# Best Practices and Areas of Improvement in Child Death Review:

# A qualitative analysis to inform policy change in Illinois

Sonia Harris

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CE Advisors: Dr. Karen Sheehan and Dr. Arthur Elster

## Abstract

**Background:** Child Death Review teams (CDRTs) emerged as a professional response to rising public awareness of child abuse and maltreatment. CDRTs are multidisciplinary groups that review data on child fatality and make reports to inform prevention initiatives in communities. In Illinois, child death review is mandated to review only deaths of children age 17 and younger if the child was a ward of the Department of Children and Family Services (DCFS), involved in a pending investigation, or whose death was reported to the DCFS hotline due to suspicion of abuse and neglect.

**Objective:** This study aimed to establish understanding of best practices and areas of improvement in child death review in order to inform policy recommendations for Illinois.

**Methods:** 21 professionals who serve on child death review teams agreed to participate in this qualitative research study. Interviews were conducted using a semi-structured open-ended format. Interviews were transcribed and then hand coded for recurring themes, similarities, and differences among participants.

**Results:** Participants included child abuse pediatricians (n=2), state child death review coordinators (n=4), nurses (n=3), leaders at the Department of Children and Family Services (n=2), therapists (n=3), public health workers (n=4) and social workers (3). Participants identified procedural strengths that improved their review process, emphasized the importance of collaboration, and mentioned that when teams have non-adversarial discussions they are most successful. Participants identified education and the lack of data, legislation and funding as areas of improvement. Unanimously, participants were in support of a comprehensive child death review program where deaths from all causes are reviewed.

**Conclusion:** Respondents of this study identified strengths, best practices, areas for improvement, and unanimously agreed that a comprehensive child death review model wherby all child deaths are reviewed best supports the prevention of future child deaths. Reviewing all child deaths of all causes centers the CDRT on prevention, which allows for greater focus on the leading causes of death and more specific prevention interventions. Illinois would benefit from adopting this comprehensive model to discover accurate trends regarding patterns of death in the communities.

## INTRODUCTION:

### Child Death Review Teams

Child death review teams (CDRTs) emerged in the late 1970s as a professional response to rising public awareness of child abuse, child maltreatment, and the lack of accurate data regarding these unexpected deaths. CDRTs were founded on the premise that coordinated and collaborative information-sharing among child protection professionals decreases the possibility of missing child maltreatment (Webster, 2003). According to the National Center for Fatality Review and Prevention (NCFRP), as of 2016, all 50 states and the District of Columbia had some form of a child death review program.

CDRTs are multidisciplinary groups tasked with the responsibility of reviewing data on child fatalities in their communities. These community-based teams report their findings to local or state advocacy boards or legislators. Since their inception, CDRTs have increased public awareness of children's lives lost due to accidents, unintentional injury, neglect, and abuse (Durfee, 2002; Douglas 2020). The gathering of data informs prevention initiatives that save lives.

CDRTs have four goals: identify cause and manner of death, provide recommendations for prevention efforts, review agency involvement or inaction that may have contributed to death, and collect comprehensive data (Quinton 2017; Douglas 2020). Some review boards assist with the prosecution of child maltreatment cases (Quinton, 2017). Although the CDRT movement has advanced the conversation around child maltreatment in many communities, federal policy standards and national databases for CDRTs do not exist. This lack of standardization and collective information hinders the success of prevention efforts (Douglas,

2020). The National Center for Fatality Review and Prevention (NCFRP) has established objectives for child death review, which inform major considerations for forming a team (Table 1).

The NCFRP identifies four main models of child death review teams (Figure 1) (Quinton 2017; National Center for Fatality Review and Prevention). In the model considered best practice (Model 1), a local review board investigates cases, and the state offers oversight and produces annual reports. In Model 2, state and local teams review cases separately. In Model 3, there is only a state review board and Model 4 only a local review board. Reviews can be conducted retrospectively, as part of the investigation, or parallel to the investigation (Quinton 2017; Durfee 2002; Douglas 2018). Teams are composed of individuals who work directly with children, or whose work intersects with the care of children. The NCFRP recommends seven core members: child abuse pediatrician, law enforcement representative, medical examiner or coroner, child protective services representative, prosecutor or district attorney, public health representative, and an emergency medical services representative. State team membership tends to be politically based, while local teams are formed by statute (National Center for Fatality Review and Prevention).

Historically, communities have criticized CDRTs for not providing clear evidence that their efforts actually reduce child deaths (Douglas, 2018; Douglas, 2020). Today, common areas of prevention focus include unsafe sleep position, water safety, vehicular safety, and gun safety (Quinton, 2017). However, because of a lack of standardized data and reporting, metrics that establish success are limited.

In recent years, many CDRTs have adopted a public health model; teams review deaths from all causes, including accidents, unintentional injuries, and child maltreatment. This is a shift from the previous structure of only reviewing deaths caused by abuse/neglect. The American Academy of Pediatrics and the American Bar Association endorse this new model.

**Child Death Review in Illinois and Public Health Significance**

From 2015-2019, 2729 children died in Illinois, 618 from unintentional injury. In 2019 alone, 505 children died in Illinois (Illinois Department of Public Health). In 2019, the leading cause of death in children 1-17 years was unintentional injury (103): drownings, motor vehicle crashes, falls, suffocation, and fire and burns. Figure 2 shows the five leading causes of death.

Illinois law requires that child death review teams review these categories of death among children age 17 and younger: children who are wards of the Department of Children and Family Services (DCFS); children involved in a pending DCFS investigation; and children whose death was reported to the DCFS hotline for suspicion of abuse and neglect (Fuller et al, 2016; Child Death Review Team Act). The CDRTs members have permission to review any unexplained or unexpected child death, at their own discretion. Unlike 37 other states, Illinois does not review deaths of all non-medical causes (Fuller et al., 2016; National Center for Fatality Review and Prevention). Figure 3 shows a model of how the Illinois system works.

Deaths and disability from unintentional injuries are considered preventable (CDC, Lurie Children's hospital). Child death review is a critically important facet of the public health and policy effort to reduce these tragedies. Current CDRT focus within Illinois misses the opportunity to advance prevention initiatives that are focused on unintentional injuries because the program still only reviews deaths related to maltreatment.

**Explanation of Study**

This qualitative study was designed to gather data from professionals across the country who serve on child death review teams. The information gathered intends to offer insight into successful procedural structures, explore significant challenges in child injury and violence prevention, and provide a framework for policy recommendation for Illinois's program.

## METHODS

*Sampling Design*

This study involved conducting a series of semi-structured interviews to obtain in-depth information and perspectives from a variety of child protection professionals. The dual goals of these interviews were to understand the processes, strengths, and areas of growth for child death review teams across the United States, and to bring this information to the conversation regarding policy change in Illinois. The semi-structured interview model allowed asking follow-up questions and probe deeper as the interview progressed.

The style of study morphed throughout the process. Based on the recommendation of my CE and APEX advisor I did not originally apply for IRB approval, however I informed the participants that their name would be kept confidential.

In December of 2020, 32 potential interview participants were identified. Participants were chosen for contact based on proximity to Illinois (i.e., Midwest States); legislative similarities or significant differences in their child death review statute; or state population size. States contacted included: California, Illinois, Indiana, Minnesota, Michigan, Missouri, Kansas, South Dakota, Wyoming, Wisconsin, New York, and Pennsylvania.

Potential participants were contacted by email from the NCFRP website list or through existing contacts. The introductory letter identified the investigators/interviewers, explained the study's aim, and proposed how the information gathered would be used.

*Data Collection and Analysis*

Interviews were conducted using a semi-structured open-ended question format that allowed for long form responses. Each interview lasted between thirty minutes and one hour. Questions were chosen from a pre-written question list. At the beginning of each interview, the purpose of the project was explained, along with how the interviewee's expertise would add value. Participants were informed names and locations would be redacted from the final report so that they would not be identifiable. Table 3 shows the list of questions. All interviewees responded to these three questions: what aspect of the review process is most useful and beneficial for the community, what is missing from your review process, and why is it—or why would it be—important to review deaths of all causes.

Interviews were conducted over Zoom or by phone and recorded in order to transcribe and analyze the results. Each participant granted permission to record the interview. After interviews had been conducted, participants were deidentified and recordings were transcribed using a third-party software. Transcripts were manually reviewed for accuracy. The transcriptions were reviewed and hand-coded each using a color scheme and a spreadsheet to summarize recurring themes and similarities. Then, they were independently validated be a second coder.

## RESULTS

Of the 32 potential participants contacted, 21 agreed to participate (65 percent). From January 2021 through March 2021, 21 qualitative interviews were conducted. Participants included child abuse pediatricians, state child death review coordinators, leaders at the Department of Children and Family Services, therapists, and social workers. These interviewees represented child death review teams from California, Illinois, Indiana, Kansas, Michigan, Missouri, Pennsylvania, South Dakota, and Wisconsin. Table 2 shows the key characteristics of participants including: profession, region, and administrative level.

Three main themes were identified from the interviews, which were later independently validated: strengths and best practices, areas of growth, and the benefit of reviewing all child deaths.

## Strengths and Best Practices

### *Procedural strengths*

Child death review boards differ on a state-by-state and sometimes county-by-county basis. Variables include number of cases reviewed at each meeting, frequency of meetings, method for choosing a case for review, individuals present, presence of subcommittees, collaboration, and social environment on the board. Respondents across the board discussed the format of their review board. Emphasis was placed on how established review structures allowed for greater transparency and efficiency during meetings. Medical examiners and pediatricians focused more on the logistical layout of team meetings than did social workers and therapist respondents.

One registered nurse described a unique format for team review:

> Each month we review a different mechanism of death. So one month is homicide, one month is suicide and overdoses, one month is unintentional deaths and motor vehicle crashes. One month is safe sleep, one month is child abuse. And we rotate those through the year. Then we go through each case. People ask questions, people make recommendations. It keeps the meeting focused. It allows for a better investigation into each death.

This format meets the established criteria for a successful review board, but using this topical emphasis structure allows for focused prevention initiatives.

Respondents also focused on the presentation format (PowerPoint presentation, Google slides, no visual aid), identification of the presenter (medical examiner, district attorney), and key areas of focus.

> The three things that are always rotating in discussion: Was it preventable? Was there an autopsy and adequate investigation? Was there anything that our board was missing that we needed to understand or would benefit our understanding? And then from there, what could have been done differently to maybe protect this child? What are things that we want to note down about this case, that could be helpful in the future? (Pediatrician)

> It's helpful having the PowerPoint presentation for each child death, because it gives the team gestalt of what the scene looks like, what the cause of death was. And I think that was an improvement in the team that I started years ago, that I think allows for a platform of a more robust discussion. Because prior to that, we didn't have PowerPoint presentations, so the team members couldn't really get a good feel for what the scene looked like or what the significant autopsy findings were. (Medical Examiner)

Interview participants who are social workers and therapists did not place heavy emphasis on the specific presentation format, but all 3 pediatricians and medical examiners did.

*Collaboration*

The recommended multidisciplinary structure of child death review teams promotes collaboration among professionals with different areas of expertise. Collaboration can take the form of interpersonal communication between members of the team—inside and outside the

meeting—or through collaboration with community organizations. One social worker explained:

> I think the greatest collaboration that happens is at the local level, at a community level, when different county or jurisdictional agencies come together and improve their relationships. And they just start this sort of, like, free flow of information sharing. They're relying on each other, they're tapping into other agencies resources, they're working together as a team. And I got to see this a lot in my work.

The multidisciplinary structure was mentioned by all 21 participants emphasizing that it is central to success. The composition facilitates opportunities to hear diverse perspectives, which allows for a more comprehensive picture of that child's death.

*Non-Adversarial*

Six participants, specifically those from psychology backgrounds, mentioned that successful teams operate in a non-adversarial manner, in that representatives from different constituencies do not seek to blame colleagues and collaborators. This approach recenters the focus of the child death review team on prevention rather than investigations and accusations. Further, collaborative and non-adversarial communication fosters meaningful conversation that advances the work. One psychologist said:

> I think there's two parts. So, one is coming together to have the discussion about what happened. We make a lot of assumptions about how our systems interact, and how families live in our community. And I think by having the discussion we see where sort of policy lives and where real life lives and how they don't always overlap. I think in that discussion, when we're sort of willing to be transparent and honest, we also see how our systems need to change and shift.

**Weaknesses and Areas of Growth**

*Education and Training*

Three respondents—all from medical backgrounds-- identified that the training of professionals and community members is often the first step in prevention initiatives, but, unfortunately, education efforts may not garner solid community engagement and support.

> There is excellent information that we acquire, and document, both on the patient-by-patient level and also on the community level. How do we transmit that information to the larger community and get people to really change their behavior? How do you get parents to really practice 100% of the time? How do you get parents to understand that having a child in [Location Redacted]—any of the excellent schools in [Location Redacted]—puts them at real physical risk of suicidality compared to normal communities? (Pediatrician)

> Education is important, but not enough. And there's a tendency, when something goes wrong, to say, 'we're going to put on a training for people'. You need training, but training in and of itself doesn't change behavior. (Pediatrician)

Behavior change through community understanding—including cultural competence in community-based education initiatives—is needed to strengthen education efforts. Although successful educational messaging has emerged from CDRTs, growth is still needed in this area. Additionally, community-based initiatives must recognize structural racism and generational trauma, which was emphasized by 4 respondents from both psychology and public health backgrounds:

> So when that threshold is reached, you got to do something to make those kids safe—the least intrusive thing. You want to connect them with all those resources, but when you connect them with those resources, it's got to be more than handing them a slip of paper or a phone call. (Psychologist)

*Data, legislation, and funding*

Respondents who served at the state or national level noted logistical difficulties related to the lack of established legislation to solidify the practices of their review board, and the lack of

comprehensive and coordinated data systems. Legislation may establish who sits on the board, how cases are reviewed, which cases are reviewed, and how prevention initiatives are carried out. Comprehensive data systems link local CDRTs to each other and to the state. The absence of a unified data system impedes abilities to see trends in child death across the nation. Additionally, respondents mentioned that local boards may code death differently, which creates more gaps in the system. Also, 18 out of 21 respondents mentioned that their board operates without any funding and that a lack of financial resources limits their ability to hire full time staff, or fund prevention initiatives:

> So, we need that data. And then the state does have to put out that report and they do have to make recommendations to policymakers to prevent children's deaths. So I mean, that's important as well, but there's no requirement of any particular agency, or anyone named in the recommendations to have any kind of response. (Public Health Representative)

> We do not have any mandates for death review. None of the law enforcement or none of the hospital systems have to provide data. We have data use agreements, but there's no law. So, there's, you know, they can decide now, we don't want to send you information. Okay, so that's definitely missing. Legislation. (Nurse)

**Comprehensive Model of Child Death Review**

Respondents highlighted that comprehensive models in child death review—in this context, models where the team reviews deaths of all causes—benefit the community and paint a clearer picture of true trends. Respondents from a variety of professional backgrounds supported this model unanimously, regardless of their own board model.

> I think that it would probably help to paint a clearer picture for the state that the deaths of children are all tragic and only a fraction of them are child maltreatment. (Social Worker)

> Well, first of all, it helps to understand what happened to that child and to help their family get to closure. On a community level, it helps us understand what's going on in our community, so that we can intervene because things do come in clusters. (Therapist)

> We're able to keep kids safer and healthier, if we're able to learn from these deaths and implement things that we have learned to prevent them. (Public Health)
>
> Not reviewing accidents short-changes children, because it doesn't allow you to look at how this death could have been prevented. (Medical Examiner)

Respondents noted that some events that laypeople might dismiss as "just an accident" are actually preventable, which a dedicated CDRT working in a comprehensive model can identify. A social worker said:

> I think that people don't always realize where prevention starts and ends, especially folks that aren't from a public health perspective. I think that a lot of times folks have to, like, say, like a car crash, right? And they'll go, 'Well, it was an accident'. And it's like, they don't understand that whole picture. There are instances of preventability, even in death, that folks might think of as not being all that preventable. (Social Worker)

Respondents concurred that the review of all child deaths from a public health approach creates more opportunities for targeted prevention work, and ultimately protects children.

## DISCUSSION

Robust and productive child death review depends on successful collaboration between professionals and community members, which minimizes judgment and blame. Areas of potential improvement included: adequate funding for programs, targeted education campaigns that take into account community needs, and legislation to help establish local programs. Child protection professionals interviewed in this study supported unanimously a comprehensive model in child death review. These findings can help inform policy recommendations for the Illinois child death review system.

These findings build on previous work that analyzed models and successes in child death review. Douglas et al. (2018) conducted a qualitative analysis of CDRT activities using annual

report data. This study found that the two most common activities noted by CDRTs was "fostering coalitions and networks" and "engaging in community education" which further validates the findings in this study about the strength of collaboration within CDRT. Regarding education, the current study indicates that while education is an established activity of CDRT, growth is needed in this field. Webster et al (2002) conducted a survey to assess commonalities among CDRT boards and concluded that national standardization is a needed next step. Shanely et al. (2010) indicate in their findings that only 15 review teams reported reviewing all child deaths, this study builds on this by establishing that while not all review boards currently review all deaths, among study participants unanimous support exists for this model.

These results can be used to inform policy recommendations for changes in Illinois child death review. Currently, the Illinois Child Death Review Team Act mandates review of all deaths of children with DCFS contact. In 2019, over 500 children's lives were lost, 103 to unintentional injury. Based on the current policy, less than 20 percent of these deaths were reviewed, a lost opportunity to investigate preventable causes and develop advocacy and education programs. The findings on the comprehensive model of child death review indicate that a policy change has sufficient support and is necessary. Illinois should change its death review policy so that all deaths are reviewed to provide accurate trends in each community. Further, this approach could reemphasize preventability, allow for focused educational initiatives, and save future lives of children. Illinois could also benefit from using a model wherein deaths are reviewed by cause instead, as mentioned in the procedural strengths section, because this would further emphasize prevention. Finally, Illinois should adopt a uniform data collection system

throughout the state, perhaps the NCFRP data reporting system, so that all deaths are coded in the same manner regardless of county and accurate numbers are recorded.

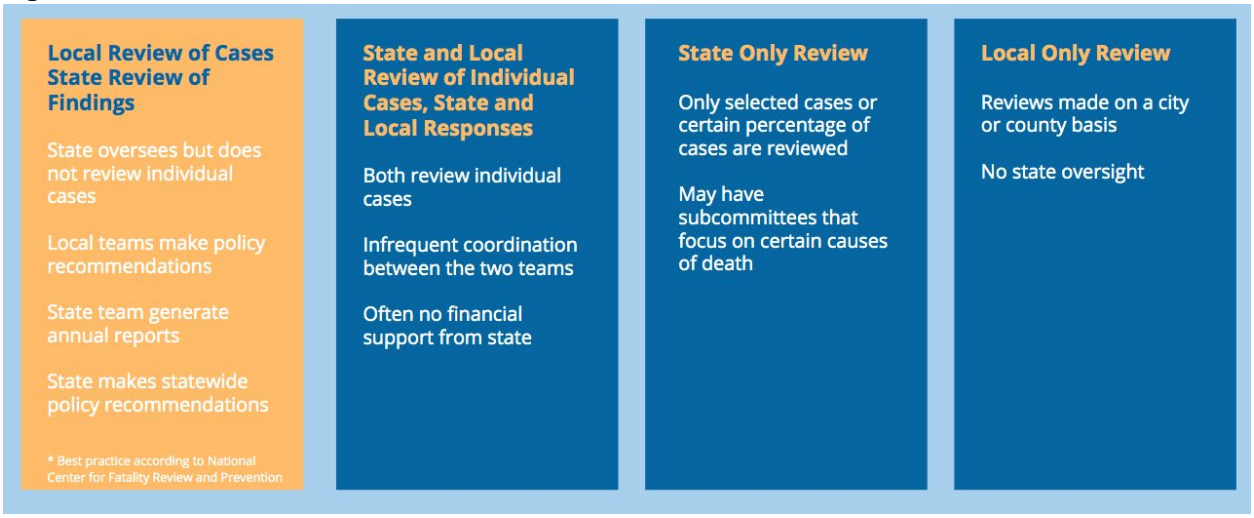
In this study, the sample size was 21 participants, which limits the generalizability of information gathered through the interviews. Additionally, participants were recruited by email or through connections. While this enhanced ability to connect with participants outside of Illinois, participants may have been willing to participate due to a personal interest, calling into question the generalizability of their opinions. While the diverse locations of participants strengthened the findings, the study was limited to only respondents from predetermined places. More respondents from Illinois would also have been useful in assessing the extent to which support exists for policy change. Future studies analyzing best practices and areas of improvement with representatives from all states could gather a more comprehensive understanding of CDRT programs and future studies with more Illinois respondents would increase understanding of community support. Still, this study brought in perspectives from diverse professional groups and a large range of areas of the country, which suggests that widespread support exists for the changes mentioned, specifically the adoption of a public health approach.

## CONCLUSION

Respondents of this study identified strengths, best practices, areas of improvement, and unanimously agreed that a comprehensive child death review model wherein all child deaths are reviewed best supports the prevention of future child deaths. While further research may be useful to solidify program procedures nationwide, this study demonstrates that Illinois would benefit from policy change in its death review program. Reviewing all child deaths of all

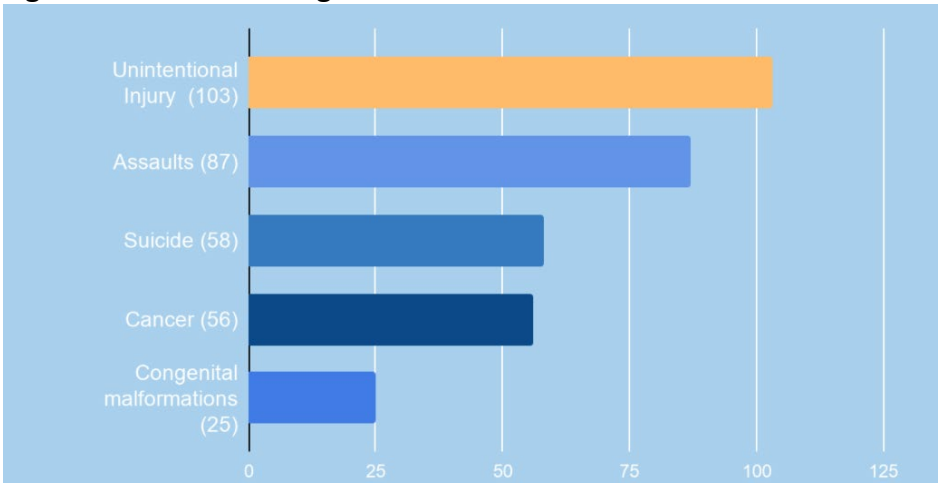
causes centers the CDRT on prevention, which allows for greater focus on the leading causes of death and more specific prevention interventions. However, without unified data systems, legislation, and funding, death review teams are at a disadvantage and cannot establish widespread prevention initiatives.

**Figure 1: Four Models of Child Death Review**



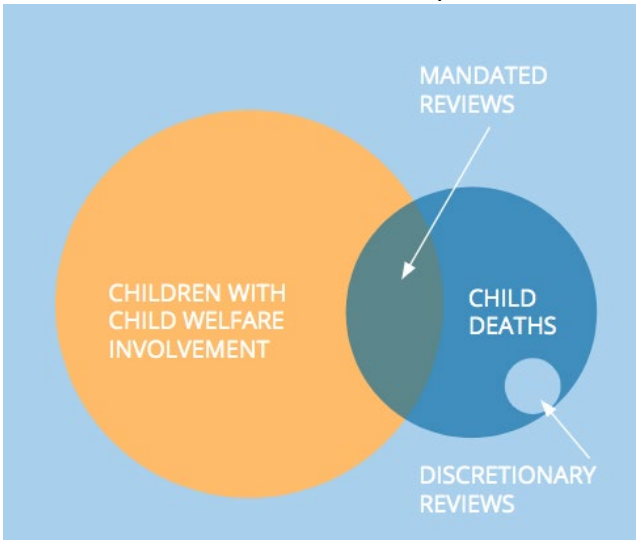

Source: National Center for Fatality Review and Prevention

**Figure 2: 2019: 5 Leading causes of Child Death in IL**




Source: Illinois Department of Public Health

**Figure 3: Representative Model of Child Death Review**
*In 2020:* 102 child deaths were reported to the DCFS Hotline




Source: Fuller et al.; DCFS

**Table 1: National Center for Fatality Review and Prevention Child Death Review Objectives**

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|---|---|
| **Ensure the accurate identification and uniform, consistent reporting of the cause and manner of every child death.** | 1. Reviews ensure team members are informed of all deaths and thus they are more likely to take actions for investigation, services and prevention.<br>2. More complete information may help to identify cause and manner.<br>3. Reviews can lead to modifications of death certificates. |
| **Improve communication and linkages among local and state agencies and enhance coordination of efforts** | 1. Meeting regularly can improve interagency cooperation and coordination.<br>2. The benefits of sharing information and clearly understanding agency responsibilities can make the CDR process worthwhile in and of itself.<br>3. Reviews facilitate valuable cross discipline learning and strategizing.<br>4. Reviews improve interagency coordination beyond the review meetings. |
| **Improve agency responses in the investigation of child deaths.** | 1. Reviews promote early and more efficient notification of child deaths, facilitating more timely investigations.<br>2. Sharing information on the type of investigation conducted leads to improved investigation standards.<br>3. Reviews can identify ways to better conduct and coordinate investigations and resources. |

| | |
|---|---|
| | 4. Many teams report that new policies and procedures for death investigation have resulted from reviews. |
| **Improve agency responses to protect siblings and other children in the homes of deceased children** | 1. Reviews can often alert other agencies, such as social services, that other children may be at risk of harm; and they identify gaps in policies that may have prevented the earlier notification to these agencies. |
| **Improve criminal investigations and the prosecution of child homicides** | 1. Reviews can provide new case information to aid in better identifying intentional acts of violence against children.<br>2. Reviews may bring a multidisciplinary approach to assist in building a case for adjudication.<br>3. 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.** | 1. Reviews can identify the need for delivery of services to families and others in a community following a child death.<br>2. Reviews can facilitate interagency referral protocols to ensure service delivery. |
| **Identify specific barriers and system issues involved in the deaths of children.** | 1. Team members can help agencies identify improvements to policies and practices that may better protect children from harm. |
| **Identify significant risk factors and trends in child death.** | 1. Reviews bring a broad ecological perspective to the deaths, thus medical, social, behavioral and environmental risks are identified and more easily addressed. |
| **Identify and advocate for needed changes in legislation, policy and practices** | 1. Every review should conclude with a discussion of how to prevent a similar death in the future.<br>2. Reviews are intended to be a catalyst for community action.<br>3. Teams are not expected to always take the lead, but should identify where and to whom to direct recommendations, then follow-up to ensure they are being implemented. Solutions can be short-term or long term. |
| **Increase public awareness and advocacy for the issues that affect the health and safety of children.** | 1. When review findings on the risks involved in the deaths of children are presented to the public, opportunities can be identified for education and advocacy. |

Source: NCFRP Manual

**Table 2: Characteristics of Participants**

*Professions and Regional Demographics of Participants*

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**21 participants:**

- 5 California
- 4 Illinois
- 1 Indiana
- 1 Kansas
- 2 Michigan
- 1 Missouri
- 1 Pennsylvania
- 1 South Dakota
- 2 Wisconsin
- 3 National Organizations

**2 males, 19 females**

**Professions:**

- 2 Pediatricians
- 1 Medical Examiner
- 8 Public Health
- 3 Nurse
- 4 Social Work
- 2 Psychology

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**Table 3: Interview Guide**

*Pre established questionnaire*

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|---|
| 1. What is your primary role in Child Death Review? |
| 2. What aspects of the review process do you think are most useful and beneficial for the community? |
| 3. What is missing from your review process? |
| 4. How could your organization/coalition benefit from a more comprehensive review process? How could your review board benefit from a more comprehensive model? |
| 5. What obstacles would you face if there was a more comprehensive review process? |

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|---|
| 6. What is the primary goal of your organization? |
| 7. What prevention projects that have emerged from CDR have been the most successful? How could others have been more successful? |
| 8. Where do you see the greatest collaboration among your review board? |
| 9. What do you see as the greatest challenge in child injury prevention in your field? |
| 10. What is beneficial about a comprehensive review process? |

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