



Keeping Kids Alive

Child Death Review in the United States, 2020

June 2021

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Source of Information:

The National Center for Fatality Review and Prevention State Profile Database:
Reports from State Child Death Review Program Coordinators

State Child Death Review Coordinators are surveyed bi-annually on the status of their programs. In spring 2021, they were surveyed regarding their 2020 activities. Thirty-seven programs responded to the survey. For states that did not respond, their most recent responses were used in compiling data for this report.

Citation:

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Introduction

Each year almost 40,000 children, ages 0-18, die in the United States. Child Death Review (CDR) is a process in which local or state-level multidisciplinary teams meet to share and discuss case information in order to understand how and why children die. Diverse agencies send representatives to the case review meeting to share relevant records to help the team create a complete picture of the factors that increased risk. Teams use this information to catalyze action to make their communities safer.

The ultimate goal of a CDR team is to take action to prevent future deaths.

The National Center for Fatality Review and Prevention (National Center) is funded by the Maternal Child Health Bureau (MCHB) of the Health Resources and Services Administrations (HRSA), United States Department of Health and Human Services, to provide technical assistance, training, and data support to CDR and Fetal and Infant Mortality Review (FIMR) programs across the country.

There are CDR programs in every state, the District of Columbia, and several Native American/Alaska Native tribes. These systems differ in their scope both at the state and local level. They vary in composition of state and local teams, level of state support, placement of administrative leadership, supporting legislation, the types of deaths reviewed, and reporting systems used. To better understand these similar but diverse programs, the National Center conducts a bi-annual query of state-level CDR program leaders to assess program status. The following report is a synopsis of the responses from 2021 and represent the status of the programs in calendar year 2020.

The purpose of this report is to provide a summary of the status of child fatality review programs across the United States in 2020: what agencies participate in and fund them; the legal bounds within which they function; factors that guide case selection within states; how data are collected and used; and actions teams take to decrease childhood fatalities. The National Center provides this report to inform review teams, their partners, local, state, and federal governments, and other concerned parties about the breadth, diversity, and impact of the child death review process. The information in the following report is not static, as states often make changes to their programs, adopt new legislation to support their programs, or build new teams; it provides a comprehensive snapshot of the status of CDR in the United States in 2020. More complete information and links to individual state programs can be found on the National Center website (www.ncfrp.org).

CDR in 2020: Effects of COVID-19

The majority of CDR programs are led by state health departments, and all of them rely on multidisciplinary teams meeting in person to review cases. Prior to the pandemic, many teams were prohibited from meeting virtually due to confidentiality concerns and legislative requirements. During the pandemic, states and agencies were impacted in different ways, and CDR programs responded differently.

While in-person review meetings continued in some jurisdictions, most teams responded by **meeting remotely or temporarily halting reviews.**

In addition to stay-at-home orders and new remote work requirements, some state and local teams faced reassignment of key staff in support of the COVID-19 response—to activities such as surveillance, contact tracing, or COVID testing. Even after the worst of the pandemic had passed, some staff continued to be reassigned to support mass vaccination efforts. In many jurisdictions, teams' ability to conduct reviews was a moving target throughout the year, as some were early adopters of virtual platforms. COVID-19 did not impact each jurisdiction similarly, and state policies related to COVID-19 varied.

State and local programs displayed creativity and resilience in the face of the challenges of 2020. They shared effective strategies in regional networking opportunities and through the National Center's listserv.

Not surprisingly, there were fewer cases entered into the National Fatality Review-Case Reporting System in 2020, compared to the previous year. **In 2019, CDR programs entered 1180 cases per month on average; in 2020, they entered 980 cases per month on average.**

Even when CDR systems continued to review cases or resumed reviews, the pandemic presented challenges to completing case reviews, including:

- *Team member/staff deployments*
- *Lag in access to death certificates*
- *Delay in receiving records from other agencies*
- *Building capacity for remote meetings*
- *Challenges with case identification*
- *Records had less information than usual*

Report Highlight Summary



Child Death Review (CDR) is a multidisciplinary, prevention-focused process where teams meet to discuss case information to better understand how and why children die.

There are CDR teams in all 50 states, the District of Columbia, and within tribes.



55% of these teams are led by state health departments. Others are led by social service agencies, medical examiners offices, attorneys general or departments of justice.

71% of states mandate a *state* CDR program.

16% of states *permit* CDR based on legislation or administrative rules.

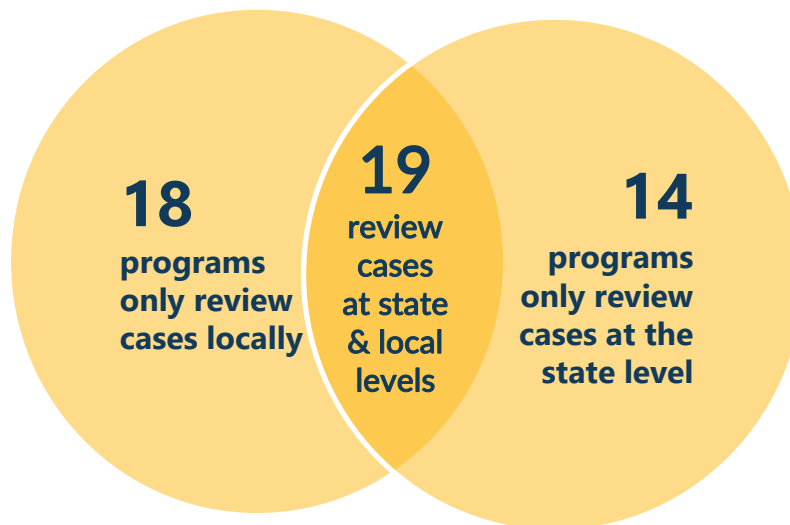
37% of states mandate *local* CDR teams.

Another 26% permit local CDR.

43 states have CDR state advisory boards.



Cases are reviewed by local and state-level teams.



10 states also review selected near-fatal injuries. Near-fatal injuries and fatalities can be studied together to better support injury prevention efforts.



46 states use the National Fatality Review-Case Reporting System (NFR-CRS) to collect data from CDR reviews.

There were more than **239,000** cases in the NFR-CRS by the end of 2020.



CDR teams commonly collaborate with other review processes, including:

- *Citizen Review Panels*
- *Fetal and Infant Mortality Review*
- *Domestic Violence Fatality Review*
- *Maternal Mortality Review*
- *Suicide Fatality Review*
- *Homicide Fatality Review*
- *Other Child Abuse and Neglect Reviews*
- *Overdose Fatality Review*

Teams



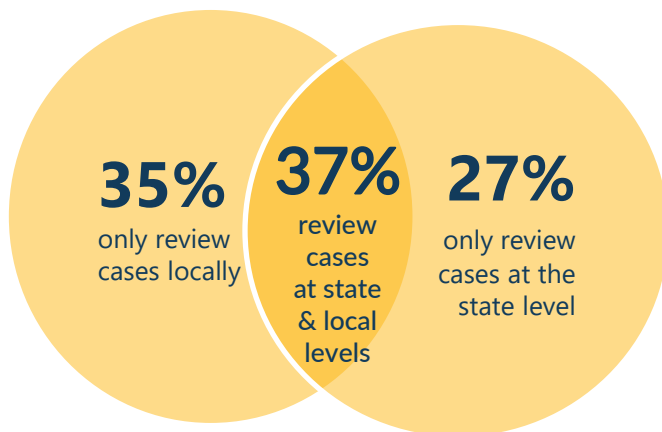
Composition of state and local CDR teams vary, but standard participating professional representation includes:

- *Child welfare*
- *Public health*
- *Pediatrics*
- *Law enforcement*
- *Prosecutors*
- *Medical examiners or coroners*
- *Injury prevention professionals*
- *Mental health professionals*
- *Suicide prevention professionals*
- *First responders*

- More than 1,350 CDR Teams
- All 50 states
- Washington, D.C. and Tribal Nations

Team participants bring relevant case records from their respective agencies to case review meetings to help create the full picture of the child’s life environment and factors contributing to how and why a child died. Teams identify risk factors, protective factors, systems gaps and root causes contributing to the deaths. This information is used to catalyze prevention actions at the local and/or state level to prevent similar deaths in the future.

Structure



State vs. local models

While every state and the District of Columbia has a CDR system, these systems differ in their scope at both the state and local level. Every state conducts reviews, but they vary in terms of how and where the reviews are conducted. Some states conduct fatality reviews in a state-level context; others conduct local-level reviews, often at the county level, contributing their data to a larger, state-level dataset to

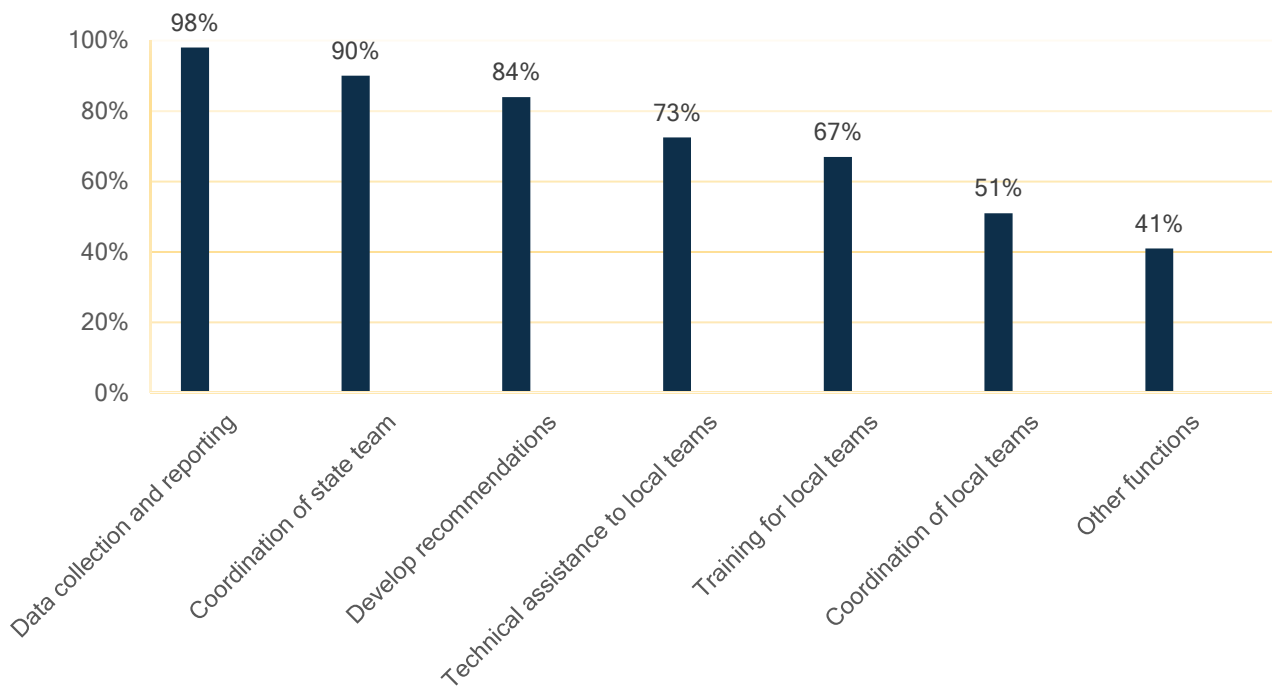
support broader prevention efforts. In some states, reviews take place at both the local level and the state level. Some state programs select certain cases to review for quality assurance,

or to inform the state team and contextualize the data from local programs. States' approaches vary based on several factors, including state statutes, geography, population size and density, funding, and program staffing.

Annual CDR training was provided by 47% of state programs in 2020, while 33% of state programs provided training on use of the National Fatality Review-Case Reporting System.



State CDR programs provided broad programmatic support to state and local review teams in 2020.



Other functions of state programs included:

- *Generating reports*
- *Collaborating with other partners or programs for prevention*
- *Providing investigative assistance to local agencies upon request*
- *Analyzing findings, recommendations, and fatality review data*

State advisory boards

Most states convene a state-level advisory board, regardless of which agency leads the effort or whether

reviews take place in state or local contexts, Advisory boards work to:

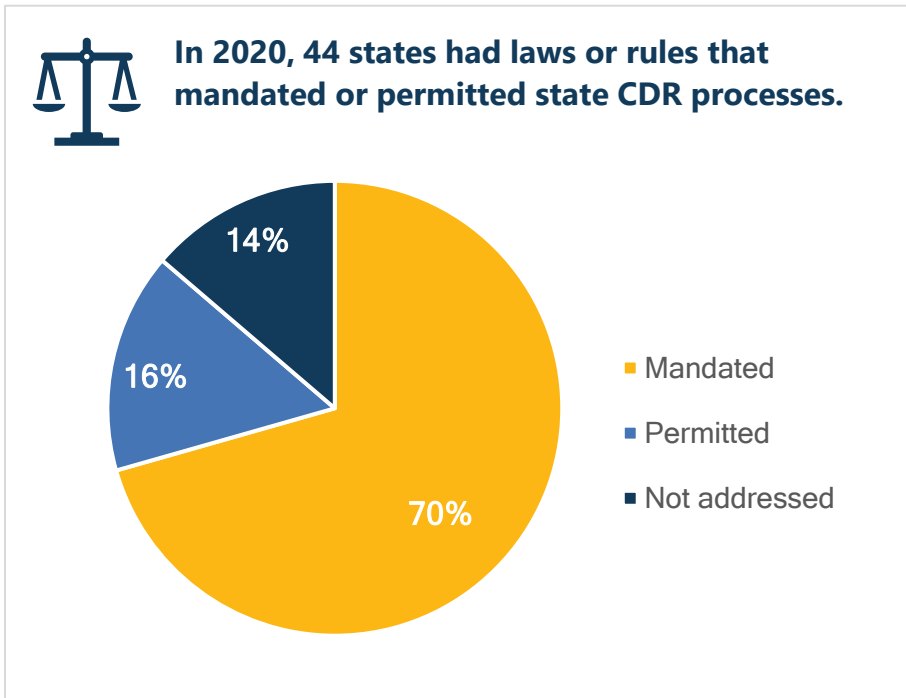
43 states had a state-level advisory board for CDR.

- *Understand case review findings, data, and recommendations*
- *Craft and advance state-level recommendations*

- *Write annual reports*
- *Conduct state-level reviews when appropriate*

It is common for state advisory teams to have subcommittees focused on specific causes of death, such as sleep-related infant death, child abuse and neglect, and suicide. They often produce required reporting to state legislatures, governors, or other specific agencies; partner with other fatality review processes; and provide guidelines and protocols for local case review teams.

Statutes and rules that apply to CDR



Most states (44) have legislation or administrative rules that mandate or permit a **state** CDR program. These statutes may make it easier for teams to access case records for review, create a reporting mechanism for teams to inform specific agencies, the governor, or legislature of their findings and recommendations, or require agencies to respond to or act on CDR recommendations. Language mandating fatality review generally facilitates improved records sharing with CDR teams. Permissive

language generally facilitates a more responsive programmatic approach. In general, whether mandated language or permissive language, a higher level of specificity in legislative language can sometimes limit program flexibility.

Local CDR teams are mandated under state statute/rules in 19 states and permitted under similar policies in 13 states.

Staffing

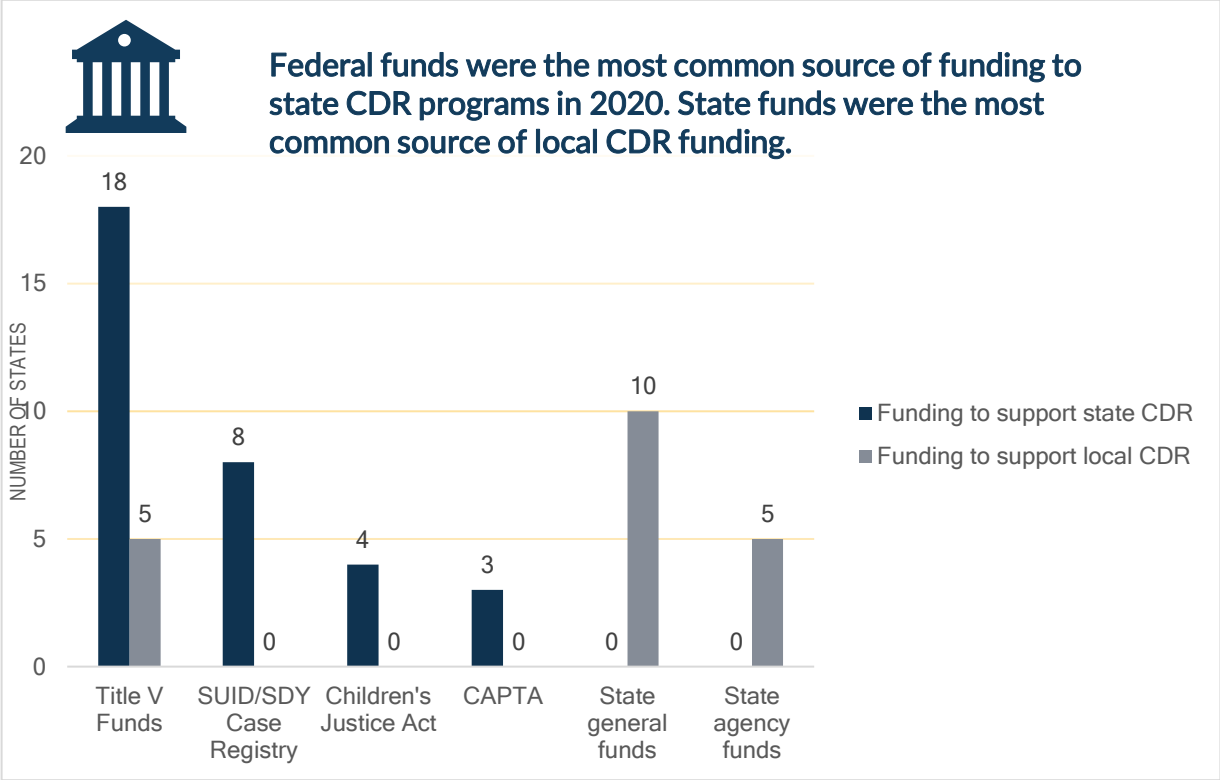


Programs have diverse levels of funding and staffing to support state CDR activities. These are significantly impacted by state budgets. State-level full time equivalent staff positions (FTEs) dedicated to CDR ranged from 0 to 6 across states; the median FTE for state programs was 1.5 FTE, and the average was 1.8. At the local level, FTEs ranged from 0 to 10 FTEs; the median was 1 FTE, and the average was 2.14.

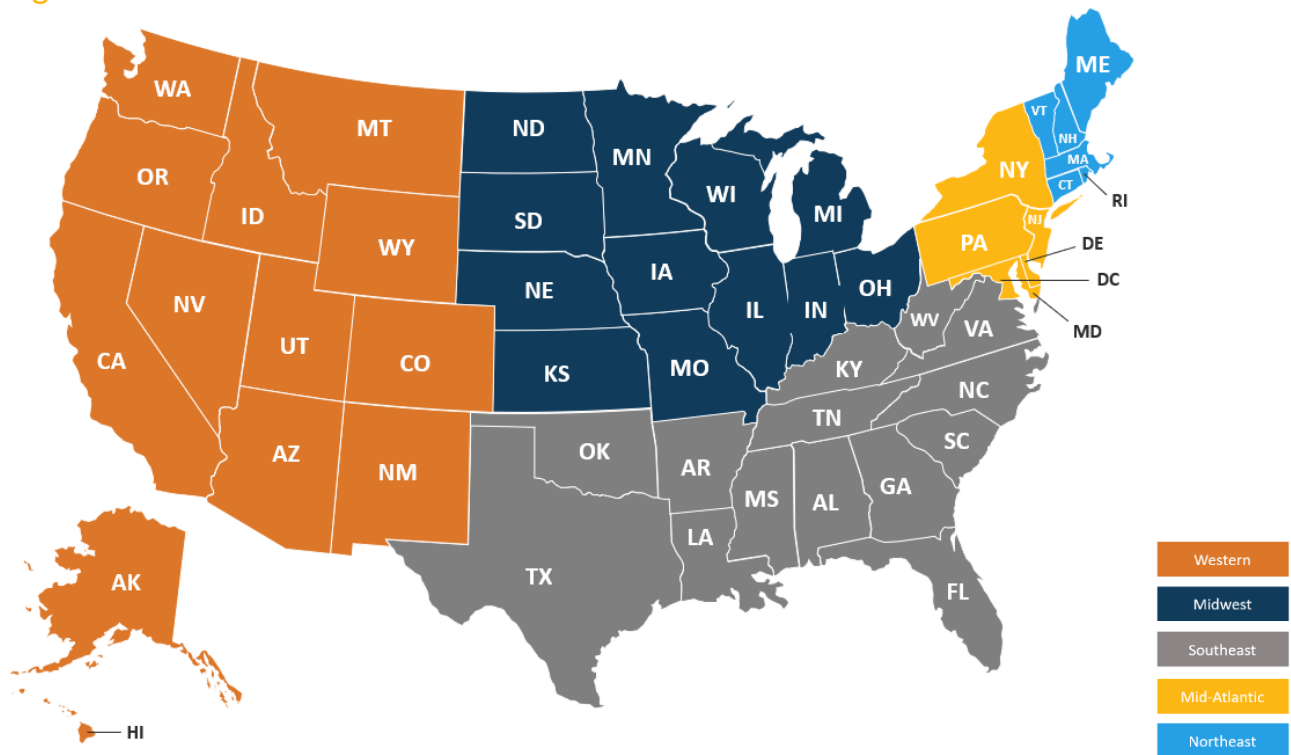
State-level funding amounts ranged from \$0 per year—relying heavily on in-kind support from partnering programs—to \$1.2 million per year. The

median funding amount was \$150,000; the average amount was \$247,708. This diversity of staffing and financial support can influence program capacity, caseloads and case selection criteria. Several states provide funding to support local CDR teams.

Federal grants were the most commonly reported source of funding to state-level programs; state general funds and agency funds were the most commonly reported source of local CDR funding. The most common sources of federal funding that states allocate to support CDR at the state level are Health Resources and Services Administration (HRSA)-administered Title V Block Grants—or Maternal Child Health (MCH) Block Grant funds; Sudden Unexpected Infant Death/ Sudden Death in the Young Case Registry (SUID/SDY) funds; Child Abuse Prevention and Treatment Act (CAPTA) funding; and Children’s Justice Act funds.



Regions



Fatality review is a unique function within states, and coordinators often do not have local colleagues who can share lessons learned, provide input, or give advice from a place of in-depth programmatic understanding.

The National Center for Fatality Review and Prevention (National Center) supported five regional collaboratives for state CDR program participation, divided into West, Midwest, Southeast, Mid-Atlantic, and Northeast. State coordinators participated in regional collaborative opportunities, including regional coordinator community of practice calls in 2020. Each region has a coordinator from one of the participating states who works closely with the National Center to plan and execute regional activities.

The regional networks provide opportunities for state CDR coordinators to interact with professional peers, share resources, learn from colleagues, and provide professional support on a regular basis. These opportunities for shared problem solving were particularly valuable in 2020, as state programs responded to the pandemic.

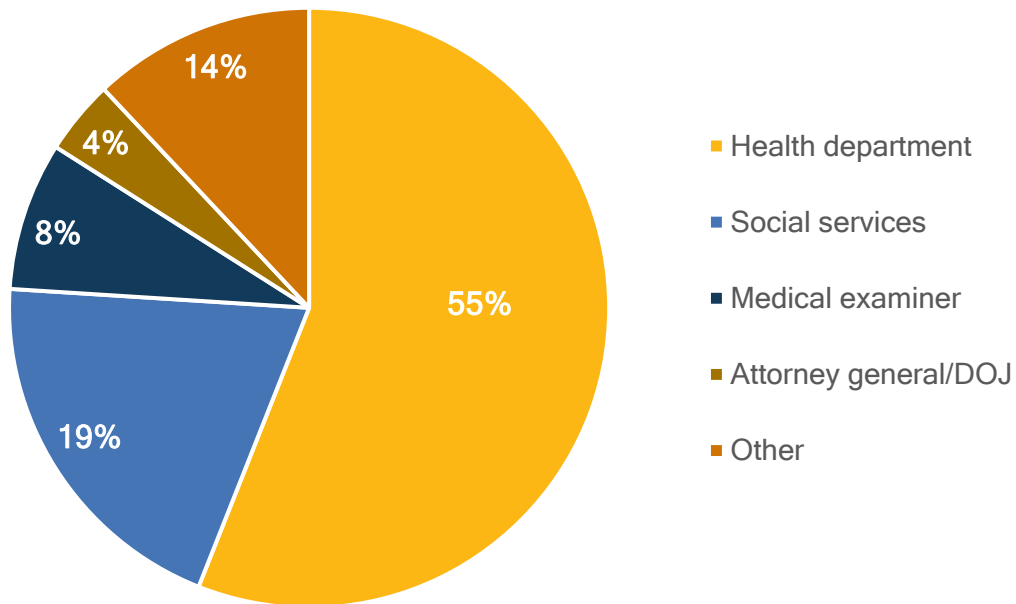
Lead Agency

Like many other aspects of CDR, the agency that leads coordination of programs varies by state. The lead agency can influence diverse aspects of CDR teams including team composition, natural program partnerships, types of cases reviewed, and the type of recommendations that result from reviews. Child death review began as a response to the underreporting of child abuse and neglect-related fatalities, and as such, its roots are in child welfare and social services disciplines. During the last decade, more CDR program coordination has migrated to health departments.

While more than half of state programs were coordinated by the state health department in 2020, some were coordinated by social service agencies, medical examiner's offices, attorneys general, or departments of justice (DOJ).



In 2020, 3/4 of teams were coordinated by the state health department or social services agency.



Case selection

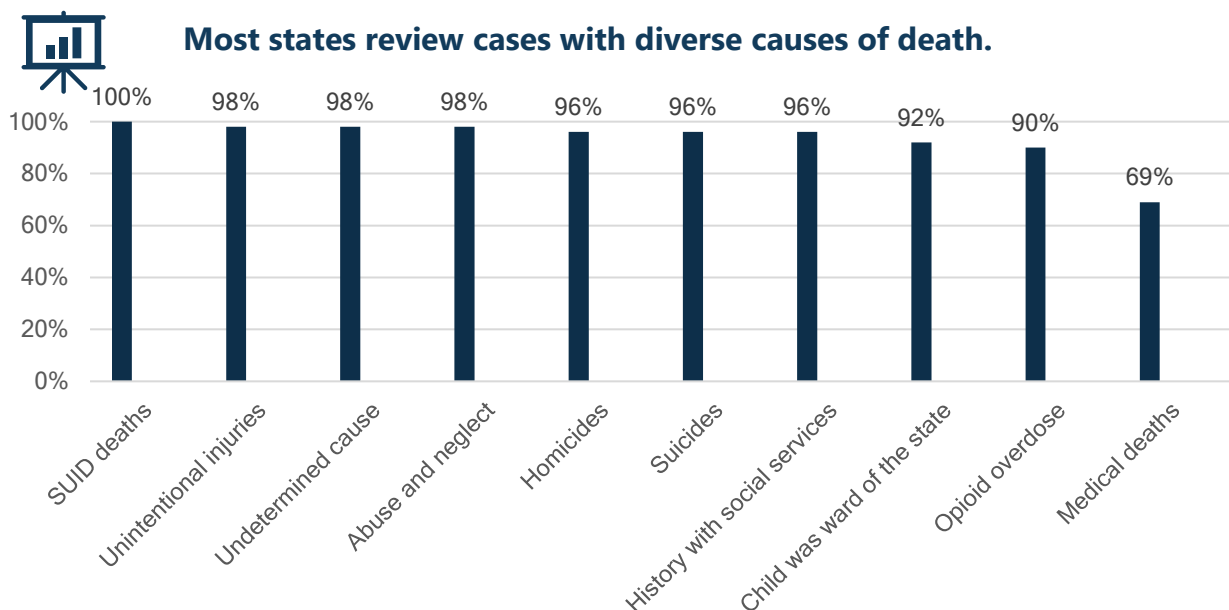


The selection of cases to be reviewed also varies by state. Throughout the country, state-level teams are reviewing deaths from sudden and unexplained infant deaths (SUID), unintentional injuries, suicide, homicide, abuse and neglect, and the deaths of children who were wards of the state or had a history with child protective services. In 2020, there was an increase in the number of states that reviewed SUID deaths, deaths due to undetermined cause, child abuse and neglect deaths, homicides, suicides, and deaths where the child had a history with social

services. There was a notable increase in the number of states reviewing cases where the child was a ward of the state, from 75% to 92%. Case selection criteria are influenced by multiple factors including:

- *Statutory requirements*
- *Lead agency*
- *Program capacity*
- *Residency*
- *Cause/manner of death*
- *Medical examiner jurisdiction*
- *Age*

This diversity of case selection criteria creates important context when examining CDR data from the state level or aggregated at the national level.



Teams also use different age ranges for inclusion in fatality review. One state only reviews deaths to children age 12 and younger. Seventy-eight percent of teams review deaths of children and youth up to and including age 17 years. Four states include deaths occurring to youth and young adults older than 18 years.

In addition to reviewing fatality cases, 10 states review some serious injuries or near fatalities at either the state or local level. These cases provide important information to inform injury prevention efforts.

In 2020, **all reviews** conducted at the *state level* were retrospective or periodic in nature, while **10%** of states also conducted some reviews within 48 hours of the death at the *local level*.



Review Process



Standardizing the fatality review process leads to better data, which ultimately leads to more effective prevention and systems-improvement efforts. Eighty-six percent of states have legislation or administrative rules that mandate or permit the CDR process at the state level. Similar statutes or rules permit or mandate local CDR reviews in 63% of states. These regulations can determine or require such features as:

- *Confidentiality of CDR meeting records and discussions*
- *Access to records*
- *CDR program reporting*
- *Designation of required state and local team members*
- *Required review protocols*
- *Protection of reviews from subpoenas/discovery and Freedom of Information Act (FOIA) requests*

Partners

The unique, multidisciplinary nature of fatality review is what makes it so effective. In particular, the impact of teams' prevention work is increased through strategic partnerships with injury prevention, maternal child health public health programs, child welfare agencies, and injury prevention coalitions.



Every state and the District of Columbia reported formal coordination with their child welfare agency in 2020.

Additionally:

- **46 jurisdictions** coordinated with their state maternal child health program
- **44 jurisdictions** coordinated with their state injury prevention program
- **13 jurisdictions** indicated that the state's Safe Kids coordinator was on their advisory board, up from 9 in 2018
- **11 jurisdictions** indicated that the state's suicide prevention coordinator served on their advisory board, up from 9 in 2018

Coordination with other reviews

A commonly recognized best practice within CDR is programmatic coordination with other types of fatality reviews. It is common that a case that falls under the purview of CDR will also be selected for review in a different fatality review process, such as a suicide or overdose fatality case review. Additionally, CDR teams serve as the Child Abuse Prevention and Treatment Act (CAPTA) Citizen Review Panel (CRP) in 18 states, up from 16 in 2018. Under CAPTA, states are required to convene CRPs to provide ongoing monitoring and annual reporting on state efforts to meet child protection requirements¹. Several states coordinate their CDR and Fetal and Infant Mortality Review (FIMR) programs out of the same administrative office, sharing staff and other resources.



CDR coordinates with:

- Child protective services review system in **27 states**
- Fetal & Infant Mortality Review (FIMR) in all **27 FIMR states**
- Citizen Review Panels (CRPs) in **25 states and D.C.**
- Maternal Mortality Review (MMR) in **25 states**
- Domestic Violence (DV) fatality review in **20 states and D.C.**
- Other SUID review in **15 states**
- Overdose review in **14 states**
- Suicide fatality review in **7 states**
- Homicide fatality review in **6 states**

In 35 states, there is separate child abuse and neglect death review system in addition to CDR. These are often conducted at the agency level to improve agency processes or protocols; it is common for these agencies to be members of a CDR team. Overall, forty-seven states conduct internal agency-level reviews of child deaths.

Coordination with other fatality review processes has increased over time.

Between 2011 and 2020, based on state-level programmatic reporting:

- *Programs coordinating with Maternal Mortality Review increased from 15 to 25.*
- *Programs coordinating with CRPs increased from 19 to 26.*
- *Programs coordinating with FIMR programs increased from 23 to 27.*

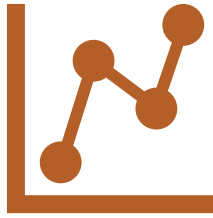
¹ Child Welfare Information Gateway.

<https://www.childwelfare.gov/topics/management/administration/partnerships/oversight/citizen/>

Programs coordinating with Sudden Unexpected Infant Death (SUID) reviews other than CDR have increased 150%, from 6 to 15 from 2011 to 2020. In addition to reviews focused on different types of deaths, military communities conduct their own child death reviews. Six states partner with military CDR teams at either the state or local level, and 14 states have military participation in their state or local CDR process, up from 11 in 2018.



National Fatality Review-Case Reporting System



In 2005, the National Center initiated its web-based National Fatality Review Case Reporting System (NFR-CRS) and made it available at no cost to all local and state CDR teams. **In 2020, 46 states contributed CDR data to the NFR-CRS, up from 44 states in 2018.** There were over 239,000 cases in the NFR-CRS by the end of the year.

The data collected through fatality review is a rich data source that highlights risk factors not available from other data sources. The nature of in-depth multidisciplinary case review through record sharing and deliberation provides more contextual data, family history data, data on underlying health or psychosocial vulnerability, and community systems to inform robust prevention planning.

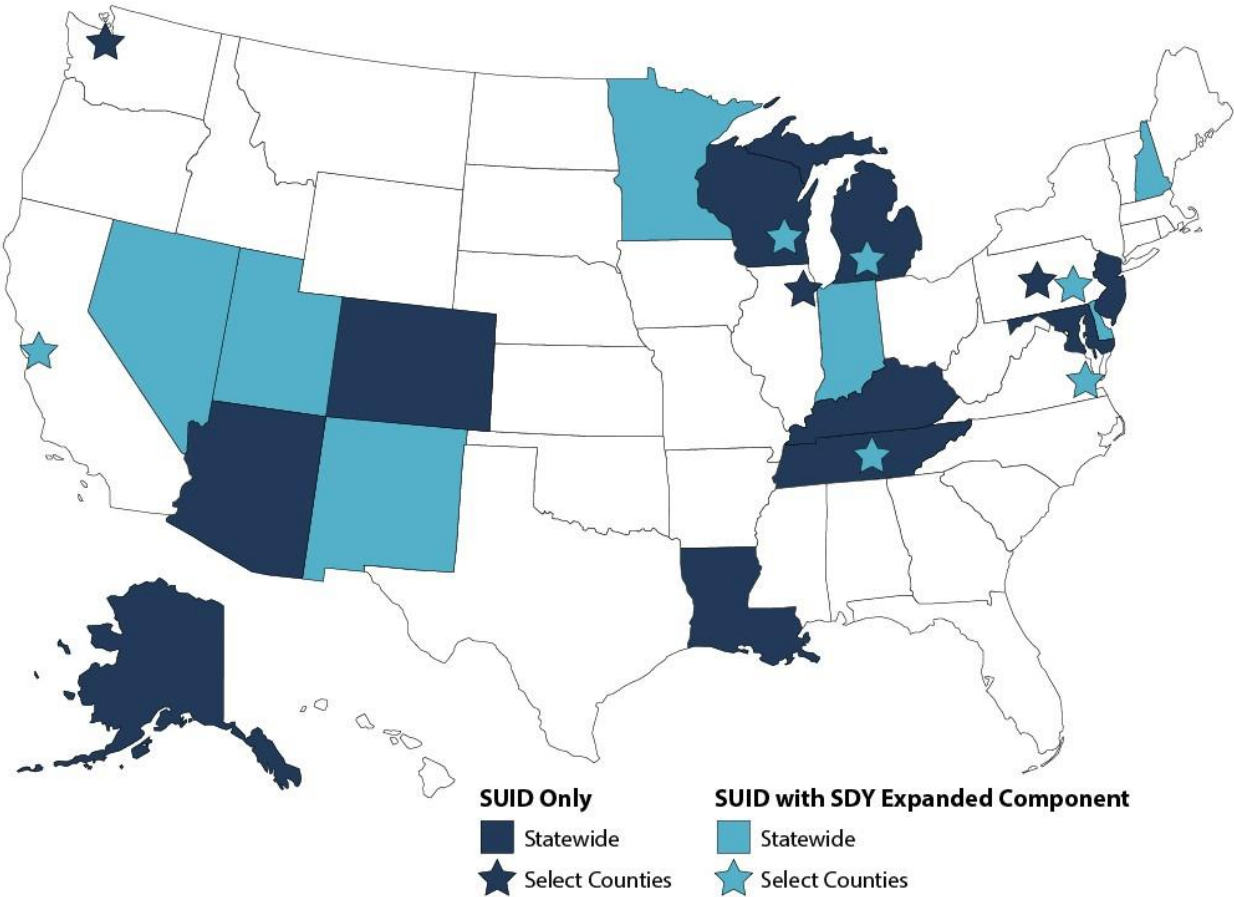
In 2020, 43 states reported that they used their CDR data to produce Annual Reports. Audiences for these reports include state governors, legislatures, state agencies, local teams, and the general public. State and local teams also use the data to:

- *Identify risk and protective factors in child deaths*
- *Inform prevention recommendations*
- *Improve community systems*

Partner projects

In 2020, 22 CDR states/jurisdictions were funded by the Centers for Disease Control and Prevention (CDC) to participate in the Sudden Unexpected Infant Death (SUID) Case Registry. Through a collaboration with the National Institutes of Health (NIH), 13 of these awardees were also funded to participate in the Sudden Death in the Young (SDY) expanded component. Through these cooperative agreements, states or jurisdictions use NFR-CRS and existing CDR programs as the foundation for reporting 100% of their SUID and/or SDY deaths into the registry, providing population-level surveillance for those participating. For more information on the SUID/SDY Case Registry, visit <https://www.cdc.gov/sids/case-registry.htm>.

SUID and SDY Case Registry Jurisdictions



Prevention

The transition of state CDR program coordination from social service agencies to public health agencies likely influenced the evolution of CDR toward a prevention model.

Child death review teams have a strong focus on primary and secondary prevention and systems-level improvements.

Examples of state-level prevention recommendations are highlighted below to illustrate the diverse actions CDR teams identified in 2020 to help prevent future deaths of children and youth in their communities. This is in no way an exhaustive representation, as CDR teams are functioning to prevent childhood fatalities across the country.

Examples



Tennessee

Based on broad-ranging fatality reviews of 929 deaths by 34 local teams in 2018, Tennessee's Child Fatality Review system made key prevention recommendations in 2020 focusing on prevention of suicide deaths; motor vehicle crash fatalities; infant deaths due to premature birth, birth defects, and unsafe sleep; and drowning².

- *Increase suicide prevention and mental health services in high-risk areas identified by the Tennessee Department of Health suicide prevention program*
- *Increase the number of schools in high-risk counties implementing evidence-based motor vehicle safety programs in local high schools*
- *Prioritize funding to reduce unintended pregnancies, reduce smoking during pregnancy, and increase enrollment in group prenatal care, evidence-based home visiting, and care coordination.*
- *Increase prevention of the leading drivers of birth defects including diabetes, substance use, high blood pressure, and high body mass index.*
- *Partner with state and community agencies to promote safe sleep, with a particular focus on intergenerational caregivers, to provide consistent, culturally appropriate messaging to address disparities.*

² Tennessee Department of Health. 2020 Child Fatality Annual Report: Understanding and Preventing Child Deaths in Tennessee, 2020. <https://www.tn.gov/content/dam/tn/health/documents/child-fatality-reports/2018-Child%20Fatality-Review-report%20.pdf>

- *Tennessee Department of Health will promote drowning prevention recommendations from the American Academy of Pediatrics Drowning Prevention Toolkit through social media and press releases and will promote resources for swimming lessons.*



Ohio

Ongoing prevention activities in Ohio focused on preventing child abuse and neglect fatalities included county and state-level efforts. The Ohio Children's Trust Fund coordinates primary and secondary child abuse and neglect prevention services for all of Ohio's 88 counties through a regional service-delivery model that focuses on the implementation of evidence-based child abuse and neglect prevention programs.

Based on reviews of 152 child abuse and neglect fatalities between 2015 and 2019, Ohio's Childhood Fatality Review program made the following prevention recommendations in 2020³:

- *Promote the use of 24-hour parenting hotlines as a safe and confidential source for parents in crisis*
- *Support educational programs that assist parents and guardians in understanding age appropriate behaviors, using alternatives methods of discipline, and choosing suitable caregivers*
- *Implement public service announcements educating lay people on signs of child abuse and neglect and how to report it*
- *Change the child protective services policy of closing a case after it has been referred to another agency; instead, ensure the agency to which the case has been referred has received and acted on it*

³ Ohio Department of Health. Ohio Child Fatality Review 20th Annual Report, 2020.
<https://odh.ohio.gov/wps/portal/gov/odh/know-our-programs/child-fatality-review/media/2020-cfr-annual-report>

Conclusion

The CDR field remained active and engaged in 2020, despite myriad challenges presented by COVID-19. By the end of the year, there was data from over 239,000 completed child death reviews submitted to the NFR-CRS. Most states engaged in state-level networking and technical assistance opportunities and built or maintained strategic partnerships with key service agencies. Despite diverse lead agencies, protocols, case selection criteria and intra-program coordination, in-depth, multidisciplinary fatality review continues to support prevention efforts across the country.

The diversity of various aspects of these programs reflects the diversity among the states in which they operate. The information from the bi-annual state profile surveys provides an opportunity for child fatality prevention systems and CDR programs to learn from the structure, methods, and experiences of other programs to support ongoing efforts to review child fatality cases to inform prevention efforts, and ultimately save children's lives.

For more information about child death review in the United States, please contact the National Center for Fatality Review and Prevention ([URL:http://www.ncfrp.org](http://www.ncfrp.org)) at info@ncfrp.org.

