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Saving Lives Together!

**The National Child Death
Review Case Reporting System**

**Access to Death Review Data:
Research Opportunities to
Save Children's Lives**

Child Death Review

Child Death Review (CDR) brings together teams of professionals in states and communities to systematically share information on circumstances of child deaths and to identify risk factors that can be mitigated to prevent other deaths. There are more than 1,300 state and local CDR teams operating in all states and DC. The scope of reviews varies among states with respect to the types and percentages of deaths reviewed. Most states review a high percentage of all sudden and unexpected deaths, and at least seven review all child deaths.

National Center for Fatality Review & Prevention (NCFRP)

NCFRP was established in 2002 to provide support and technical assistance to child death review teams across the country and expanded to include Fetal and Infant Mortality Review (FIMR) teams in 2015. In 2005 it established the National CDR Case Reporting System (NCDR-CRS) for the purpose of gathering comprehensive information about how children die and using those findings to prevent other deaths and improve child safety.

The National CDR Case Reporting System and Database

NCDR-CRS is a standardized, web-based reporting tool and database used by CDR teams to record, analyze and report on case information and findings from child death reviews. The tool contains over 2,600 data items, including information on the child, caregivers, supervisors, cause and manner of death, risk factors relevant to the death (for example, whether the child was in proper restraints in the car, or whether a pool had a fence) and review team recommendations for prevention, services, and improvements to agency systems. It is managed by NCFRP at the Michigan Public Health Institute (MPHI). Forty-five states are enrolled in and using the system; each participating state has an agreement with MPHI that protects its data while permitting limited access by researchers to de-identified datasets.



Using the Data for Research

NCFRP has developed policies and guidelines for access to the data by researchers and government policy makers. NCFRP encourages researchers to apply to use the data to advance evidence-based studies in order to prevent future deaths. There are countless topics researchers could potentially investigate to enhance current knowledge about how to keep kids safe and alive. The data provided is always de-identified. A number of peer-reviewed journal articles have been published describing studies using the NCDR-CRS data.

The database includes only the deaths of infants and children reviewed by CDR teams, not all infant and child deaths, so national population studies cannot be created with this data. Despite this limitation, the database is a rich source of comprehensive information on infant and child deaths not available through other sources. Data are not associated with the originating state without specific permission.

Requesting Access to the Data

Researchers can download the Data Dissemination Policy and Application Packet for requesting data from the NCDR-CRS or obtain it by emailing info@ncfrp.org. Applications are reviewed by a committee of experts as to the quality of the research questions, proposed methodology, and consistency with the NCFRPs mission to prevent further deaths.