



Chapter 9. Types of Reviews

Child Death Review began in Los Angeles County in 1978 in order to identify, evaluate and prevent child abuse and neglect-related fatalities. Because of the value of Child Death Review, the CDR model was expanded to include other types of child-related deaths, such as sudden infant death syndrome (SIDS) and fetal deaths. Other Review Teams were later established to examine teen suicide, maternal mortality, domestic-violence-related deaths and elder abuse fatalities. Following, is a brief summary of the various types of common reviews as well as a brief mention of the issues around multi-county and multi-state reviews.

Fetal Infant Mortality Review (FIMR)³⁸

FIMR is a community-based, action-oriented process that results in improved service systems and resources for women, infants and families. The FIMR process brings a community team together to examine confidential, de-identified cases of infant deaths. The purpose of the review is to understand how a wide array of local, social, economic, public health, educational, environmental, and safety issues relate to the tragedy of infant loss. Having gained a comprehensive understanding of these issues from case reviews, a broad forum of interested community members, elected officials, providers, agencies, advocates, and consumers are able to reason together and act to create or improve services and resources. There are currently 17 FIMR California county teams: Alameda, Contra Costa, Fresno, Humboldt, Kern, Los Angeles, Placer, Sacramento, San Bernardino, San Diego, San Francisco, San Joaquin, Santa Barbara, Solano, Sonoma, Ventura, and Yolo Counties.

FIMR began as a public health model focusing on prenatal fetal deaths. Natural deaths are chosen for review and information is collected from an interview with the mother. Reviews are done by a Team of medical experts who are looking for specific causes of death and possible contributing factors, including problems with health care access. These reviews lead to suggestions for improvement of the health care system with a focus on perinatal issues. A separate team addresses system changes and attempts to find resources to make those changes. FIMR exists in most states today. The National Fetal-Infant Mortality Review (NFIMR) was established to help states implement a fetal infant mortality review team.³⁹

³⁸ For more information on FIMR in California, call the California Department of Health Services, Maternal and Child Health Branch at (866) 241-0395 or visit www.mch.dhs.ca.gov. You can also contact Leona Shields, Nurse Consultant II at (916) 650-0314 or lshields@dhs.ca.gov.

³⁹ Refer to www.acog.org/from_home/departments/dept_web.cfm?recno=10 for information on the National Fetal Infant Mortality Review.

Sudden Infant Death Syndrome (SIDS)⁴⁰

SIDS is the sudden and unexpected death of a baby who seems perfectly healthy. The diagnosis of SIDS is made under the criteria of one-year of age, a sudden unexpected death, and no other significant factors. Victims are most often between the ages of one month and six months. The

Every two hours in the United States, a baby dies of SIDS. SIDS occurs in families of all social, economic and ethnic groups. It is a recognized cause of death and is only determined after completion of an autopsy, a death scene investigation, and a case history review of both the baby and family. Scientists from the United States and around the world are conducting large-scale, ongoing research into deaths from SIDS. These researchers are coming closer to understanding SIDS, but the cause remains unknown. They have identified ways to reduce the incidents of SIDS through certain infant care practices, such as sleep position, breast-feeding and proper infant care.⁴¹

Studies of SIDS began decades ago and developed into effective prevention programs during the 1980's. Programs addressing SIDS are not so much a system of review as they are a system of service. Federal funds support national and state programs that provide education, prevention, research, and support for family survivors.

The California protocol on SIDS appeared in 1991 with legislation that defined cases for review, and required standardized autopsies, police training and intervention. Funds were included for cases that met the criteria. SIDS cases have dropped significantly statewide with the introduction of the back-to-sleep program for all young infants, the campaigns against smoking when pregnant and around children, and the multiple efforts to reduce pre-maturity. Between 1992 and 1998, among U.S. infants, stomach (prone) sleeping decreased from more than 70 percent to approximately 20 percent. During that same time frame, the number of SIDS deaths declined by more than 40 percent.⁴² Not surprisingly, most researchers, policymakers, and SIDS professionals agree that this significant decline occurred largely as a result of changing sleep position.

SIDS diagnosis has also decreased since the beginning of 2000, with an increase in the use of the category "Undetermined" as a manner of death for cases that have additional factors like co-sleeping and maternal substance abuse. SIDS programs, faced with this dramatic decrease in SIDS deaths, are beginning to change the criteria for the families served to include other cases of infant deaths.

⁴⁰ Refer to www.sidsalliance.org and www.sids-network.org for information on SIDS Alliance and SIDS Network.

⁴¹ Santa Clara County California Website, "What is not Child Abuse?" 30 Sept. 2004 www.scvmed.org/channel/0,4770,chid%253D16968%2526sid%253D13397,00.html.

⁴² M Willinger, HJ Hoffman and KT Wu, et. al, "Factors Associated with the Transition to Nonprone Sleep Positions of Infants in the United States: The National Infant Sleep Position Study," Journal of the American Medical Association 1998; 280: 329-335.

Back-to-Sleep Campaign

Back-to-Sleep is a national educational campaign. It is suitably named for its recommendation to place healthy babies on their backs to sleep. Placing babies on their backs to sleep reduces the risk of Sudden Infant Death Syndrome (SIDS), also known as "crib death." This campaign has been successful in promoting infant back sleeping to parents, family members, childcare providers, health professionals, and all other caregivers of infants. This campaign is sponsored by the National Institute of Child Health and Human Development, the Maternal and Child Health Bureau, the American Academy of Pediatrics, the SIDS Alliance, and the Association of SIDS and Infant Mortality Programs.⁴³

CDR-SIDS-FIMR Relationships

The United States Department of Health and Human Services (USDHHS) sponsored a meeting in November 1997, with professionals involved in Child Fatality Review (CFR), Fetal Infant Mortality Review (FIMR) and Sudden Infant Death Syndrome (SIDS). This group recommended that CFR and FIMR should work together on data collection, noting that CFR and FIMR have a parallel process for gathering data. SIDS programs add treatment for surviving family members.

Maternal Mortality Review (MMR)

Maternal Mortality Review (MMR) began primarily as an academic endeavor focused on studying the causes of death of pregnant women, women who had recently given birth, and women with children less than one-year-old. MMR later became a public health model for review of deaths. The CDC definition includes all deaths of mothers from pregnancy to a year after birth. MMR has included studies of such deaths and in some studies may include deaths from domestic violence. Some states have ongoing systems to review such deaths from public health records.

Suicide Review⁴⁴

The process described below uses Los Angeles County as a model for a Child & Adolescent Suicide Review Team (CASRT). CASRT conducts follow-back studies of suicides among children and adolescents up to age 18. The Team reviews cases once a month, which have been classified as "suicide" by the medical examiner. The Team focuses on warning signs, risk factors, protective factors, intervention and post intervention.

For prevention purposes, the CASRT disseminates its findings and recommendations to policy makers and child services professionals, promotes the adoption of the National Strategies for Suicide Prevention among agencies and professionals throughout the county, and advocates for

⁴³ National Institute of Child Health and Human Development, "SIDS Back to Sleep Campaign," 30 Sept. 2004 www.nichd.nih.gov/sids/sids.cfm.

⁴⁴ Refer to www.yspp.org/, www.yellowribbon.org and www.mentalhealth.org/suicideprevention for information on the Youth Suicide Prevention Program, the Yellow Ribbon Suicide Prevention Program, and the National Strategy for Suicide Prevention.

prevention policies, procedures and training. The team will soon embark on the establishment of a county- wide prevention protocol.

The same agencies that are represented in CDRs are represented at the CASR (schools, law enforcement, mental health, probation, health services and child protective services). Representatives from other agencies, stakeholders and advocacy groups are invited on a case-by-case basis, but do not attend regularly. Members of the family are *not* invited to participate. Confidential information is exchanged under the authority of the Child Abuse Reporting Law (WIC Sections 18951 and 19865) and HIPAA.⁴⁵

Public Health Model vs. Psychological Autopsy

In the Public Health Model, the focus of the review is on system improvement. The review is brief (about 40 minutes) and identifies patterns of suicide and suicidal behavior throughout the county or area. Usually, all teen/adolescent suicides that occur within a calendar year are reviewed.

In contrast, a Psychological Autopsy is a medical clinical study of an individual case. The study is extensive and in-depth and may take several weeks to complete. The purpose of a psychological autopsy is to assist the Medical Examiner or Coroner to determine the cause of death. The Medical Examiner/Coroner only requests these investigations when necessary.

The CASRT review uses a public health model. Patterns of suicidal behavior throughout the county are examined. The team attempts to review all cases of child and youth suicide each year.

Prevention is the main goal of the Suicide Review Team. It is vital that Team members and others participate in reviews when invited, support Team recommendations, and are leaders in the awareness of suicide prevention.

Domestic Violence Fatality Review (DVFR)^{46, 47}

Domestic Violence Fatality Review began in the 1990's. As of January 1995, California counties were authorized to establish Domestic Violence Fatality Review Teams (DVFRTs) under California Penal Code section 11163.3 to assist local agencies in identifying and reviewing domestic violence deaths and facilitating communication among the various agencies involved for prevention of future violence. DVFRTs work to strengthen system policies and procedures as well as identifying prevention strategies to reduce future domestic violence-related incidents and deaths.

⁴⁵ Refer to SECTION II, CHAPTER 5 for Confidentiality Issues and SECTION VI, APPENDIX E: Legal Issues for HIPAA information.

⁴⁶ Refer to <http://safestate.org/index.cfm?navID=9> for information on California Domestic Violence.

⁴⁷ Bill Lockyer, California's Domestic Violence Death Review Team Protocol 30 Sept. 2004 http://safestate.org/documents/dvdr_protocol.pdf. Contact Sandra for more information at Sandra.Gaarder@doj.ca.gov

DVFR teams now exist in 24 California counties and 21 states.⁴⁸ Many of these teams are housed within the criminal justice system. Some teams review only domestic violence cases involving both homicide and suicide. Others have a broader intake. Smaller counties may have the same teams reviewing both child deaths and domestic violence fatalities, adding domestic violence experts for those cases. DVFRs may include gay and straight couples, adolescents and adults. Victims may be either male or female, but the vast majority is females who have died at the hands of their male partners.

DVFR Teams have a membership similar to that of CDR Teams, with more emphasis on the inclusion of representatives from the Domestic Violence community. Domestic Violence Fatality Review in California has been sponsored primarily by the criminal justice system. The strong roles played by prosecutors and community members, and a stated desire to balance the team with non-governmental community resources has created a different focus from Child Death Review. Some counties combine their DVFR and CDR Teams. Others keep them completely separate. A national forum has begun to coordinate the continuing development of DVFR in all states. Local efforts to combine CDRT and DVFR will be augmented by a working relationship between the National Domestic Violence Fatality Review Team (NDFRT) and ICAN/NCFR.

Every year in the United States, 1,000 to 1,600 women die at the hands of their male partners, often after a long, escalating pattern of battering.⁴⁹ Other homicide, suicide and accidental deaths may also involve domestic violence. DVFR began in Reno Nevada by some of the same people who helped develop the local child death review. DVFR Teams then spread to California beginning with Shasta County, again involving the local CDRT.

California DVFR Protocols

In accordance with Penal Code section 11163.5, the Department of Justice, in April 2000 issued California's Domestic Violence Fatality Review Team Protocol. DOJ, in coordination with the Department of Health Services and an advisory committee consisting of local DVFR members representing law enforcement, health and social services, and the judiciary, along with representatives from state domestic violence coalitions, designed the protocol. The protocol contains recommendations on DVFR structure, procedures and policies that appear to be working and which should be helpful in establishing additional teams in California.

The protocol includes examples of recommendations made based on cases reviewed by local DVFR teams, such as the Santa Clara County DVFR which was formed in October 1994. One significant finding in the team's first report produced in 1998 was the over representation of Asians as victims and perpetrators in the reviewed deaths (17 out of 51 cases). As they further investigated the cases, they found that in all but one case there had been no prior contact by the victim or the perpetrator with the system. The DVFR committee realized a need for more education and intervention with the Asian community. As a result, the Santa Clara DVFR designated three Asian representatives on the team and has established the Asian Community

⁴⁸ Refer to <http://www.safestate.org/index.cfm?navid=352> for a list of California county DVFR Teams. Refer to www.vaw.umn.edu/documents/fatality/fatality.html for a list of State DVFR Teams.

⁴⁹ Neil Websdale, "Reviewing Domestic Violence Deaths," 30 Sept. 2004
www.ncjrs.org/pdffiles1/jr000250g.pdf.

against Domestic Violence Coalition. The Coalition meets regularly and has organized a domestic violence conference for the Vietnamese, Korean, Cambodian and Filipino communities.

Confidentiality and its impact on DVFR

Confidentiality has proven to be a significant issue in establishing DVFRTs. Penal Code 11163.3 (e), (f) and (g) established confidentiality guidelines for DVFRTs. Upon completion of a review, recommendations, but not cases, of DVFRTs, may be disclosed at the discretion of a majority of the Team members.

The Importance of Data

The California Domestic Violence Fatality Review Team Protocol stresses the importance of collecting data to provide the basis for identifying trends. Data should include:

- Details of the incident
- Race and age of the parties involved
- Prior history of the victim and perpetrator
- Prior intervention contacts with the system
- History of substance abuse
- Pregnancy information
- Use of weapons
- Whether children were present at the time of the homicide

From the data, Teams can make recommendations to assist in preventing future incidents of domestic violence-related injuries and deaths.

Vulnerable Adults and The Elderly⁵⁰

Elderly people are expected to die, but old age can be used as a cover for negligent or deliberate deaths. Older people with complex medical problems can die and be buried without an autopsy or without a close look at the circumstances of their death. For example, cancer can leave an elderly body emaciated but so can malnutrition. Bumps can easily cause bruises but fists do too. Falls can break bones but broken bones also can come from being thrown down.

In response to the above concerns, all 58 counties in California are required by legislation (SB 2199) enacted in 1999 to provide services to combat and prevent elder and dependent adult abuse by providing the following services: a 24-hour hotline to receive reports of abuse response to all reports of elder abuse case management services to all victims coordination of community resources to provide victims with treatment emergency services intervention early in the cycle of abuse.

⁵⁰ Refer to www.calregistry.com/resources/eldabpag.htm for more information on Elder Abuse.

Incidents of Elder Abuse⁵¹

- It has been estimated that one of every 20 elderly people is the victim of neglect or physical, psychological or financial abuse. (House Select Committee on Aging, 1994)
- Only one in 14 cases of elder abuse is reported to authorities.
- Over 2 million elders are abused every year. (National Aging Resource Center on Elder Abuse, 1999)
- In 1999-2000, the California Department of Aging's Long-Term Care Ombudsman's Office received 3,728 complaints of elder abuse occurring in long-term care facilities. (California Department of Aging's Long-Term Care Ombudsman's Office, 2001)
- A November 1999 General Accounting Office report found that nearly one-third of the nursing homes in California caring for Medicare/Medicaid patients had been cited for serious care violations.

Professionals who may come in contact with the elderly may be ill prepared to unravel the complicated circumstances surrounding the aged person's death. Social workers aren't prepared to conduct criminal investigations. Law enforcement is often poorly trained to differentiate between age-related health problems and physical abuse. And, prosecutors find it difficult to build a case due to a lack of evidence or witnesses. Team case reviews provide an opportunity to more closely examine the circumstances leading up to elderly person's medical, and other psychosocial conditions.

California

Statistics uncover a frightening picture of elder abuse in California. Over 225,000 cases of elder and dependent adult abuse are handled by protective service agencies each year. Unfortunately, more than two-thirds of abusers are family members. Currently it is estimated that only one in five cases is reported within our state. Nationally, one of every 20 elderly people will be a victim of neglect abuse this year.

In response to this situation, legislation (AB 1819 Shelley) was signed in 2000, authorizing the California Attorney General's Office to develop and implement a three-year statewide public education campaign to prevent the abuse of elders and dependent adults. The campaign, *Face It - It's a Crime*⁵² is designed to educate Californians about the impacts and prevalence of elder and dependent adult abuse. It also provides information on how to recognize and report abuse, and what resources are available to the elderly and dependent adult community and their families and caregivers. In order to simplify the process for reporting suspected abuse, the Attorney General's Office has created a hotline, 1-888-436-3600, that will directly connect individuals wishing to report abuse to their local Adult Protective Services Agency or the Long Term Care Ombudsman Crisis Line.⁶⁷

Objectives of the Adult Death Review⁵³

⁵¹ California Attorney General's Crime and Violence Prevention Center. "Elder and Dependent Adult Abuse. *Elder Abuse in California*," 30 Sept. 2004 www.safestate.org/index.cfm?navid=243.

⁵² California Attorney General's Office, "Face It. It's a Crime," 30 Sept. 2004 <http://safestate.org/documents/ea%20press%20release.pdf>.

⁵³ Refer to <http://www.safestate.org/index.cfm?navid=243> for information on Elder Abuse in California.

- Ensure timely notification to and cooperation with law enforcement, the medical examiner, the state attorneys office, health services and other involved community agencies
- Identify the causes and circumstances of the vulnerable adult deaths and use that information to assess what could have prevented the death
- Identify programmatic or operational issues that indicated the need for training.

The deaths of Vulnerable Adults are tracked and logged so that data may be collected. Team membership includes the Coordinator (preferably the Registered Nurse Specialist), the Protective Investigator, Adult Services representative, a physician with expertise in adult abuse and neglect, and legal counsel. Law enforcement, state attorney, medical examiner, mental health and experts in developmental disabilities or the elderly may also be included.

Unique Issues for the Multi-county and Multi-state Case Review Process

Cases are frequently lost between counties. A child hurt in one county may travel to another county for medical care or may live with parents in separate counties. Records from Coroners, law enforcement, social services, and health systems may not cross those county lines or may be sent through state agencies that take months for the transfer and then may keep them separate from the local teams.

In California, counties are encouraged to meet with each other. The counties of Butte/Glen and Inyo/Mono have joined to form teams. Imperial County takes cases to San Diego for consultation or because the child crossed county lines when hospitalized. These exchanges have required extra efforts on the part of team members and County systems.

California is rather unique in the way it deals with interstate transportation of sick and injured persons. Because the state has one of the largest interstate borders in the U.S., children crossing county lines are common occurrences. Severely injured children living near the border in counties such as El Dorado, Placer and Sierra may be transported to emergency medical facilities in Reno, Nevada. If the child dies and death is pronounced in Nevada, the information about the case is routinely sent to the coordinator of the CDR Team in the child's county of residence. The exchange of information between different counties is assisted by ICAN/NCFR-sponsored training and professional education.

The border with Mexico presents an even wider and more complex set of circumstances to address. For example, families stranded in the Imperial Desert in the scorching heat of summer may never make it back to the United States. Bodies are returned to the areas of residence when identification is possible. There is also the issue of illegal and dangerous border crossings into the United States by Mexican citizens, which are fielded by the Border Patrol. Additional work with Border Patrol agents is required to improve the consistency of complete and timely review of these cases. San Diego county hospitals may also be a source of information about children who are brought to the U.S. for medical treatment and die within California's jurisdiction. ICAN/NCFR held the first combined training for California CDR professionals and interested and involved counterparts from Mexico. Presented in both San Diego and Riverside Counties,

these training sessions used UN style simultaneous translation services to provide a seamless presentation that both sides found helpful.

Cases from distant states have also been exchanged with local teams. For instance, Los Angeles County received a referral from a team in South Carolina that had a case of a suspicious death in a family that was moving to Los Angeles. The LA team took the case as an interstate referral and involved Child Protective Services. The family was evaluated and found to have multiple problems that required intervention.

Cases may even get lost within the same county, as officials from one law enforcement agency, local courts and health systems may not communicate with their counterpart on the Team. Systems of communication and accountability are developing to improve intervention with children families when records are lost crossing geographic and political lines. Part of this system includes case tracking and part involves personal relationship as professionals travel to meet each other. A growing number of professionals have traveled to visit neighboring Teams.

Non-fatal Severe Injuries⁵⁴

The next wave of multi-agency case reviews on the agenda of the National Center on Child Fatality Review will involve nonfatal severe injuries. Some states have already begun to look at these injuries in the form of a formalized review. Although 2002 data from the Children's Bureau National Child Abuse and Neglect Data System (NCANDS) estimated a total of 1,400 child maltreatment fatalities that year, the number of "near fatalities" is not collected by NCANDS, nor is the number of children severely injured by child maltreatment. It is possible that far more children are hospitalized in serious or critical condition, than die as a result of parental maltreatment.

There were 168,278 substantiated child victims of physical abuse in 2001, according to NCANDS. Some unknown (and likely small) percentage of these cases involved victim children who were hospitalized and listed in serious or critical condition as a consequence of their maltreatment.

It may therefore be reasonably suggested that at least several hundred thousand children a year are "seriously injured" as a result of child maltreatment. That is certainly an intimidating number, as it represents 100 times the number of child maltreatment deaths reported by CPS agencies. Clearly, existing child fatality review teams and their members lack the time and resources to review all those cases.

According to information on state child fatality review team information collected by M. Gabriela Alcalde and Nanette R. Elster,⁵⁵ there are at least eight states where CFRTs already have an authorization, or a mandate, to review cases *other than fatalities*.

⁵⁴ To obtain a copy of Howard Davidson's article on non-fatal severe injury, "Mandating Multidisciplinary Review of Serious Child Maltreatment Cases," contact Sabina Alvarez, ICAN/NCFR, at (626) 455-4585.

⁵⁵ Nanette R. Elster and Gabriela M. Alcalde, "Child Fatality Review in the United States: A National Overview," 30 Sept. 2004
www.louisville.edu/medschool/ibhpl/publications/Child%20Fatality%20Review%20in%20the%20United%20States%20-%20A%20National%20Overview.pdf.

These states are—

- Maine: Team is called the “State Fatality and Serious Injury Panel”
- Maryland: Team also reviews “near fatalities”
- New Jersey: Team is called the “Child Fatality and Near Fatality Review Board”
- New York: Team also reviews “near fatalities” resulting from child abuse and neglect
- Oklahoma: Team reviews “near fatalities” and has a process for review of near death cases
- Rhode Island: “Child Death and Injury Review Teams” review cases involving critical injuries
- South Dakota: Team reviews “near fatality” cases
 - Wyoming: “Child Major Injury/Fatality Review Team” reviews “near fatalities” and major injuries to children who at time of injury were in child welfare agency custody.

Interestingly, the states listed above are a mix of large and small states. For a small state, the review of major injuries to children may require little additional effort. For example, Wyoming’s report on major injury cases reviewed in 1999 listed 9 such cases.

Some hospitals have already started this process by connecting in patient care injuries to the hospital Suspected Child Abuse Neglect (SCAN) Team. With time this will lead to a multi-agency review of non-fatal injuries. The California Department of Health Services has a federal grant to use hospital discharge records to study severe nonfatal injuries. A protocol for such review was developed in Rochester New York over a decade ago.

The Federal Centers for Disease Control and Prevention (CDC) is developing a national data system to include all interpersonal injury deaths. Definitions and data collection are being developed. Child Fatality Review will be a player to add data and resources to the review of those deaths.

Summary

In a little over two decades, death review has grown to include different populations and has brought diverse resources to work together. Local, state and national efforts are connecting these reviews. Professional dedication to identifying the causes of reviewed deaths is leading to tangible prevention programs that are successfully keeping children and vulnerable persons safer.