Purpose

The death of a child is a tragedy that should invoke a community response. In most child deaths, the circumstances are multidimensional and responsibility does not rest in any one place.

The purpose of this guidebook is to establish the need for child death review and assist communities in starting the child death review process.

Acknowledgments

Children’s Health Alliance of Wisconsin (Alliance) leads the Keeping Kids Alive in Wisconsin program through funding and support from the Wisconsin Department of Health Services (DHS) Maternal and Child Health Title V Program. These guidelines were developed in partnership with DHS to build a comprehensive, statewide child death review system and offer consistent guidance to local review teams.

The Alliance also receives funding from the Wisconsin Department of Justice to support child death review, and from the Centers for Disease Control and Prevention for participation in the Sudden Unexpected Infant Death and Sudden Death in the Young Case Registry.
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“Nothing compares to the death of a child, in the sadness, the sense of loss, the unfulfilled promise. It reverses the natural order, and challenges our belief in a universal good.”

- William H. Perloff, MD
I am the mother of Brian Jacob Paulus. He was a silly, happy three-year-old who loved soccer, Skittles candy, McDonald’s Playland, and running around with little on but his boots.

Finally, he got to go and spend a weekend at grandpa’s cottage and hang out with dad and all of the other guy relatives. He gave me one last kiss and in his usual Brian way shouted to me, “Goodbye doodyhead!”

An officer showed up at my door and told me Brian wandered out of grandpa’s cottage in the middle of the night and fell into the nearby pond. This should not have happened! Brian died of an unintentional, but preventable injury: near drowning.

The loss of one child is immense. Everyday my heart hurts. I miss Brian’s hugs and sweet silliness. Dad misses his buddy. His sister, Sara, struggles with not having her brother to grow up with. Alyssa, born after Brian died, struggles with the sadness of never having the chance to know her brother. The world is missing out on Brian. He had so much to offer!

So many kind people helped us, but were also at a loss of what to do. “If there is anything I can do, let me know,” they would say. Child death review is the answer to this question.
In the words of Dr. Perloff, Brian’s doctor and the first chair of the state CDR Council, “A measure of a society’s worth is how well it cares for its most vulnerable members. How then can we not treat the loss of even one child as an event to be prevented? To do this we must study each child death to learn the lessons contained in the events leading to the death and find ways to translate these lessons into actions that will prevent future deaths.”

This is the purpose of the CDR Team.

I thank you for your commitment to Keeping Kids Alive. Know that your dedication makes a difference. At times, you may feel at a loss for what you can do for prevention.

Be patient. Your efforts are valuable. Each review contributes to a larger picture of how our children are dying and leads to future local, state and nationwide prevention efforts. Your compassion for attending to the needs of the family left behind helps with the grieving hearts of these people. People like you give me strength to go on. Thank you for keeping our children safe and alive.

With gratitude,

Teresa Paulus
Brian’s mom
Winnebago County Child Death Review Team
**Keeping Kids Alive in Wisconsin**

The death of a child is a tragic event. From 2008 through 2017, an average of 652 children (ages 0-17) died each year; more than 60% of these were infants younger than age 1 (Wisconsin Interactive Statistics on Health, 2018).

Many of these deaths are preventable, but require a better understanding of risk factors in order for effective prevention initiatives to be developed and implemented.

Death records provide statistics on the number of Wisconsin child deaths and causes. However, we know very little about the specific circumstances, such as who, what, when, why and how.

Many questions remain unanswered, such as: How was the death investigated? What services were provided to the family and community? Did state and local agencies review their policies, programs and actions as they related to the death, or take action to prevent similar deaths?

Child death review (CDR) aims to answer these questions in order to understand how a child death may be prevented. The goals of CDR are to:

- Improve our understanding of how and why children die
- Identify the need to influence policies and programs
- Improve child health, safety and protection
- Prevent other child deaths

CDR teams were originally established throughout the country to identify and prevent child deaths caused by abuse and neglect. However, like a number of other states, Wisconsin desires a broader death review process that addresses all preventable child deaths from a public health perspective. This public health approach not only addresses under-reporting of maltreatment-related deaths, but also promotes better understanding of all causes of potentially preventable child deaths.

In 1999, the Department of Justice (DOJ) created a state CDR team under the federal Child Justice Act grant. At that time, Wisconsin was one of 12 states without a statewide CDR program.

In 2006, the Department of Health Services (DHS) called upon the Alliance to develop a comprehensive county-based CDR and fetal infant mortality review (FIMR) system as part of its maternal and child health program. This system was named Keeping Kids Alive in Wisconsin (KKA). Given the focus on health, safety and prevention, the state CDR team was formally transferred from the DOJ to DHS in 2010.

KKA is modeled after the National Center for Fatality Review and Prevention’s recommended CDR and FIMR frameworks. The Alliance is contracted by DHS to provide technical assistance to Wisconsin CDR and FIMR teams.

More than 50 of Wisconsin’s 72 counties have a CDR or FIMR team. These multidisciplinary teams work to
understand how and why children die in order to improve interagency communication and cooperation, investigation methods, and delivery of services to families that have lost a child.

DHS supports local CDR and FIMR, however, Wisconsin remains one of six states without specific CDR legislation.

DHS and DOJ partner to encourage and facilitate the development and ongoing work of local teams. These state partners are committed to providing guidance, technical assistance and training to foster a statewide, coordinated CDR program.

The ultimate goal of Keeping Kids Alive in Wisconsin is to prevent future deaths by applying a public health approach to prevention.
Wisconsin Child Death Review State Advisory Council (Council)

The Council is a multi-disciplinary group that advises the Keeping Kids Alive in Wisconsin program. The mission of the Council is to prevent child death and injury through local multidisciplinary reviews, leading to community prevention. The Council seeks to:

1. Facilitate the development of local/regional CDR and FIMR teams
2. Identify training needs and make training resources available to local teams, statewide professional organizations, advocacy groups and others
3. Respond to local requests and provide any necessary technical assistance and support
4. Review infant and child deaths upon request of a local CDR team, or when a county does not have a team
5. Educate the public regarding the incidence and causes of fetal, infant and child deaths, including recommendations that identify needed policy change or action to prevent future deaths
6. Provide information to the legislature, state agencies and local communities on the need for modifications to law, policy or practice
7. Utilize prevention-focused data analysis to facilitate the above purposes
The Council is comprised of members who represent a related field, provide a contributing perspective, are invested in reducing deaths, and committed to prevention of future injuries and deaths. The Council was housed in the Department of Justice until 2010 when it transitioned to the Department of Health Services. A list of Council members can be found on the Alliance website.
“Every child who dies or suffers serious injury has a story that could help another child and family. Child death review is essential if we are to learn from these stories and prevent the next tragedy.”

- Lynn Sheets, MD, FAAP
Child Death Review

What is the purpose of implementing a CDR team?

The purpose of child death review is to prevent future deaths. The death of a child should invoke a community response, but in order to respond we must learn and understand what happened.

A CDR team is a group of local professionals from various disciplines and agencies. They convene to identify and discuss the risk factors and circumstances surrounding infant and child fatalities. The information learned informs local prevention strategies.

Oftentimes, when a child dies all that is known are the cause and manner of death listed on the death certificate. Child death review strives to answer the who, what, where, when, why and how.

The goals of CDR are to:

- Improve our understanding of how and why children die
- Identify the need to influence policies and programs
- Improve child health, safety and protection
- Prevent other child deaths

These goals are achieved through the following objectives:

- Report cause, manner, risk factors and prevention opportunities for child deaths in the National Fatality Review Case Reporting System
• Improve communication and coordination of agency responses to child deaths in the investigation and delivery of services

• Create and implement standardized guidelines for the investigation of certain categories of child death

• Evaluate policy and practice changes needed to improve child health and safety

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**CDR teams are not a mechanism for criticizing or second-guessing agency decisions; they are a forum for sharing information essential to the improvement of a community’s response to child deaths.**

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**How is a CDR team established?**

Review teams are created through voluntary agency efforts and cooperation, with assistance from the Alliance Injury Prevention Initiative staff. To establish a team, one or two local agencies must be willing to commit the time and effort necessary to form the team.

Individuals interested in organizing a review team can come from various agencies. However, these individuals most often represent the local health department and coroner or medical examiner office.
Each community should adopt an approach that best suits its unique characteristics. The steps below are a general guide for establishing a CDR team, but they can be tailored to meet unique team needs. The Alliance will provide assistance in team establishment. Visit our website for contact information.

1. Identify a team coordinator. Typically, the individual who organizes the team becomes the team coordinator.

2. Identify a member or members who will collect and enter CDR data into the Case Reporting System.

3. Contact the Alliance to observe a CDR meeting in a nearby county. This may help provide you with direction on how to organize your team and recruit members.

4. Contact local agency directors or department leaders to discuss establishing a team. Agency directors and department leaders will need to identify a representative to attend meetings. The representative should be able to share expertise as well as knowledge of the child and circumstances leading to the death. The same representative should attend every meeting to promote consistency and build rapport with other team members.

5. Schedule a CDR team training conducted by Alliance staff. The training is held in person and takes about two hours. All potential team members should be invited to attend. The training will discuss:
   - The importance of establishing CDR teams
- Team member responsibilities and confidentiality
- An overview of the case review process
- The importance of data collection to prevent future deaths
- The importance of self-care

**Who should be represented on a CDR team?**

A death review is most effective when all agencies with knowledge of the circumstances before, or at the time of death are represented. Comprehensive reviews occur when the team members are:

- Drawn from community agencies responsible for the health and safety of children or investigation of child deaths
- Honest and open with one another
- Advocates for making changes to prevent child deaths

**Core members**

Core team members should attend each review meeting and represent the following agencies and disciplines:

- **Child protective services (CPS):** CPS has the legal authority to investigate child deaths and provide protection for at-risk siblings. As team members, CPS representatives provide information on families and child death investigations, including reports of neglect or abuse on a child or siblings as well as services
provided to a family. Their knowledge on issues related to child abuse and neglect are essential to understanding how similar deaths can be prevented.

- **County-based coroner or medical examiner (ME):** Coroners/MEs are central to child death investigations. All unexpected infant and child deaths are reported to the county coroner/ME who investigates the death and determines the final cause and manner. The ME or coroner lays the groundwork for discussion by presenting information about cause and manner of death, including findings from the scene investigation and autopsy.

- **District attorney’s office:** District attorneys provide information about child deaths involving criminal or civil actions. Deaths involving a crime are often not reviewed until the case has been closed. The information provided by the district attorney provides a greater understanding of the circumstances surrounding the death.

- **Emergency medical services (EMS):** EMS providers are frequently first at the scene and observe critical information regarding the circumstances, including reports from witnesses. The EMS run report also is useful in providing a complete understanding of the scene where the incident occurred.

- **Grief and bereavement:** A representative from this field is helpful in ensuring grief and bereavement resources have been provided to the family and community members affected by the death.
- **Law enforcement:** Law enforcement team members provide information on investigations of infant and child deaths. Law enforcement representation may include the sheriff and/or local police, specifically from the jurisdiction that investigated the child death. Law enforcement professionals provide context on risk factors identified in the scene investigation.

- **Mental health provider:** The mental health representative provides information regarding psychological issues related to events that caused or contributed to a death. The participation of a community mental health professional at the review can provide valuable insight into the behavior of the child and family. Additionally, mental health professionals are well positioned to assist the team with self-care.

- **Health care provider:** Health care providers offer review teams information about medical conditions and child development. The health care provider may come from several disciplines including obstetricians, pediatricians, neonatologists, perinatologists, family practice, internal medicine or hospital pathologists.

- **Public health department:** Public health members provide information on the child’s vital records and local public health services. If public health services were provided to a child or family, they can provide pertinent history and explain previous contacts. Often public health can provide a critical link between the team’s prevention recommendations and prevention implementation.
• **School district:** School district members provide teams with perspective on education and social development in children, as well as services offered by a school in response to a child death. The schools may provide leadership in implementing prevention recommendations.

• **Women Infants and Children (WIC) program:** WIC representatives provide the team with information on services provided to pregnant women, mothers and their children enrolled in WIC. The information shared provides context for identifying social risk factors contributing to the death.

**Ad hoc members**

Some teams may consider inviting additional disciplines to participate in meetings, depending on the type of case being reviewed. Typically, ad hoc members will only be invited if their agency or department was directly involved in a case. These members provide valuable information without increasing the number of core members. Examples include:

• Child advocacy centers

• Clergy

• Injury prevention specialists

• LGBTQ advocates

• Tribal members
Some CDR teams may determine an ad hoc member from the list above should serve as a core member in order to best represent the community.

**What are the team members’ responsibilities?**

Effective reviews are dependent upon full participation by all members. Member responsibilities include:

- Attend meetings
- Share case-specific information from agency records
- Serve as a liaison to professional counterparts
- Explain the legal responsibilities and limitations of his or her profession or agency
- Contribute to prevention or system change
- Share ownership for the well-being of the team, including respect for fellow team members

**What are the team coordinator’s responsibilities?**

A team coordinator is selected at the organizational meeting or prior to the first review. The team coordinator serves at the discretion of the team. Teams can decide to rotate this position. The duties included below are described in further detail throughout this guidebook.

- Schedule and set agenda for meetings
- Lead meetings and maintain professional decorum
- Send meeting notices to team members
• Obtain names and compile the case summary to be reviewed for distribution to team members at least one week prior to each meeting

• Ensure the case report is entered into the National Fatality Review Case Reporting System within one month of review

• Ensure the team operates according to the guidelines adopted by the team

• Ensure all attendees sign the confidentiality agreement

**How does a CDR team select cases to review?**

The team should review as broad a category of deaths as possible to improve their ability to identify trends, enhance prevention and develop policy. There are three major criteria for selecting cases for review by a team:

**Cause of death**

At a minimum, CDR teams should review all infant and child deaths where the coroner or medical examiner investigated the incident and signed the death certificate. For a full list of circumstances that mandate reporting to the coroner or medical examiner, please see [Wis. Stat. § 979.01](https://lawwisconsin.wiscontext.org/979.01). These deaths include, but are not limited to:

• Accidents

• Homicides

• Infant asphyxia/suffocation
- Sudden unexpected infant deaths (SUIDs)
- Suicides
- Undetermined causes

**County of residence**

CDR teams should review the deaths of infants and children who are residents of their county. Teams may also learn of the death of a resident that occurred in another county. In Wisconsin, death certificates are filed in the county where the death occurs.

The Alliance recommends a coordinated effort between resident and incident counties and will assist the team coordinators. For more information, please refer to the flow chart in Appendix A.

**Age**

At a minimum, teams should review the deaths of children ages 0-18. Teams may choose to expand the age range to include young adults. For example, a county may review all deaths ages 0-18 certified by the coroner or medical examiner, plus all deaths by suicide younger than age 26. This decision may depend on population demographics, number of cases and public health burden of the community.
How does the coordinator prepare for a CDR meeting?

1. Create a case list

There are multiple methods teams can utilize to select cases for review depending on which agency coordinates the team. Local public health departments have access to all deaths that occur in their counties through State Vital Records Reports. The Office of Health Informatics created a Vital Records Report entitled “Child Deaths Under Age 19” to assist CDR teams in creating case lists for review. Team coordinators should consult with the coroner or medical examiner to determine when cases are ready for review.

Teams should review cases after government agencies have concluded their internal investigations and the case is considered closed. Most often this will apply to law enforcement and coroners or medical examiners. A case list template can be found on the Alliance website.

2. Schedule the review meeting

Teams should consider setting a consistent meeting schedule. Meeting frequency should reflect the needs of the county and the number of deaths. More populated counties may choose to meet bi-monthly or monthly while rural counties may choose to meet less often. All teams should meet a minimum of once annually to be considered a CDR team. For example, the team will meet quarterly, on the third Monday from 11 a.m. - 1:00 p.m.
If possible, consider sending meeting dates for the entire calendar year at the end of December or beginning of January. Doing so will allow team members to save each meeting date in their calendars ahead of time. The average meeting length should be 1.5 to 2 hours.

How does the team maintain confidentiality?

Confidentiality is essential to the function of a death review team, and safeguards for the confidential exchange of information must be in place. At a review meeting, all case-specific data and information shared must be kept confidential.

- Specific case reviews should be closed to the public.

- Case information disseminated to team members before the review meeting should be sent by U.S. mail or password-encrypted email.

- Every three years, an interagency confidentiality agreement should be signed by a supervisor or department leader from each agency. See the Alliance website for an interagency confidentiality agreement template.

- All team members should sign a confidentiality agreement at the beginning of each meeting. See the Alliance website for a case review confidentiality agreement template.

- Team members should come and leave with only their records.
• All team members should agree to keep the discussions of specific case information confidential.

• Aside from the team member(s) responsible for entering data into the Case Reporting System (CRS), notes taken during the meeting should not include any case information. Notes should be limited to prevention recommendations and general updates. Meeting minutes should not include any case-specific or identifiable information.

What permits team members to share information?

Many current local, state and federal laws allow for participation and disclosure during CDR. CDR is a public health program administered by DHS. CDR teams are administered by or in coordination with local health departments, and Wis. Stat. § 250.04 requires that the department (DHS) maintain surveillance activities to detect and analyze factors affecting maternal and child health and injuries. Further, the statute authorizes the department to conduct follow-up investigations of public health problems which are causes or potential causes of morbidity and mortality.

Meetings of CDR teams may be subject to the Wisconsin Open Meeting Law (Wis. Stat. § 19.85). Each team should confer with the county Corporation Counsel for direction. Consequently, notice of the meeting, time, location and agenda may need to be posted at least 24 hours before the meeting, and be open to the public. A sample meeting notice can be found on the Alliance website.
However, a provision in the law allows for the meeting to be closed to the public when reviewing deaths and sensitive information, such as medical and social histories of individuals. When reviews of specific child deaths are to occur, the meeting can be closed to the public. Please see Appendix B for a motion to close the CDR meeting.

**How much time should be spent on each case?**

On average, it takes 30-40 minutes to review a case, but it may take longer if there are special circumstances.

**What is the recommended review process?**

**Phase 1: Information sharing**

Reviews are conducted by discussing each child death individually. Team members share information from their agency’s records that describe the agency’s role in the incident, investigation or services provided to the family. The agency with the most information should start the discussion. This is typically the coroner, medical examiner or another first responder such as law enforcement or an EMS provider. This is the recommended order for sharing information:

1. **Coroner or medical examiner** will present a summary of the death, including circumstances leading up to the death, autopsy and toxicology results, and final cause and manner of death.

2. **Emergency medical services** will present the run report, resuscitative attempts by the family and/or other medical personnel, and services provided.
3. **Medical providers** will present services provided at the hospital after the incident, if applicable.

4. **Law enforcement** will present the reason they were called to the scene, activity that took place at the scene and other important investigative details.

5. **Child Protective Services** will present if services were provided to the child or family before, during or after the incident.

6. **Public health** will present if services were provided to the child or family before, during or after the incident.

7. **Additional members** will present any information relevant to the circumstances or cause and manner of death. Examples include: school history, bereavement support, legal action, or other treatment and services.

Once all information is shared, team members should feel confident that they understand the timeline of events. If not, this is an ideal time to ask for clarification or raise questions. When this is complete the team should move into the discussion phase of the process.

**Phase 2: Discussion**

The purpose of the discussion is to examine system issues, not the performance of individuals. Teams are not peer reviews. The team review is a professional process aimed at improving system response to child deaths. The following questions are recommended to guide the discussion. These questions should be answered thoroughly before moving to the next case. Please see Appendix C for a quick reference list of the discussion questions.
1. Does the team have enough information to discuss possible prevention recommendations? If not, identify what information is missing and which team member will be responsible for gathering the information.

2. Are there services that should be provided to the family, professionals or community as a result of this death?

3. Has CPS determined other children are at risk of harm or neglect? If so, have safety measures been established for them?

4. What risk factors were present in this case?

5. Was the incident leading to the death preventable?

6. Based on the information presented, could this death have been prevented?

7. What actions can be taken to prevent a similar death?

8. Should state and local agencies review their policies, programs and actions as they related to the death, or take action to prevent similar deaths?

9. What agency or individual should take the lead in implementing prevention recommendations?

10. Is the review of this case complete, or should it be discussed further at the next meeting?
Phase 3: Data entry

The team coordinator and/or data entry person will start a case by entering as much information as possible prior to the review meeting. During the review meeting additional or missing information will be gathered and added to the case report. It is recommended that the case report be completed within 30 days after the review meeting. Please see the Data section on page 51 for additional information.

How is the review process used to guide prevention?

The ultimate purpose of CDR is to prevent future injuries and death among infants and children in our communities by understanding how and why deaths occur. Teams are encouraged to review their local data on a regular basis in order to develop prevention recommendations. At a team’s request, the Alliance will analyze risk factors across cases and facilitate prevention discussions on the most common causes of death in a county.

CDR team members are not expected to design and implement prevention recommendations; however they should catalyze community action.

- Utilize the risk factors identified to create policy and program prevention recommendations. Remember, not every death will result immediately in a prevention recommendation.
- Discuss where prevention efforts already exist.
• Share your prevention recommendations with community groups to move recommendations to action.

• Identify additional state and national programs that may be available to assist communities with implementation of recommendations. Visit the Alliance website for resources.

CDR teams are encouraged to track their prevention recommendations and the subsequent action steps. The Alliance has a prevention tracking template to help teams get started; however, teams should customize their tracking tools to fit the needs of their community. Please visit the Alliance website for a prevention tracking template.

Some teams may also find inspiration for prevention activities through collaboration with other local teams. Reach out to the Alliance to be connected with other CDR teams working on similar prevention activities.

**What if there is not enough information to review a case?**

Occasionally, the team may determine additional information is necessary before proceeding with the case review. Before the next scheduled meeting, members should spend time gathering missing information.
“FIMR reviews help give us the wisdom to comprehend the complexities of the lives of the families we serve. Their deaths make us want to overcome both our own and society’s limitations.”

- Karen Michalski, FIMR Project Manager
City of Milwaukee Health Department
Serving as a public health nurse in Wisconsin since 1993, as well as being an engaged community member, I have had the privilege of meeting heart-to-heart with families in Wisconsin who are grieving the loss of their babies, the loss of their dreams. Moms and dads shared their stories of hope, love, dreams, loss, shock, heartbreak and grief during interviews with me.

Entrusted with their tragic but powerful stories, I became their voice through the work I do professionally as a member of the Dane County Fetal and Infant Mortality Review (FIMR) and personally as a community member.

The death of a baby during pregnancy or after birth represents a tragic loss to parents, families and the community. These deaths may create lasting negative impacts. They reflect the complex factors that influence the health outcomes of pregnancies and are important markers of the overall health of the community.

Through the FIMR process, we have the opportunity to hear directly from parents who experienced a loss. Maternal interviews provide critical information about health inequities, families’ health knowledge, attitudes and beliefs, accessibility of culturally-appropriate services and insights into service and resource gaps.
Parents shared with me their appreciation and the desire to help improve maternal and child health outcomes for others. They had positive remarks about the care they received. They also identified concerns related to racial discrimination within health care systems and social isolation. Families faced racial discrimination, social isolation, language and economic barriers, and inadequate information and education during pregnancy related to their loss.

A crucial aspect of the FIMR Cycle of Improvement is the sharing of findings and taking action to shape policy and system-level change. These findings need to be addressed in collaboration with many partners representing a broad array of the community. It is integral to have participation from public health, hospitals, clinics, schools, mental health, substance use disorder treatment providers, businesses, the faith community, diverse neighborhood representatives, childcare providers, injury prevention advocates, policy makers and decision makers.

I hope that my thoughts help you to become involved in FIMR, where you support the health and wellbeing of the women, infants, children and families in your community!

Patricia Frazak
Retired public health nurse
Dane County FIMR coordinator
Fetal Infant Mortality Review

A fetal or infant death is a sentinel event in a community. It speaks to the overall health of a community and how it cares for its families. The circumstances involved in most fetal and infant deaths are multidimensional.

**FIMR puts a face to the problem of infant mortality and looks for prevention opportunities within communities.**

Currently, seven of Wisconsin’s 72 counties have a FIMR team. These multidisciplinary teams work to improve interagency communication and cooperation, understand how and why fetal and infant deaths occur, and ensure delivery of services to families that have experienced the death of an infant.

FIMR cases are reviewed **de-identified**, primarily because an effective review includes a maternal interview, discussion about the mother’s prenatal history and abstraction from her medical record.

**What is the purpose of implementing a FIMR team?**

FIMR is an evidence-based process that convenes local multi-disciplinary professionals to examine fetal and infant deaths, determine prevention opportunities, and engage communities to take action. The team makes recommendations for agency and system improvements
based upon case reviews. The National Center recommends a Community Action Team (CAT) made up of community and agency leaders to move recommendations to action.

The goals of FIMR are:

- Improve our understanding of how and why fetal and infant deaths occur
- Identify the need to influence policies and programs
- Improve maternal and infant health, safety and protection
- Prevent other fetal and infant deaths

These goals are achieved through the following objectives:

- Report cause, manner, risk factors and prevention opportunities for fetal and infant deaths in the National Fatality Review Case Reporting System
- Improve communication and coordination of agency responses to infant deaths and delivery of services
- Evaluate policy and practice changes needed to improve maternal and infant health and safety

How is a FIMR team established?

Review teams are created through agency efforts and voluntary cooperation among agencies and professionals. In order to establish a multi-agency and multidisciplinary team, one agency must be willing to commit the time and effort necessary to form a team. Most often teams are coordinated by the local health department.
Each community should adopt an approach that best suits its unique characteristics. The steps below are a general guide for establishing a FIMR team, but they can be tailored to meet the needs of the individual team. Teams are typically developed through the following steps. The Alliance will provide assistance in team establishment. Visit our website for contact information.

1. Identify a team coordinator. Typically, the team organizer becomes the team coordinator.

2. Identify a member to abstract and enter FIMR data into the Case Reporting System.
3. Contact the Alliance to observe a FIMR meeting in another county. This also may provide direction on how to organize your team and recruitment of potential members.

4. Contact local agency directors or department leaders to discuss establishing a team. Agency directors and department leaders will need to appoint a representative to attend meetings. The representative identified should be able to share expertise as well as knowledge of the type of services provided to families in the community when a tragic incident occurs. The same staff member should attend every scheduled meeting to promote consistency and build rapport with other team members.

5. Schedule a FIMR team training conducted by Alliance staff. The training is held in person and takes about two hours. All potential members should be invited to attend the initial team training. The training will provide:

   • The importance of establishing FIMR teams
   • An explanation of team member responsibilities and confidentiality
   • An overview of the case review process
   • The importance of self-care
Who should be represented on a FIMR team?

Comprehensive reviews occur when team members are:

- Drawn from community agencies responsible for the health and safety of women and children
- Honest and open with one another
- Advocates for necessary changes to support prenatal health and prevent infant deaths

Core membership

FIMR cases are reviewed de-identified. Core team members represent professionals and agencies integral to maternal and child health in the community and offer their expertise to understanding how a fetal or infant death may have been prevented. Core team members should attend each review meeting and represent the following agencies and disciplines:

- Care providers (e.g., obstetricians, pediatricians, neonatologists)
- Child protective services
- Community advocacy organizations (breastfeeding, etc.)
- Health insurance companies
- Midwife and/or doula
- Pathologist
- Public health department
• Social workers
• Women Infants and Children (WIC) program

**Ad hoc members**

Ad hoc members are not permanent and do not receive team notices. Ad hoc members attend based on the request of the team coordinator and provide specific information to the FIMR team. Ad hoc members provide valuable information without increasing the number of core team members.

**What are the team members’ responsibilities?**

Effective reviews are dependent upon participation by all members. Member responsibilities include:

- Attend meetings
- Serve as a liaison to professional counterparts
- Provide definitions of professional terminology
- Explain the legal responsibilities and limitations of his or her profession or agency
- Share ownership for the well-being of the team, including respect for fellow team members

**What are the team coordinator’s responsibilities?**

FIMR teams are coordinated most often by the local public health agency. The duties included below are described in further detail throughout this guidebook.

- Schedule and set agenda for meetings
• Lead meetings and maintain professional decorum
• Send meeting notices to team members
• Ensure the case report is entered into the National Fatality Review Case Reporting System within one month of review
• Ensure the team operates according to the guidelines adopted by the team
• Ensure all attendees sign the confidentiality agreement

How does a FIMR team select cases to review?

FIMR teams review fetal deaths after 20 weeks gestation or 350 grams, and infant deaths (less than 365 days of age). The FIMR coordinator learns of infant deaths through local health department access to death certificates. Fetal deaths after 20 weeks gestation or 350 grams are reported to DHS. Most often, a FIMR team will establish a Memorandum of Understanding with DHS to access fetal death records.

Depending on the volume of cases, a team may decide to abstract all cases but review a select number. Cases may be selected based on the community disparities for infant mortality. Contact the Alliance to establish the best method for identifying and selecting fetal death cases for review.
County of residence

Maternal residence determines cases for review. Teams may also learn of a resident fetal or infant death that occurred in another county.

In Wisconsin, death certificates are filed in the county where the death occurs. The Alliance recommends a coordinated effort between resident and incident counties and will assist the team coordinators in this effort. Please refer to the flow chart in Appendix A.

How is case information gathered?

Abstraction

Once a case is identified, the next step in the FIMR process is record abstraction.

Each FIMR team should identify a records abstractor who will establish a relationship with community hospitals and clinics to access medical records related to prenatal care and birth for each case.

Comprehensive FIMR abstraction involves review of the medical and social service records of all fetal and infant deaths that occur in a given locality. These records can include but are not limited to:

- Autopsy reports
- Police records
- Maternal and infant hospital records
- Social services
• Outpatient records

• Physician office records

The FIMR team coordinator and data abstractor should meet with the primary hospitals from which they will be requesting records to establish a relationship and identify a process for obtaining record information. This should be repeated if the leadership of the FIMR team changes. The process will most likely be different for each hospital in the community. A similar process for requesting records from other agencies can be used.

Once there is an understanding in place, the abstractor can utilize a variety of methods for accessing medical records, including:

• Onsite review

• Electronic copies

• Access to electronic health records

Maternal Interviews

A maternal interview allows the mother’s voice to be heard and provides her with the opportunity to share her experiences before, during and after pregnancy. With the mother’s permission, pieces of information from the interview can be added to the abstracted information in order to provide the mother’s perspective to the team during a case review.

Typically a public health nurse serving as a member of the FIMR team contacts the mother within a few months of the death and completes a maternal interview. If the father is
available, his perspective can be valuable as well but it is recommended that he be interviewed separately. Whenever possible, these interviews should be conducted in-person.

A maternal interviewer should be trained in interviewing techniques, understanding grief, cultural competence, confidentiality, community resources and the maternal interview template.

Maternal interviews can be arranged in several ways. One method is to contact the mother directly by phone or email to introduce the idea of FIMR and explain the benefits of a maternal interview.

Another is to arrange for the hospital to provide the mother with a brochure outlining information regarding FIMR and maternal interviewing. The interviewer would then follow up with a phone call or email requesting an interview. Contact the Alliance for more ideas and for maternal interviewing tools, training and assistance.

How does the coordinator prepare for a FIMR meeting?

1. Create a case summary

A case summary is created using the information abstracted from the above mentioned records and the maternal interview. Each case summary is de-identified to assure the confidentiality of patients, providers and health care facilities. Identifiers to be excluded are:

- Names of the child, mother, medical and social service provider
• Dates of service, birth and death (year can be identified)

• Address information, including zip code if the population is small

• Telephone and fax numbers, email addresses and physical addresses

• Birth, death, marriage and other license or certificate numbers

2. Schedule review meetings

Meetings are scheduled during a designated time period. Meeting frequency may be determined by case load and community capacity. Teams should consider setting a consistent meeting schedule. For example, the team will meet quarterly, every third Monday from 11 a.m. - 1:00 p.m. If possible, consider sending meeting dates for the entire calendar year at the end of December or beginning of January. Doing so will allow team members to save each meeting date in their calendars ahead of time.

How does the team maintain confidentiality?

Each person in the room during the review meeting must sign a confidentiality agreement prior to the start of a case review. Confidentiality is essential for each agency to fully participate in case reviews. Although cases are reviewed de-identified, team members must commit to not sharing information outside of the FIMR meeting. It is recommended that the team coordinator restate the purpose of FIMR at the start of each meeting.
How much time should be spent on each review?

The average time for a case review is 20-30 minutes, but may take longer if there are special circumstances.

What is the recommended review process?

**Review Process**

1. Share printed case information.

2. Discuss the care received during pregnancy and/or the incident.

3. Discuss the delivery of services.

4. Identify risk factors and any gaps in care, including inequitable treatment.

5. Discuss bereavement support offered.

6. Discuss impact of policies/procedures.

7. Develop prevention recommendations.

8. Share recommendations with Community Action Team (CAT) or identify agencies or individuals in the best position to implement prevention recommendations.
Data entry into National Fatality Review Case Reporting System

The team coordinator and/or data entry person will start a case by entering the abstracted information prior to the review meeting. Following the review meeting additional information, including risk factors and identified prevention recommendations, may be entered.

**What is a Community Action Team (CAT)?**

A Community Action Team (CAT) is a group composed of community leaders representing government, consumers, key institutions, and health and human service organizations. Members may vary depending on the needs of the community and may differ from the FIMR team membership. The CAT members meet in order to review, prioritize and implement recommendations from the FIMR team. More specifically, the role of the CAT is to:

- Develop new and creative solutions to improve services and resources for families
- Enhance the credibility and visibility of issues related to women and children by informing stakeholders through presentations, media events and written reports
- Work with the community to implement interventions that will improves services and resources
- Determine if the needs of the community are changing over time and decide which interventions should be added or altered to meet them
- Safeguard successful FIMR systems changes from being discontinued in the future

**How do CDR and FIMR compare?**

Some communities may have both a FIMR and CDR team. The key differences between CDR and FIMR are outlined below in the table. In communities with both a CDR and FIMR team, collaboration is imperative for maximizing prevention activities and resources.

<table>
<thead>
<tr>
<th></th>
<th>CDR</th>
<th>FIMR</th>
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<tbody>
<tr>
<td>Cases</td>
<td>Identified</td>
<td>De-identified</td>
</tr>
<tr>
<td>Families</td>
<td>Not contacted</td>
<td>Mother may be contacted for maternal interview</td>
</tr>
<tr>
<td>Records</td>
<td>Team members bring their agency’s records to the review meeting</td>
<td>A record abstractor prepares case summaries to present to team members at the review meeting</td>
</tr>
<tr>
<td>Data</td>
<td>Entered into NFR-CRS</td>
<td>Entered into NFR-CRS</td>
</tr>
<tr>
<td>Prevention</td>
<td>Prevention activities are discussed by the team and carried out by appropriate community agencies</td>
<td>Prevention activities are discussed and carried out by the CAT</td>
</tr>
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</table>
How should CDR and FIMR collaborate?

In order to successfully collaborate, the following steps are recommended for FIMR and CDR coordinators:

1. Outline a process for determining which infant cases will be reviewed by each team

2. Discuss when meetings will be held, keeping in mind overlap in membership

3. Discuss potential data entry collaboration (contact the Alliance for more information)

4. Collaborate on prevention recommendations and activities including joint reports, education, policy changes and other activities

Some counties have determined that forming a joint CDR and FIMR team best meets the needs of their communities. Please contact the Alliance to discuss this option.
Data

“CDR data is important to improve child safety and prevent harm to other children. Quality data (data that are complete, consistent, accurate and timely) are critical to ensure that the data are useful to support prevention efforts at all levels.”

- Heather Dykstra, MPA
National Center for Fatality Review and Prevention
The Case Reporting System

Local review team members collaborate in understanding the risk factors and circumstances leading to a child’s death to develop prevention recommendations. The Alliance encourages local teams to capture information in the National Fatality Review Case Reporting System (CRS), a comprehensive, standardized, web-based tool.

The Department of Health Services has a data use agreement with the National Center for Fatality Review and Prevention which manages the CRS. Identifiable information is removed when cases are included in the national database.

Analysis of data entered in the CRS allows identification of common risk factors and tracks trends in child death at the local and state levels. The completeness of case reports and utility of the data for informing prevention activities relies upon the confidential sharing of information from members of the CDR team.

Information from five sources assist in completing a majority of the case report. These include:

- Investigation report (law enforcement and coroner or medical examiner)
- Autopsy report
- Toxicology report
- Birth certificate
- Death certificate
Additional information shared by team members during case reviews assists in completing the remainder of the case report.

The Alliance, in cooperation with DHS, manages utilization of the CRS by CDR and FIMR teams in Wisconsin. The following data supports are offered by the Alliance:

- CRS training for new data users
- In-person and web-based training on CRS updates and utilization for current data users and team coordinators
- Analyses of county-based data and facilitation of prevention conversations for local teams
- Creation of an annual report on sudden, unexpected infant deaths
- Identification of priority variables and guidance on improving data quality
Sudden Unexpected Infant Death and Sudden Death in the Young Case Registry

The Alliance participates in the Sudden Unexpected Infant Death (SUID) and Sudden Death in the Young (SDY) Case Registry through the Centers for Disease Control and Prevention (CDC).

- **SUID**: The death of an infant less than one year of age that is sudden and unexpected, and whose cause is not immediately obvious before investigation. This includes deaths ruled Sudden Infant Death Syndrome (SIDS), Undetermined/Unknown, and Accidental Suffocation and Strangulation in Bed. In Wisconsin, SUID surveillance is statewide.

- **SDY**: The death of an infant, child or young adult less than 20 years of age that occurs suddenly and unexpectedly. In Wisconsin, SDY surveillance occurs in four counties.

The CDC has identified a number of variables as high priority within the Case Reporting System (CRS) for SUID and SDY cases and timeline guidance for completion of a SUID case report. These high priority variables are listed in Appendix D.

To ensure data quality and completeness, the Alliance reviews case reports for SUID and SDY cases in collaboration with the team’s data entry member.
The Alliance asks that local CDR coordinators inform their Alliance support person when they learn of an infant death that may qualify for the SUID Case Registry. This communication allows the Alliance to support the local team in gathering the priority variables and completing the review within the CDC’s recommended timeframe.

Annually, the Alliance releases a report which provides aggregate information on the SUIDs which occurred in a given year. Partners across the state utilize the report to understand populations most impacted by SUID and to tailor prevention strategies to address the risk factors identified among Wisconsin SUIDs.

### Timeline for Case Completion

<table>
<thead>
<tr>
<th>Day 0</th>
<th>Day 30</th>
<th>Day 120</th>
<th>Day 150</th>
<th>Day 270</th>
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<tbody>
<tr>
<td>Death of a child</td>
<td>Case identified by team</td>
<td>Case reviewed by team</td>
<td>Data entry complete in CRS</td>
<td>Case cleaning complete</td>
</tr>
</tbody>
</table>
Prevention

“Child Death Review enables our team to identify the risk factors associated with a particular injury or death. Becoming aware of these risk factors is instrumental, as it guides our team to develop prevention strategies and work plans, which in turn, helps us to reach our goal—preventing childhood injuries and deaths.”

- Clark County Child Death Review Team
Prevention

The ultimate purpose of CDR and FIMR is to prevent future injuries and death among children in our communities by understanding how and why deaths occur. Teams are encouraged to review their local data on a regular basis in order to develop informed prevention recommendations.

The Alliance can assist in reviewing risk factors across cases and facilitating prevention discussions on the most common causes of death in a county. Importantly, teams should identify where local prevention efforts already exist and may be bolstered by team recommendations. Connect your review team findings with these community groups to ensure results.

CDR and FIMR team members are not expected to design and implement prevention recommendations; however they should catalyze community action. Individual agencies or team members can assume responsibility to work with existing or new coalitions to enact changes based on the recommendations set forth by the team. Additional state and national programs may be available to assist communities with implementation of recommendations. Remember, not every death will immediately result in a prevention recommendation.

CDR and FIMR teams are encouraged to track their prevention recommendations and the subsequent action steps. The Alliance has a prevention tracking template to help teams get started; however, teams should customize their tracking tools to fit the needs of their community. Please visit the Alliance website for the prevention tracking template.
Some teams may also find inspiration for prevention activities through collaboration with other local teams. Reach out to Children’s Health Alliance to be connected with other CDR and FIMR teams working on similar prevention activities.
Additional Team Guidance

“By understanding the cause behind such a tragic loss, we have been able to implement changes and make recommendations in our county to prevent others from having to go through the same tragedy.”

- Winnebago County Coroner’s Office
Media Inquiries

Occasionally, prevention activities may spark interest from the media. Team members who are contacted by the media should not speak as a representative of the CDR team, but rather in their professional agency capacity. Team members should contact the team coordinator if approached by the media regarding CDR or a prevention activity.

Information regarding case reviews should not be disclosed outside of the meeting other than pursuant to the mandated agency responsibilities of that individual. Public statements about the general purpose of CDR and prevention activities may be made, as long as they are not linked with any specific case. Contact the Alliance for assistance in obtaining data at a regional or state level to report in media inquiries.

Conflict of Interest

A conflict of interest may arise for a team member. A conflict is defined as any vested interest in a specific case, for example a personal relationship with the child’s family. It is the team member’s responsibility to excuse him/herself from the case discussion. In this situation, the team member may elect to send another representative from the agency in his or her place.
Access to Records

Many local, state and federal laws allow for participation and disclosure of case-related information during CDR and FIMR. The content below explains what information is needed for review meetings and where the information can be found. Please contact Alliance staff for the most recent updates and additional resources.

Below are recommended sources of information for a comprehensive case review:

1. **Birth certificate and death certificates**: The public health team member can access birth records through the Secure Public Health Electronic Record Environment (SPHERE) for the first year after the child’s birth. Death records are accessible through the Statewide Vital Records Information System (SVRIS) and do not have a time limit. Birth and death records also may be obtained from the Register of Deeds.

2. **Death scene investigation report**: Reports may be generated by both the medical examiner or coroner and local law enforcement. Information from both reports may provide critical incident details.

3. **Autopsy report and toxicology results**: This report also will come from the medical examiner/coroner office.

4. **Child Protective Services (CPS) experience**: Information on previous CPS history or CPS investigation of the child’s death provide context for the social history of the child. **Wis. Stat. § 48** allows for CPS information to be shared with a CDR team.
5. **Social service program support such as Women Infants and Children (WIC):** DHS and WIC have a Memorandum of Understanding (MOU) for sharing information with CDR teams. The MOU is available on the Alliance website.

7. **Mother’s health history for FIMR:** This information most commonly comes from prenatal care and hospital records related to the infant death event. Successful abstraction of information from the mother’s record is a result of a trusting relationship between FIMR and the medical records personnel understanding the purpose of FIMR. It is important to confirm all of the mother’s protected health information (PHI) is kept confidential by the abstractor and is presented to the FIMR team in a de-identified format.

This information sharing is allowed under HIPPA, which allows for the exchange of PHI to perform public health activities such as public health surveillance, program evaluation, terrorism preparedness, outbreak investigations, direct health services and public health research.

The HIPPA Privacy Rule permits the release of PHI without authorization of the person to a public health authority.

A public health authority is defined as an agency of the U.S. government, a State, a territory, a political subdivision of a State (which in Wisconsin is a county) or an Indian tribe. The rule also covers an entity or person under a grant authority from, or under contract with, a public health agency—such as the
Alliance. Code of Federal Regulation (CFR 45 164.501) defines a local health department as a public health authority under the law.

7. **Child medical history from hospital:** HIPPA allows for information to be shared, however, hospitals may cite the lack of a clear and specific state law directing them to share records. Access to information varies from hospital to hospital. There are hospitals throughout Wisconsin that do share information in accordance with HIPPA standards.

8. **Education history:** The Family Educational Rights and Privacy Act (FERPA) is a federal law that protects the privacy of student records. A school representative can contribute general information, including the school environment, curriculum and policies related to the risk factors and cause of death. Schools can disclose student information without consent under very specific conditions, however, CDR is not specified as one of them under FERPA.

There are several Wisconsin state statutes that apply more broadly to the sharing of information between agencies and institutions for the purposes of preventing injury, death and disease. Please reach out to the Alliance for more information on which statutes apply.
Self-Care

Why is self-care important?

The child death review process is challenging work. It can leave you feeling upset or emotionally drained. Being aware of how this work impacts you and taking steps to maintain balance in your life can help.

While we cannot eliminate stress from the review process, we can take steps to ensure we practice good self-care. The Alliance recommends incorporating self-care concepts into review meetings.

How can self-care be practiced?

The following are suggestions for team activities that support self-care:

- Acknowledge that the review process can be difficult
- On your meeting agenda, add several minutes of deep breathing and/or a centering moment
- Focus on the positive (e.g. acknowledge team achievements, prevention activities, agency collaboration, etc.)
- End your meeting with a brief YouTube self-care video
- End your meeting by taking a moment to each share a small thing you might do to take care of yourself that day
The following are suggestions for individual activities that support self-care:

- Stretch or go for a walk
- Create a ritual for the end of your day (e.g. removing a name badge or listening to a particular song)
- De-clutter your work space
- Think of five things you are thankful for
- Download a self-care app

Visit the Alliance website for more self-care ideas.
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Appendix A

Incident vs resident flow chart

Is the child a resident of your county? Yes → Did the death occur in your county? Yes → Proceed through the review process.
No →

Does incident county have a CDR or FIMR team?
Yes → Work with the incident county to create the review plan.
No →

Is the child a resident of Wisconsin? Yes → Does resident county have a CDR or FIMR team?
Yes → Work with the resident county to create the review plan.
No → Review and enter the case. Contact the local health department of resident county for child information.
No →

Teams may elect to review and enter the case, particularly if any prevention opportunities are identified. The Alliance can help contact out-of-state teams.

Note: Only one team should enter the case (preferably the resident county).
Appendix B

Sample motion to convene a closed CDR meeting

Step 1: Text of motion
I move that this body convene to closed session for the purpose of discussing confidential information relating to the unexpected deaths of specific children, pursuant to the following Wisconsin Statutes: Wis. Stat. § 19.85(1)(d), Wis. Stat. § 19.85(1)(f), Wis. Stat. § 48.981(7), Wis. Stat. § 48.78(2)(a), and Wis. Stat. § 146.82(2)(b).

Step 2: Obtain second for motion

Step 3: Team coordinator announces nature of business
This Child Death Review Team brings individuals with expertise in multiple disciplines and subject areas together to share relevant information about the unexpected deaths of specific children, for the purpose of accurately identifying all of the factors that contributed to the death of each child, including the possibilities that abuse, neglect, criminal conduct, or preventable circumstances contributed to the child’s death.

The team cannot conduct its discussion without considering child-specific information from records to which public access is highly limited. The team’s discussion assists law enforcement, child protective service agencies and prosecutors in developing strategies and directions for effective investigations. Public disclosure of the information considered by the team would unlawfully disclose confidential information, and could compromise effective investigation by public agencies responsible for protecting child welfare.

Step 4: Discussion, if any, of motion

Step 5: Roll call, ayes and nays
Note: If the team votes unanimously to convene in closed session, there is no requirement to record the votes individually. If the vote in favor of closed session is not unanimous, a record must be kept of the individual votes for and against closure.

Step 6: Presiding officer announces result of the vote, and directs members of the public and the news media present at the meeting to leave the room.
Appendix C

Review discussion questions

1. Does the team have enough information to discuss possible prevention recommendations? If not, identify what information is missing and which team member will be responsible for gathering the information.

2. Are there services that should be provided to the family, professionals or community as result of this death?

3. Has CPS determined other children are at risk of harm or neglect? If so, have safety measures been established for them?

4. What risk factors were present in this case?

5. Was the incident leading to the death preventable?

6. Based on the information presented, could this death have been prevented?

7. What actions can be taken to prevent a similar death?

8. Should state and local agencies review their policies, programs and actions as they related to the death, or take action to prevent similar deaths?

9. Identify the agency or individual who should take the lead in implementing prevention recommendations.

10. Is the review of this case complete or should it be discussed further at the next meeting?
Appendix D

Infant death priority variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>Question</th>
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<tbody>
<tr>
<td>Case type</td>
<td>Indicate the type of case: death, near death, or not born alive.</td>
</tr>
</tbody>
</table>

Section A1

A2 Date of birth
A3 Date of death
A5 Race (death certificate)
A8 Resident county
A13 Child had disability or chronic illness?
A15 Child’s health insurance
A23 Open CPS case at time of death?

Section A3

A35 Gestational age
A36 Birth weight
A41 Prenatal care provided during pregnancy?
A45 Did the mother use any medications, drugs or other substances during pregnancy?
A46 Was the infant born drug exposed?
A47 Did the infant have neonatal abstinence syndrome?
A56 Was infant ever breastfed?
A57 Abnormal newborn screening results?
A63 What did infant have for his/her last meal?

Section C: Responses may be in Section B if biological parent is also caregiver.

C2 Caregiver age
C8 Caregiver’s highest education level attained

Section D

D16 At time of incident, was supervisor impaired?

Section E

E3 Place of incident
E12 Child’s activity at time of incident

Section F

F1 Was a death investigation conducted?
F4 Autopsy performed?
F5 Any X-ray or other imaging

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<th>Section F continued...</th>
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