

Tools for Public Health: Conducting Child Death Reviews under the HIPAA Privacy Rule

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Introduction

Keeping Kids Alive, the Michigan Child Death Review (CDR) Program, was established in 1995 to support the local case review of child deaths, in order to better understand why children die and to take actions to prevent other child deaths. Natural causes, accidents, homicides and suicides cause the deaths of almost 2,000 children from birth to age eighteen each year in Michigan. It is believed that at least half of these deaths could have been prevented.

The operating principle of *Keeping Kids Alive* is that the death of a child is a community problem and that the circumstances involved in most child deaths are too multi-dimensional for responsibility to rest in any one place.

The objectives of each review of a child's death are the:

- Accurate identification and uniform reporting of the cause and manner of every child death.
- Improved agency responses to child deaths in the investigation and delivery of services.
- Improved communication and linkages among agencies and enhanced coordination of efforts.
- Identification of needed changes in legislation, policy and practices and expanded efforts in child health and safety to prevent child deaths.

Public Act 167 of 1997 amends Section 7 of the Child Protection Law, to support the establishment and operation of local review teams. It defines local teams as having a team membership of at least the county medical examiner, a senior representative from local law enforcement, an FIA and local public health representative and the prosecuting attorney or his/her designee. Additional team membership depends upon community resources and needs. It is recommended that a team also include:

- A pediatrician
- An emergency medical services provider
- A representative from a community hospital
- A representative from community mental health
- A representative from the juvenile division of probate or family court
- A representative from the intermediate school district or local schools
- A child-care licensing representative

Other team members may include neonatologists and representatives from the clergy, funeral homes, child advocacy centers, SIDS professional support services, community foundation officers and tribal councils. Because agencies have special programs that relate to team activities, it may be appropriate to have more than one agency representative on a team.

PA 167 also establishes a Child Death Review State Advisory Team to provide guidance to local CDR teams and to make recommendations to the Governor and Michigan legislature based on local findings. Public Act 220 of 1995 also amends Section 7 of the Child Protection Law, allowing FIA team members to share information in the Child Protective Services Central Registry.

Reviews are conducted by discussing each child death individually. Teams most often use the CDR Report Form as a discussion guide. Participants provide information from their agencies' records and, when appropriate, distribute it to other members. If information is distributed, it must be collected again before the end of the meeting.

Information is generally shared in the following order:

1. The medical examiner presents information on the investigation, autopsy and pending or final determination of cause and manner of death.
2. The EMS provider presents the run report and any other information they may have.
3. The hospital representative or physician shares information from the emergency room and/or other health care setting.
4. The law enforcement officer presents information on the scene and other investigations related to the case.
5. FIA reports on any history it has on the family, child or circumstances.
6. The local health department reports on any information it has on the family, child or circumstances.
7. Other team members report on any other information they have and can share with the team.
8. The prosecutor reports on the status of the investigation and any legal actions related to the case.

Often, team members may be unable to share information due to superceding confidentiality restrictions or a lack of information. If information is needed by an investigative agency, it should be accessed after the team meeting, utilizing standard investigative practices and approaches as mandated by their agencies. It is important to remember that the CDR process is not a mechanism for criticizing or second-guessing agency decisions. It is a forum for sharing information essential to the improvement of a community's response to child fatalities.

In reviewing deaths of child residents of other counties, team members contact their corresponding agencies in those counties to request information. PA 167 of 1997 provides safeguards for this confidential exchange of information. These review meetings and the case report forms filled out on each death are confidential and not subject to FOIA. The meetings are not subject to the Open Meetings Act. Individual team members sign a Confidentiality Statement before participating in reviews. Failure to observe confidentiality would violate statute and contain penalty. This has not been a problem in Michigan's experience with the CDR process.

The Michigan Child Death Review Report is completed on all deaths reviewed. These reports are sent to the state CDR program office and entered as aggregate data. The statistical compilation of these data is public record, as it does not have case identifying information attached to it. An annual report is published by the Michigan Child Death State Advisory Team based on these findings and recommendations of the local review teams. This report is distributed to the Governor, legislature and CDR team members.

CDR teams exist in all but seven of the eighty-three counties in Michigan. The 1,170 volunteers, including professionals from more than 20 different disciplines, are using their findings to identify and implement changes in policy, services and programs that can prevent other deaths.

Since the Health Insurance Portability and Accountability Act of 1996 (HIPAA) was enacted, some CDR team members have become wary of sharing information at review meetings. Several questions have surfaced including:

- How does HIPAA affect CDR?
- Can we still conduct reviews?
- Is authorization needed from the deceased child's parents in order for information to be shared and/or discussed at the review meetings?
- Am I violating any laws by participating in a CDR meeting?
- Some team members are reluctant to attend CDR meetings now that HIPAA has been enacted. How can the team encourage their participation case reviews?

The HIPAA Privacy Rule

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) was enacted by Congress and signed by President Clinton. Among other things, this federal legislation included provisions related to "Administrative Simplification" in the U.S. health care system that were intended to:

1. Increase efficiency and reduce administrative costs in the US health care system by promoting and standardizing electronic data interchange,
2. Create standards for protecting the privacy and security of health data, and
3. Establish accountability & penalties for failing to use the standards and for breaches of privacy.

When Congress did not follow up on its self-imposed deadline to address the privacy standards with additional legislation, responsibility fell to the Department of Health and Human Services to develop those standards through the federal rule-making process. After seeking public comment, the final rule was published in December 2000. Covered entities must be in compliance with the Privacy Rule¹ by April 14, 2003. The Privacy Rule will require covered entities to carefully examine and possibly change how they use, disclose, and protect individually identifiable health information. Covered entities are defined as health plans, health care clearinghouses, and health care providers that use electronic data interchange for certain health care administrative transactions (e.g., for submitting claims to obtain payment for health care services).

In order to understand how this regulation will affect the conduct of child death review (CDR) projects, it is necessary to understand the basic goals of the Privacy Rule and a handful of the key points in the rule. These essential points are summarized below.

The basic goals of the Privacy Rule are as follows:

1. It sets a nationwide minimum standard for health privacy by pre-empting state privacy laws that are weaker (do not provide as much privacy protection to an individual) than the Privacy Rule, but preserving stronger state privacy laws,
2. It permits disclosures of health information that are required by existing law so that covered entities are not forced to break one law in order to be compliant with another law,
3. It establishes new federal patient rights to privacy and assigns covered entities various responsibilities to support those rights, and
4. It strikes a balance between protecting individual privacy rights and allowing use of health information for various public responsibilities (public health, research, law enforcement, etc.).

¹ DHHS published what is commonly called the Privacy Rule as 45 CFR Parts 160 and 164, Standards for Privacy of Individually Identifiable Health Information. Citations: The original final rule was published as 65 FR 82461-82829 (December 28, 2000), a technical correction was published as 65 FR 82944 (December 29, 2000), and a modification to the final rule was published as 67 FR 53181-53273 (August 14, 2002).

The Privacy Rule carefully defines protected health information (PHI) and outlines what uses and disclosures of PHI are permitted and/or required. For most practical purposes, PHI is any kind of health information that can be associated with a specific person (i.e., it is individually identifiable, and it has something to do with a person's health status, health care, or payment for health care). The general principle underlying the Privacy Rule is best expressed by Section 164.508 (a)(1), which states:

(1) Authorization required: general rule. Except as otherwise permitted or required by this subchapter, a covered entity may not use or disclose protected health information without an authorization that is valid under this section. When a covered entity obtains or receives a valid authorization for its use or disclosure of protected health information, such use or disclosure must be consistent with such authorization.

So, a covered entity must be able to point to a specific paragraph within the Privacy Rule that explicitly permits or requires a use or disclosure of PHI in order to do so without first informing the patient and getting a signed, written authorization from the patient for each such use or disclosure.

Fortunately, the Privacy Rule includes a number of provisions that make it clear that there are various public responsibilities where the privacy rights of the individual must be balanced against larger social purposes of the nation. Public health is one of those purposes, so there is explicit language in the regulation that allows covered entities to justify disclosing data for use in public health activities. The paragraphs in Section 164.512 (b) of the Privacy Rule describe the exception that permits covered entities to disclose PHI without obtaining authorization from the patient (or the patient's personal representative, which would usually be a parent in CDR cases):

(b) Standard: uses and disclosures for public health activities.

(1) Permitted disclosures. A covered entity may disclose protected health information for the public health activities and purposes described in this paragraph to:

(i) A public health authority that is authorized by law to collect or receive such information for the purpose of preventing or controlling disease, injury, or disability, including, but not limited to, the reporting of disease, injury, vital events such as birth or death, and the conduct of public health surveillance, public health investigations, and public health interventions; or, at the direction of a public health authority, to an official of a foreign government agency that is acting in collaboration with a public health authority;

(ii) A public health authority or other appropriate government authority authorized by law to receive reports of child abuse or neglect;

Thus, the questions about whether child death reviews can still occur in Michigan depend on whether or not CDR teams can be demonstrated to meet the definition of "a public health authority authorized by law" and whether the CDR activity itself can be clearly demonstrated to be a public health activity.

Conducting Child Death Reviews in Michigan under HIPAA

In Michigan, Public Act 167 of 1997 is the authorizing legislation for establishing child death review teams. The Act permits each county to establish a CDR team, specifies the membership requirements for the team and designates the team as a statutorily created task force. Thus, CDR teams meet the criterion for being a “public health authority that is authorized by law...”.

The second important criterion is that the activity for which the data are being disclosed must be a public health activity. The goal and objectives for Michigan’s CDR teams are clearly described on page 5 of the publication *Keeping Kids Alive: Michigan Child Death Review Team Protocols*:

Goal

The Goal of Child Death Review Teams is to improve our understanding of how and why children die, to demonstrate the need for and to influence policies and programs to improve child health, safety, and protection and to prevent other child deaths.

Objectives

1. Accurate identification and uniform reporting of the cause and manner of every child death.
2. Improved communication and linkages among agencies and enhanced coordination of efforts.
3. Improved agency responses to child deaths in the investigation and delivery of services.
4. Design and implementation of cooperative, standardized protocols for the investigation of certain categories of child death.
5. Identification of needed changes in legislation, policy and practices, and expanded efforts in child health and safety to prevent child deaths.

This description clearly indicates that CDR is a surveillance system as well as an investigation and intervention designed to achieve a clear public health goal. Thus, CDR meets the second criterion from the Privacy Rule’s public health activities exception. This means that covered entities may disclose protected health information to the CDR team for use in the review without obtaining authorization from the parents.