncfrp.org/cdr/tools-for-cdr-teams/>) of its website, www.ncfrp.org. Should coordinators have additional questions, they should contact their state CDR coordinator or the National Center.

- Local coordinators and teams can locate their state CDR coordinator on the [Map of Programs](https://www.ncfrp.org/cdr-map/) (URL: <https://www.ncfrp.org/cdr-map/>).
- Contact the National Center with inquiries by emailing info@ncfrp.org.
- [Request for Medical Records](https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/Tools-medrecords.pdf) (URL: <https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/Tools-medrecords.pdf>).
- [Request for Cross-jurisdictional Assistance](https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/Tools-crossjuris.pdf) (URL: <https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/Tools-crossjuris.pdf>).
- [Guidance on Improving Coordination with FIMR](https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/FIMR-CDR-Collaboration-Report.pdf) (URL: <https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/FIMR-CDR-Collaboration-Report.pdf>).
- [Improving Coordination with the Department of Defense Military Reviews](https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/GuidanceCoordMilitary-CivilianReviews.pdf) (URL: <https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/GuidanceCoordMilitary-CivilianReviews.pdf>).
- [Improving the Coordination of Fatality Review Programs with American Indian and Alaska Native Communities](https://www.ncfrp.org/wp-content/uploads/Guidance_AIAN.pdf) (URL: https://www.ncfrp.org/wp-content/uploads/Guidance_AIAN.pdf).

This guidance was made possible in part by Cooperative Agreement Numbers UG7MC28482 from the US Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB) as part of an award totaling \$944,745 annually with 0 percent financed with non-governmental sources. Its contents are solely the responsibility of the authors and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

Copyright © July 2021 MPHI



Center for Fatality Review & Prevention

www.ncfrp.org



Section Four: Child Death Review

Effective State Advisory Teams for Child Death Review

National Center Program Manual

TABLE OF CONTENTS

- Introduction 4
- Team Composition..... 5
 - Leadership 6
 - Membership 7
 - Prevention Partners 10
- Roles and Responsibilities.....12
 - Mission, Vision, and Objectives..... 12
 - Regular Meetings..... 12
 - Conduct State-Level Reviews 12
 - Training and Technical Assistance..... 13
 - Needs Assessments..... 15
 - Understand Case Review Findings..... 15
 - Making Findings and Recommendations16
 - Disseminate and Amplify Data, Findings, and Recommendations 17
 - Advocate for Local Teams 18
 - Education for State Advisory Team Members 19
- Common Features20
 - Subcommittees 20
 - Reporting..... 20
 - Alignment with Other Review Processes 21
 - Specific, Time-Limited Focus 22
- Tips.....22
- Questions to Ask as a State Advisory Team Member.....24
- Conclusion.....25

Section Four: Child Death Review

Effective State Advisory Teams for Child Death Review

Introduction

The majority of state child death review (CDR) systems have a state-level advisory team. These state-level advisory teams may be named various things, including a state advisory team, a state advisory board, or a state council. For this chapter, the term state advisory team is intended to capture all these names. Depending on the jurisdiction, the state advisory team may be required by legislation or other agency-level policy. In some states, case reviews are only conducted at the state level.

This section is written to provide an overview of the makeup, roles, responsibilities, and common features of effective state advisory teams.

Case review team makeup, roles, responsibilities, and common features are discussed further in Section One and Section Two of the CDR Program Manual.

A state CDR system is comprised of several components, typically local review teams, a state advisory team, and staff from the state CDR program. CDR systems are most effective when all of the components work together to improve the health and safety of the community.



Team Composition

The multidisciplinary nature of CDR is one of its defining features. Convening professionals from diverse disciplines who serve families, respond to fatalities, and conduct investigations equips teams to understand child deaths and create actionable and appropriate prevention findings and recommendations. This is true regardless of whether the state advisory team reviews cases or not. While state advisory team makeup discussed in this chapter may vary somewhat, the most effective teams prioritize a broad and diverse set of agencies and professionals representing similar professional disciplines to those represented on case review teams. Additionally, state advisory teams should have representation from the marginalized communities within the state.

Leadership

Child deaths have complicated root causes and implications. Depending on an individual's professional lens, it may be easier to define child deaths as a medical problem, a public health problem, a child welfare problem, or even a problem requiring a legal response.



Regardless of differing case selection criteria or which agency spearheads the advisory team in different states, **the shared goal of CDR is to prevent future deaths.**

Depending on the case selection criteria for CDR in different states, it may be more appropriate for a particular agency to convene and lead the state advisory team.

State advisory teams are commonly led by one of the following four agencies:

- 1 State Health Department:**
As the agency that tracks fatality statistics through vital records systems, state advisory teams are commonly led by either maternal and child health (MCH) or injury and violence prevention programs within the state public health agency.
- 2 Medical Examiner or Coroner's Office:**
As the agency most likely to have thorough information from the investigation, the office of the medical examiner or coroner may be tasked with leading the state advisory board. These offices sometimes sit within a state public health program as well.
- 3 Child Protective Services Agency:**
As the agency likeliest to have information on underlying risk related to children's physical and mental health and wellbeing, advisory teams are often led by child welfare agencies.
- 4 Department of Justice or Attorney General's Office:**
As the agency that responds to many cases of untimely deaths of children and the lead law enforcement body in states, some advisory boards are spearheaded by departments of justice or attorneys general.



Membership

While the previous four agencies should be consistently represented on state advisory bodies, other professionals should be included.

EFFECTIVE ADVISORY TEAMS

Effective advisory teams should consider membership from a broad swath of state agencies to position the advisory team to advance recommendations and influence agency policy based on case review findings and recommendations.

These professionals should represent the state-level bodies and have unique expertise in or access to:

- Interactions between state-level systems*
- Dissemination of information to local agencies*
- Development of agency-level policy*
- Ways in which agency policy affects local constituencies*
- Programmatic funding mechanisms*
- Legal requirements under statute and state rules*
- Legislative policy advocacy*



THE STATE ADVISORY TEAM SHOULD CONSIDER CORE MEMBERSHIP FROM THE FOLLOWING DISCIPLINES:

1

State Public Health:

The state health department supports and funds public health surveillance and prevention efforts in local/county jurisdictions. It studies the distribution of risk factors and poor outcomes within the state and can address risk through education campaigns, public health policy and guidelines, and interventions. The two most common public health programs represented are maternal and child health and injury and violence prevention, though others, such as suicide prevention programs are important state-level partners.

2

Child Protective Services Agency:

State child welfare agencies are well-positioned to understand and address the root causes and impacts of deaths related to child abuse, neglect, and exposure to hazards. They can also address statewide policies that impact families' abilities to access various social services, family preservation, and substantiation of and response to child abuse and neglect.

3

Medical Examiner or Coroner's Office:

These professionals are uniquely involved in the death investigation and autopsy processes and determine the cause and manner of death. In some states, they set investigation protocols for use by local investigators.

4

Law Enforcement:

While states have multiple law enforcement agencies with different jurisdictions, state police partners most commonly sit on the state advisory boards. They are knowledgeable about death investigations, community response to fatalities, and relevant statutes that impact cases, findings, and case reviews.

5

Emergency Response Agency:

Emergency medical services and fire departments are frontline responders to child deaths. They have unique insights that enrich case reviews, findings, and recommendations. Like law enforcement, their agencies are directly involved in response to fatalities, and their input on the feasibility of specific recommendations is essential.

6**Victims Service Agency:**

Agencies who serve and advocate for victims' rights have unique access to and understanding of the needs of victims and their families. They understand the experience of families who interact with the legal system and what services may be available or missing in communities. An office of victim services can be embedded in a law enforcement body, department of health, human services, or justice department.

7**Mental Health Services Provider:**

Mental health issues underly many of the fatalities CDR programs encounter, either for the caregivers or for the children who die. Mental health professionals can inform teams about services and evidence-based interventions to address mental health needs, provide insights related to brain development, Adverse Childhood Experiences (ACEs), and the ways childhood exposures or mental health conditions can increase risk over time.

8**Board-Certified Pediatrician and Member of The American Academy of Pediatrics (AAP):**

Pediatricians provide a clinical perspective in child death cases. They can provide insight into the clinical context, community needs, and possible intervention in the health care setting. Participation in the AAP allows them to collaborate with other professionals on issues related directly to CDR in the AAP Section on Child Death Review and Prevention.

9**Hospitals:**

Hospitals that serve children have a unique view of pediatric and community needs, service delivery, and emergency response systems. They can provide perspectives from clinical specialists and explain referral processes, billing, and insurance reimbursement processes. Hospitals also employ social workers who ensure families have what they need to complete recommended treatment plans and are connected to available wrap-around services.

10**Department of Education:**

Schools are significant contributors to state advisory bodies, as they can share the health and safety information embedded in the curriculum, trends in student outcomes and experiences, and what kinds of services and interventions are available through the school districts.

11**Department of Transportation:**

Agencies responsible for highway maintenance and safety have a unique understanding of community-level risk, including transportation access, use, and relevant licensing requirements.

Prevention Partners

In addition to state agencies, prevention-focused coalitions and non-profits are valuable participants in state advisory teams for CDR. They are already educating families and conducting targeted efforts to increase safety and reduce the risk for certain cause-specific fatalities. They often have well-established relationships that provide access to families and community agencies to help deliver consistent prevention messages.

Some of these prevention partners include:

Safe Kids Coalitions:

Safe Kids Coalitions take action to provide proven and practical ways to keep kids safe by hosting safety-focused events, conducting workshops in schools and hospitals, advocating for effective legislation to help keep children safe, and distributing safety devices such as car seats, smoke and carbon monoxide detectors, helmets, and personal flotation devices. To learn more about Safe Kids Coalitions and to connect to state and local coalitions visit the [Safe Kids Coalition webpage](https://www.safekids.org/safe-kids-coalitions-united-states) (URL: <https://www.safekids.org/safe-kids-coalitions-united-states>).

State Chapters of the American Academy of Pediatrics (AAP):

Every state has chapters of the AAP that work to achieve optimal health and wellbeing for children. They facilitate providers' education and practice support for pediatric care providers, initiatives, and advocacy at the state and local level. To learn more about AAP Chapters and connect to state or regional coalitions, visit the [AAP Chapters webpage](https://services.aap.org/en/community/chapter-websites/) (URL: <https://services.aap.org/en/community/chapter-websites/>).

Children's Hospitals:

In addition to providing clinical and wrap-around services, children's hospitals serve as regional hubs for the range of services available for children. They employ specialists from across the spectrum of pediatric medicine, including mental health care providers. Representatives from children's hospitals will be familiar with the types of risks most prevalent in children and youth, from medical issues to injuries. Additionally, they often spearhead pediatric health, safety, and injury prevention initiatives and campaigns.

Infant Mortality Reduction Coalitions:

Many states—especially those who may struggle with higher rates of infant mortality or disparities in infant mortality outcomes—have infant mortality reduction coalitions or task forces already in place. These may or may not be Fetal and Infant Mortality Review (FIMR) programs. They are commonly associated with state health departments or maternal child health home visiting programs. They are likely to have rich insights into families’ challenges and be well-connected to the infant safe sleep efforts taking place in the state.

Equity-focused Partners or Advocates:

Disparities in access and outcomes by race, gender, sexual orientation, gender identity, geography, and socioeconomic status are among the most compelling findings of fatality review programs. Many non-profit organizations specifically focus on addressing these disparities. Often, state government entities, including health departments or social services agencies, focus on eliminating disparities and advancing health equity. They may have staff specifically dedicated to examining and addressing these issues. Identifying advocates who focus on advancing health equity will meaningfully inform state advisory efforts to address disparities that drive poor outcomes.

Other Non-Profit Groups or Advocates:

One of the best resources in any community or state is the investment and commitment of non-profit partners and advocacy groups. Bringing them to the table provides perspective from organizations who are trusted community members already working on its behalf. These organizations may be civic organizations like the Shriners, philanthropic organizations that regularly invest in local communities, or religious community representatives.



Roles and Responsibilities

In addition to an effective, diverse membership, state advisory teams need a clear understanding of their role in the state's overall child fatality review and prevention effort and their responsibilities. Summarizing these expectations allows invited members to understand what they agree to when deciding to serve on the team.

Mission, Vision, and Objectives

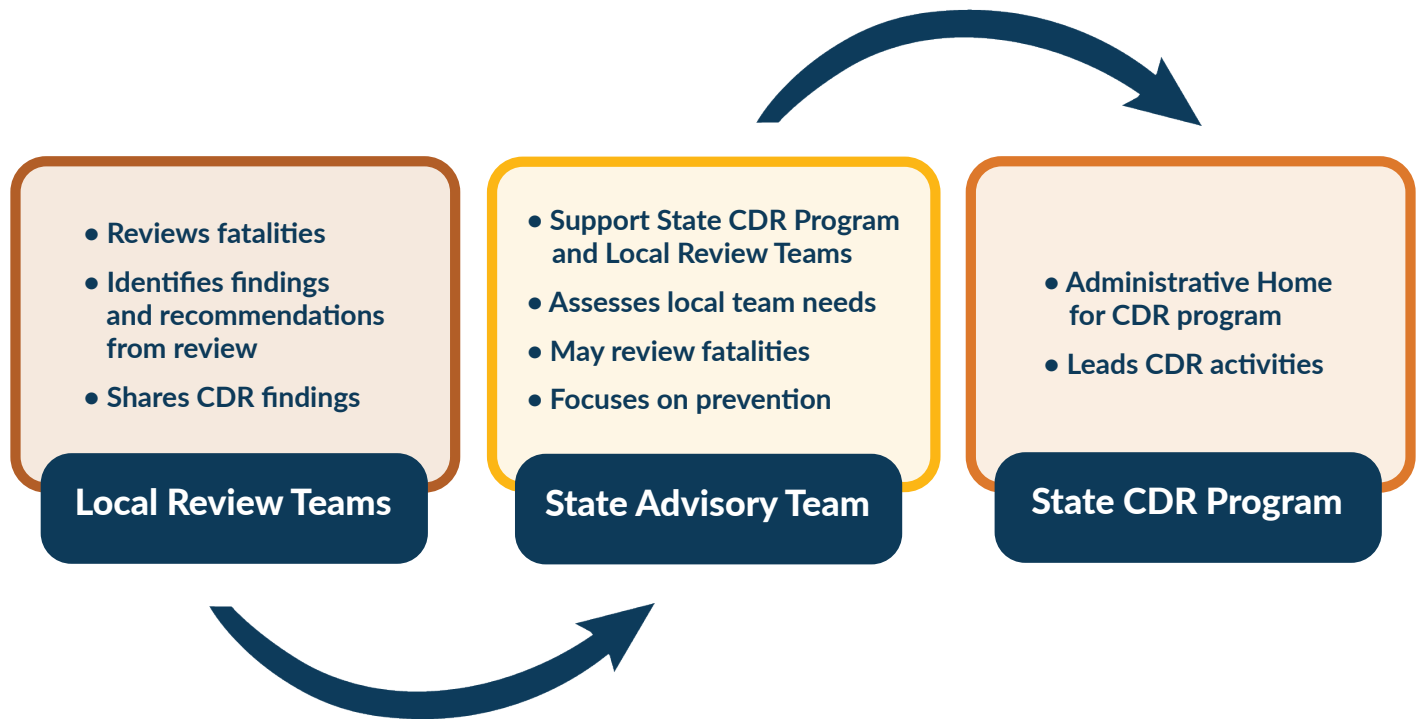
Establishing a consensus-based mission statement, vision statement, and team objectives allows team members to provide input into the ongoing effort of the state advisory team. While some may be prescribed by legislation or agency policy, team members can still provide insights to shape these documents that guide team efforts. Revisiting these statements every few years to determine if the team aligns with the mission, vision, and objectives is an effective way to re-focus team efforts. State advisory teams can also evaluate if the current mission, vision, and objectives are still meeting the program's needs and can amend them at this time. Finally, teams should decide how to measure success relative to team objectives and at what intervals.

Regular Meetings

There should be clear expectations about how often state advisory team members will convene, and annual schedules should be distributed at the beginning of the year, be it a funding year or a calendar year. State advisory teams commonly meet quarterly. A thoughtful, standing agenda that aligns with the team objectives is a helpful way to standardize meetings.

Conduct State-Level Reviews

In some states, the state advisory team also conducts individual case reviews, makes findings from the individual cases, and creates recommendations based on aggregated case data and findings. If a state child fatality review system includes local teams, the case reviews are typically conducted at the local level. Even in states with local teams, the state advisory team should make itself available to conduct reviews under particular circumstances or if requested by a local team. If a specific fatality had such a profound impact on the community that individual local team members may have difficulty conducting the review, they might request the state team review the case. This may also be appropriate in complicated cases, such as a mass casualty event. Additionally, the state advisory team may want to know more about an identified issue, deciding to review a sample of cases due to a specific cause. They may also decide to review a subset of cases for quality assurance purposes or better to understand the local teams' case review process. If the state advisory team conducts individual case reviews, it will be important to address confidentiality considerations. [Read more about conducting effective case reviews in Section Two.](#)



Training and Technical Assistance

A state’s CDR system benefits from training and technical assistance from the state level. The state advisory team is well-positioned to plan, create, and often provide training opportunities for local review teams. State advisory team members often understand the processes for accessing relevant records needed for a comprehensive case review. As leaders in partner agencies, they understand what training may exist relevant to child fatality review activities and gaps.

Some state fatality systems provide annual training opportunities for teams. These trainings often cover topics such as: relevant state policy that governs fatality review activities, effective child death scene investigation, an overview of the roles and responsibilities of the different partner agencies participating in case reviews, ways to access records, how to create effective findings and recommendations, data entry, data quality, and prevention implementation.

The state advisory team can also provide technical assistance to local review teams, creating guidance for how local teams operate and helping them improve their processes. State advisory teams commonly provide guidelines and protocols for local case reviews.

Technical assistance is an umbrella, and there's often a lot of overlap with training, but commonly it includes providing individualized consultation or formal or informal guidance on how to:

-  Convene partners and launch a new team
-  Maintain a team over time
-  Access necessary records in the state context
-  Engage new partners
-  Enter data
-  Align the efforts of the local team with state priorities
-  Ensure local reviews follow state policy
-  Create case findings
-  Write prevention recommendations

Training and technical assistance opportunities can also include education on cause-specific fatalities, emerging trends in child fatalities, and prevention efforts. The National Center is available to provide training and technical assistance. Email info@ncfrp.org to request training.



Additionally, the National Center has created a series of topic-specific training modules that can be used to support fatality review training efforts. They are available on the [National Center Website](https://www.ncfrp.org/training-modules/) (URL: <https://www.ncfrp.org/training-modules/>).



Needs Assessments

State advisory teams should consider implementing a method for local team coordinators to request individualized consultation and technical assistance. Some state advisory teams may make one of their annual meetings open to local coordinators for this purpose.

A common way to assess individual and overall needs across the state fatality review system is by conducting a needs assessment. A needs assessment can provide an opportunity for local teams to respond to both quantitative and qualitative questions—identifying the types of technical support they need most and giving them a platform to communicate with state-level stakeholders. While needs assessments are commonly conducted by state program staff, state advisory teams should provide input into the assessment. State advisory teams can help develop the types of questions and review and discuss the needs assessment findings, using them to help them prioritize technical assistance and training plans.

Examples of needs assessments can be found on the [Community Resources page](https://www.ncfrp.org/community-resources/) (URL: <https://www.ncfrp.org/community-resources/>) on the National Center website.

Understand Case Review Findings

The state advisory team should clearly understand local teams' case review data, findings, and recommendations. Aggregated case data should be reviewed regularly. This can be done in multiple ways. In some states, a data summary is distributed at or between meetings; in others, an epidemiologist or data analyst may deliver a summary data presentation.

The breadth of fatality review data is significant, but generally, state advisory teams examine:

- Leading causes of death*
 - Causes of death by age*
 - Demographic breakdown of cases by type*
 - Regional differences in cases*
 - Risk factor prevalence in leading causes of death*
 - Case review findings: For more information on findings, visit the [National Center website](https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/Findings_Guidance.pdf) (URL: https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/Findings_Guidance.pdf)*
 - Prevention recommendations from local teams*
-

State advisory teams should synthesize data from the local review teams, identifying shared risk and protective factors between communities, cases, and different types of deaths. These shared risk and protective factors are important intervention points with significant potential to reduce risk statewide, across causes of death. Local teams may not have access to enough case review data to identify these factors quickly.

Making Findings and Recommendations

Even though local teams may be conducting a review, making case findings, and creating recommendations, the state advisory team should create state-level prevention recommendations based on aggregate data and local findings. State-level findings may look similar or significantly different from the recommendations of local teams, as the state advisory team has a broader, statewide perspective on all the deaths, and it has access to state-level agencies that local programs may not. Often, state-level recommendations seek to improve state-level policy and responses, focusing on the shared risk or protective factors identified in the data review.

The team members themselves may be able to take prevention recommendations and work for implementation. They may identify the appropriate existing group, or individual best positioned to do the prevention work.



Disseminate and Amplify Data, Findings, and Recommendations

Even the highest quality data will have little impact without effective dissemination. While state CDR system approaches vary, the most critical consideration in approaching dissemination of data, findings, and recommendations is that team members consider how to strategically approach sharing the results of the case reviews for maximum prevention impact.

State advisory team members are excellent liaisons to share the state's case review data and findings with their respective agencies and organizations. As leaders, they can share data in other workgroups, task forces, or advisory bodies. They can also provide input on a state-level data dissemination plan, strategizing ways for the data to be seen by other leaders and decision-makers, including local and state government officials. Many states accomplish this by producing an annual report. In addition to summarizing data, it can summarize local findings and recommendations and highlight ongoing prevention activities implemented due to child death review.



When considering audiences for the aggregated data, **include local communities.**

If local teams conduct reviews, they are an obvious and important audience, as they should see the data to which they contributed, and they can share the data with their local partners. If local teams are not reviewing cases, the local community audience is still an important one. Consider sharing the data with county commissioners, mayors, or school districts.

Typical audiences for fatality review data include:

- Participating agencies, including child welfare, public health, schools, or pediatric practices*
 - Policy makers*
 - Maternal, infant, or child advocacy organizations*
 - Local review teams*
 - Funders*
 - Community-based organizations*
 - Media*
 - Healthcare systems, including providers and insurance companies*
 - State and local membership organizations such as a state coroners association or network of child abuse resource centers*
-

***It is important to understand state data reporting requirements, including minimum numbers, locations, and other confidentiality issues, before sharing data with internal or external partners.**

Similar to data dissemination, the state advisory team can have a strategic role in amplifying the findings and recommendations from the local and state reviews. This can be by being a champion for the recommendations in other contexts or advocating for a specific recommendation to a key stakeholder or in a relevant agency or collaborative context.

Advocate for Local Teams

In states with local review teams, the state advisory team members should leverage their state-level influence to reduce barriers for local team operations.

This can play out in different ways, but a state agency can streamline or clarify policies or processes that impact local teams, such as access to records or local team member participation.

Education for State Advisory Team Members

A state advisory team is an excellent place for team members to educate each other about multiple relevant topics, including fatality and responses to fatalities. Experts on specific causes of death can share insights with team members about risk and prevention, helping them better understand the data they examine from case reviews. Team members may request a presentation on ongoing evidence-based interventions before finalizing state-level recommendations. Team members can also educate each other on what an appropriate agency-level response should look like, providing insights into what recommendations may be reasonable and feasible for local partners to implement.



Common Features

In addition to a clear understanding of their roles and responsibilities, state advisory teams have found specific approaches and structural considerations to increase their effectiveness.

Subcommittees

Subcommittees of state advisory teams often focus on cause-specific fatalities or shared risk factors; they are commonly tasked with writing or refining recommendations or education or prevention work of some kind. The subcommittees can also educate the larger team on their focus topics or operate as an implementation body to advance fatality review recommendations.

Common subcommittees include:

- Sudden Unexplained Infant Death*
- Sudden Death in the Young*
- Overdoses*
- Child Abuse and Neglect*
- Medical Deaths*
- Suicide*
- Health Equity*
- Motor Vehicle Crashes*

Reporting

Many states are required to report on CDR data, findings, and recommendations annually. This may align with ongoing data dissemination strategies or sit outside them. State advisory team members can serve as advisors, contributors, and reviewers for published reports. Subcommittees can help support these efforts if they take a deeper dive into specific data within their topic areas.

Alignment with Other Review Processes

Multiple states have a range of fatality review processes in addition to CDR. The most common include:

- Citizen Review Panels (CRPs)
 - Agency-level reviews, especially related to child abuse and neglect fatalities
 - Fetal and Infant Mortality Review (FIMR)
 - Maternal Mortality Review (MMR)
 - Overdose Fatality Review (OFR)
 - Suicide Reviews
 - Child Abuse and Neglect Reviews
-

It is common for a specific death case, case findings, or recommendations to be similar between teams when a death falls into more than one of these review processes' purview. A teen mother dying in a motor vehicle crash, a sudden unexpected infant death, or an overdose suicide would be instances in which more than one team may review the same death in a case review.

Strategic alignment of these parallel processes with an eye toward collective impact is important to reduce redundancy and advance prevention. This is an area where a state advisory team can be incredibly effective, partnering with other review processes to advance shared recommendations.

Information about collaboration between FIMR and CDR, view the National Center's [FIMR and CDR Collaboration Report](https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/FIMR-CDR-Collaboration-Report.pdf) (URL: <https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/FIMR-CDR-Collaboration-Report.pdf>).

Specific, Time-Limited Focus

As an alternative to topic-focused subcommittees, some state advisory teams will choose to take a time-limited team focus on a specific topic area based on identified trends, leading risk factors, or specific types of fatalities. When multiple states saw alarming increases in suicide deaths, some state advisory teams undertook a focus on understanding how suicide impacted local communities, what factors were protective or increasing risk, and what prevention strategies had been proven to be effective. State teams can serve as a statewide leader in advancing education, awareness, and prevention through these efforts.

Tips

When it comes to convening, participating in, or leading a state advisory board for CDR, these tips will help increase effectiveness, engagement, and team impact.

1

Follow the data:

Committing to a data-driven process will ensure that team recommendations and prevention activities address the most significant issues driving infant and child fatalities. Cultivate relationships with data analysts and epidemiologists within the state team, ask for their insights, and clarify the data. Track the data over time to identify changes or trends.

2

Create a feedback loop to local teams:

If local review teams review cases, ensure that they are informed of state advisory team activities. Some states provide a newsletter or an annual update to local partners. Review teams should be confident that their work reviewing cases matters and is making an impact. This helps sustain the engagement of local team members and lends credibility to local case review efforts.

3

Champion the work of local teams:

Advocate for the work of the local teams within individual agencies and be available to answer questions from local teams.



4

Advance health equity:

If a state advisory team reviews cases, focus on social factors that may have increased risk for the children whose deaths are reviewed. Think especially about what risk may be most common in marginalized populations, including racial and ethnic minorities, children with lower socioeconomic status, and LGBTQ+ children and youth. When crafting or implementing recommendations, consider how recommendations will impact these populations and if there could be any unintended consequences.

5

Prioritize partnership:

The CDR process hinges on effective partnerships. Look for opportunities to build reciprocal relationships with other team members, agencies represented on the board, and other groups who support health and safety, understanding that improving these relationships will help achieve collective impact toward decreasing risk for children and youth.

6

Model self-care:

The experience of participating in CDR can be challenging. Team members should be offered opportunities to engage in self-care activities to minimize the risk of burnout, compassion fatigue, and secondary trauma. The state advisory team can set the example by engaging in self-care activities and sharing those opportunities with local teams that conduct case reviews.



Questions to Ask as a State Advisory Team Member

As a state advisory team member, it is helpful to personally evaluate your relationship to the work—both at the state and the local level. These questions can help team members creatively consider how they can individually contribute to the larger work of child fatality review.

- *What expertise or access do I have that can support review or prevention efforts?*
- *How can I champion prevention efforts within my own agency? To outside groups?*
- *How do the state-level systems impact local outcomes?*
- *What can I do at the state level that local partners may not be able to do?*
- *What other expertise, skills, or input would make these efforts more effective?*
- *What traditional and non-traditional partners am I connected to that can help advance these efforts?*



Conclusion

State advisory teams have an important role in the overall effectiveness of a state's child fatality review system. They can take local findings from far-flung communities, examine them together, and clearly picture the burden of fatalities in infants, children, and youth statewide. Their insights can help refine case review processes at both the state and local levels; their advocacy can reduce barriers for effective case reviews; and their leadership can advance prevention efforts driven by case review data.

State advisory teams must have a clear understanding of their roles, provide leadership and guidance to case review teams, and advance the prevention recommendations that arise from case reviews to prevent future deaths.



This guidance was made possible in part by Cooperative Agreement Numbers UG7MC28482 from the US Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB) as part of an award totaling \$944,745 annually with 0 percent financed with non-governmental sources. Its contents are solely the responsibility of the authors and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

Copyright © July 2021 MPHI



www.ncfrp.org