



Chapter 5. Confidentiality

CDR teams are forums for sharing information necessary to improve communities' responses to child fatalities. They must, by their very nature, deal with sensitive and confidential information. The issue of confidentiality relates to two different, but related matters: Access to information by the team and access to the team's information by individuals or organizations outside the team. Most of what CDR Teams encounter are issues surrounding their ability to access needed information for their reviews.

According to *Every Child Matters and Legacy Family Institute*, the pendulum is swinging towards opening the child welfare system of services for abused and neglected children to greater public scrutiny through the release of information. Congress has recently approved changes to the Child Abuse Prevention and Treatment Act, which now requires a state to "disclose confidential information to any Federal, State or local government entity, or any agency of such entity, that has a need for such information in order to carry out its responsibility under law to protect children from abuse and neglect." At the same time, a federal court in New Jersey has required the state child welfare agency to release hundreds of pages of documents that were held confidential on children in the foster care system. At least 13 states have passed statutes to open court hearings involving child protective matters to the public.²⁰

There are also forces moving in the opposite direction. HIPAA, *The Health Insurance Portability and Accountability Act of 1996* went into effect in April 2003. The rule is intended to protect the privacy and security of individual health data, and establishes accountability and penalties for failing to use the rule to protect health information privacy. The American Bar Association (ABA) has written an opinion on HIPAA, which is included in the APPENDIX.²¹

The team cannot do its work without having access to information about the child, the family and the death. The public has an interest in knowing why and how children are dying and what can be done to prevent those deaths. Although there are valid confidentiality concerns that have to be addressed to ensure smooth team operations, confidentiality should not be a barrier to conducting child death reviews.

Some teams may have mandated access; others may enter into agreements with the providers of the information. There may be certain federal restrictions that supercede state or local information access mandates. For example, team members from substance abuse services, mental

²⁰ For the booklet, "Making Good Decisions about Confidentiality in Child Welfare," published by *Every Child Matters and Legacy Family Institute*, e-mail KCaler@hornbyzeller.com. Refer to www.everychildmatters.org and www.legacyfamilyinstitute.org for information on Every Child Matters and Legacy Family Institute.

²¹ The opinion written by Howard Davidson, Director of the ABA Center on Children and the Law, appears in its entirety in SECTION VI, APPENDIX E: Legal Issues on HIPAA and Child Death Review.

health, education or others may not be able to share case-specific information at reviews. In those cases, they may be able to provide information about their services and give ideas about improving linkages and referrals in the future

Accessing Team information

To determine whether there will be problems related to the access of the Team's information by those outside the team, consider whether the information requested is identified (information that provides the identity of the child and family) or de-identified (information that does not provide the identity of the child and family). Naturally, teams will generally have fewer constraints regarding the sharing of de-identified information than identified information.

There are four groups that might be entitled to access a Team's case information: Team members, other government officials or agencies, the press and the public.

Following are some of the statutes that give the public access to what the government does and has:

- Public information acts, also called "freedom of information acts (FOIA)," are state (and federal) laws that give the public access to the records maintained by government entities. Many states that have enabling CDR legislation have specific exemptions from that coverage
- According to law, the meetings of government organizations are open to the public. These laws often include a listing of exemptions for certain types of meetings, of which CDR meetings may be a part

Just as there may be restrictions that hamper the team's ability to obtain case information, the same kinds of statutes may also restrict the access of others to the team's information, such as:

- Other local CDR teams within the state (especially if there are cross-jurisdictional issues)
- The State Office of the Children's Ombudsman or State Department of Social Services
- The agency that sponsors the CDR process
- The CDR support staff

Brady vs. Maryland

In Brady vs. Maryland of 1963, the Supreme Court determined that if prosecutorial evidence favorable to the accused is suppressed by the prosecution during the trial phase, and the accused is convicted, the defendant's right to due process has been violated and a retrial on the sentence is required.

Connecting with others involved in the process

Sometimes, a person or entity new to CDR may be reticent to become involved because they have no experience with the process, and they feel like they are going out on a limb by sharing sensitive information. Often, the way to best resolve this is to connect those persons or organizations with others in their specific professions who are already involved in CDR.

A recent case:

Clarissa died in California at the age of 18 months of post-traumatic seizure disorder, but her autopsy showed the evidence of past assaults: old subdural injuries and fluid collection. The local sheriff had taken Clarissa away at eight months of age with the head injuries that eventually led to her seizures, but a physician who had raised suspicions of abuse withdrew his suspicion and Clarissa was released to her parents. Social Services followed the family with six months of voluntary services, and Clarissa was sent for a medical work-up to a children's hospital and a regional medical center. Both hospitals theorized, without having access to her medical or family history, that Clarissa must have been injured by a traumatic birth. After Clarissa died, a coroner finally reviewed Clarissa's medical records and discovered that she had not experienced a traumatic birth. The Medical Examiner ruled her death a homicide.

Concerns over confidentiality were cited repeatedly by experts testifying before the Board as a real obstacle to saving children's lives. Child Death Review Teams encounter this problem daily. However, the ABA's published documents and testimony to the Board should allay fears among CPS workers, doctors, police, teachers, prosecutors, and others over criminal penalties or loss of Federal funding. The ABA has found that as long as Child Death Review Teams carefully manage their records, fear of criminal penalties or loss of funding within agencies who share their information is unfounded.

Federal regulations require that, in order to qualify for Federal funds under the Child Abuse and Prevention Act (CAPTA) and Titles IV-B and IV-E, States must enact laws providing that all records concerning reports of child abuse and neglect are confidential. Unauthorized disclosure is a criminal offense. However, these Federal regulations have specifically exempted multidisciplinary review teams from restrictions on sharing information within team settings (Regulation 45 C.F.R. 1340.11). Nevertheless, misconceptions about the law are widespread.

Many researchers and front-line workers believe that these widely misinterpreted confidentiality regulations hinder the protection of children. Coroners and medical examiners, public health officials, and other agencies often encounter resistance from officials who believe they must withhold their case information.

Teams with established procedures for handling confidential information are proving that it is possible to handle sensitive information in a responsible way. However, the issue presents such a major obstacle that legislative clarification is needed at the state and federal levels. We urge the ABA, National District Attorney's Association, National Association of Medical Examiners, American Academy of Pediatrics, CDC, American Public Health Association, and law enforcement and child protection associations to push for implementation of model confidentiality legislation.