Public Health Efforts to Build a Surveillance System for Child Maltreatment Mortality: Lessons Learned for Stakeholder Engagement

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Context: Reducing the number of largely preventable and tragic deaths due to child maltreatment (CM) requires an understanding of the magnitude of and risk factors for fatal CM and targeted research, policy, and prevention efforts. Public health surveillance offers an opportunity to improve our understanding of the problem of CM. In 2006, the Centers for Disease Control and Prevention (CDC) funded state public health agencies in California, Michigan, and Oregon to implement a model approach for routine and sustainable CM surveillance and evaluated the experience of those efforts. **Objective:** We describe the experiences of 3 state health agencies in building collaborations and partnerships with multiple stakeholders for CM surveillance. **Design:** Qualitative, structured key informant interviews were carried out during site visits as part of an evaluation of a CDC-funded project to implement a model approach to CM surveillance. **Participants:** Key informants included system stakeholders from state health agencies, law enforcement, child protective services, the medical community, and child welfare advocacy groups in the 3 funded states. **Results:** Factors that facilitated stakeholder engagement for CM surveillance included the following: streamlining and coordinating the work of Child Death Review Teams (CDRTs); demonstrating the value of surveillance to non–public health partners; codifying relationships with participating agencies; and securing the commitment of decision-makers. Legislative mandates were helpful in bringing key stakeholders together, but it was not sufficient to ensure sustained engagement. **Conclusions:** The engagement process yielded multiple benefits for the stakeholders including a deeper appreciation of the complexity of defining CM; a greater understanding of risk factors for CM; and enhanced guidance for prevention and control efforts. States considering or currently undertaking CM surveillance can glean useful insights from the experiences of these 3 states and apply them to their own efforts to engage stakeholders.

KEY WORDS: child abuse, child maltreatment, collaboration, surveillance

In 2009, more than 700 000 children in the United States were victims of child abuse or neglect, also referred to as child maltreatment (CM).[1] An estimated 1770 of these children died as a result of maltreatment, and this figure is almost certainly an underestimate of the true extent of fatal CM. Accurately assessing the true magnitude of the problem is hampered by the lack of a

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CDC disclaimer: The findings and conclusions in this report are those of the author(s) and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Funding for this evaluation was provided by the Centers for Disease Control and Prevention, contract 200-2005-F-14668.

The authors thank their Centers for Disease Control and Prevention colleagues at the National Center for Injury Prevention and Control for their support and guidance. They also sincerely thank their colleagues at the California Department of Public Health Epidemiology and Prevention for Injury Control Branch, the Michigan Public Health Institute, the Michigan Department of Community Injury and Violence Prevention Section, and the Oregon Department of Human Services Office of Disease Prevention and Epidemiology for their participation and input in this effort.

Disclosure: The authors declare no conflict of interest.

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DOI: 10.1097/PHH.0b013e3182126b6b

J Public Health Management Practice, 2011, 17(6), 542–549

coherent and universal standard for defining and measuring CM. In one study of Pennsylvania physicians, wide variation was found in how they understood and interpreted reasonable suspicion of child abuse, thus calling into question the notion that thresholds for reasonable suspicion were applied in a consistent manner.[2] A similar study of prehospital providers found significant deficiencies related to identification of CM, interviewing techniques, and appropriate documentation.[3] Reducing the number of these largely preventable and tragic deaths requires an understanding of the magnitude of and risk factors for fatal CM and targeted research, policy, and prevention efforts.

Public health surveillance offers an opportunity to improve our understanding of the problem of CM through the ongoing, systematic collection, analysis, interpretation, and dissemination of data regarding a health-related event for use in public health action.[4-6] The imperative to establish robust CM surveillance systems that can inform public health practice is all the more urgent given that less than 2% of programs reported by child welfare agencies have a strong base of empirical research.[7]

Compared with other health events, surveillance of CM presents unique challenges. These include the difficulty of ascertaining causal sequences; the frequently subtle etiology of maltreatment, particularly child neglect; the diversity of definitions applied to CM across jurisdictions; and social biases that inhibit identification and reporting of maltreatment.

Public health–based CM surveillance uses multiple data sources outside of the traditional public health and medical systems. The use of multiple data resources for surveillance has been shown to be effective in identifying possible cases of intentional injury, including injury because of CM and intimate partner violence.[8-10] Data sources for CM mortality surveillance include death certificates, homicide files, medical examiner records, child protective service (CPS) records, child welfare registries, and Child Death Review Team (CDRT) reports. The latter is considered the single best source of mortality data.[11] Child Death Review Teams use a systematic, multidisciplinary, multiagency process for integrating multiple sources of data from coroners, courts, CPS agencies, and health care providers for the purpose of understanding their underlying circumstances. Although early CDRTs focused on identifying CM deaths,[12] today CDRT programs in most states identify their primary purpose as the prevention of all child deaths.[13,14] Child Death Review Teams and other multidisciplinary bodies such as the Child Advocacy Centers have the added benefit of enhancing the participants' understanding of the complex roles and responsibilities of stakeholder agencies and as a result diminishing barriers to communication.[15]

Child Death Review Teams exist in nearly all states, although not all operate statewide.[13] However, synthesizing state and local data into a uniform national system of surveillance is a work still in progress, requiring the sustained and cohesive engagement of institutional stakeholders from public health, medicine, child welfare, and criminal justice. Moreover, effective prevention of CM requires system-level changes within these various sectors. In recent years, various federal initiatives have promoted CM surveillance. Both the Health Resources and Services Administration and the Office of Juvenile Justice and Delinquency Prevention have supported the development of CDRTs.[13,14] The Centers for Disease Control and Prevention (CDC) initiated the development of state-based CM surveillance systems in 2001 by funding states to develop and test CM surveillance systems[11] and establishing definitional guidelines for public health surveillance of CM.[16]

To further advance the practice and understanding of CM surveillance, CDC funded 3 state public health agencies in 2006 to implement a model approach for routine and sustainable CM surveillance and evaluated the experience of those efforts. The 3 state health agencies worked with the evaluation team, CDC staff, and the project consultant to implement the model CM mortality surveillance system, using CDRT data and the CDC case definitions for CM.[16] The states, as part of the evaluation, also applied the definition to a number of case scenarios to gather input on the strengths and limitations of using them to identify and classify maltreatment deaths within a child death review context. Although initially the project intended to focus on both CM morbidity and mortality surveillance, the project stakeholders deemed the complexity of defining CM morbidity and lack of data sources as 2 major constraints that could not be addressed within the short project period. So, the project and this paper focus exclusively on CM mortality. A separate paper is currently being prepared that evaluates the application of the CDC CM definitions and the implications for CM surveillance.

The evaluation design for the model approach of CM surveillance in the 3 states used the *CDC Updated Guidelines for Evaluating Public Health Surveillance Systems*[17] that consists of 6 steps or phases: (1) engage stakeholders, (2) describe the system, (3) focus the evaluation design, (4) gather credible evidence, (5) justify conclusions, and (6) ensure use and share lessons learned. The findings presented here concern the first step and describe how state public health agencies were able to engage multiple institutional stakeholders in the development of a CM surveillance system.

Stakeholder engagement is critical to many collaborative efforts in public health[18,19] and, the engagement of stakeholders from multiple sectors has proven to be

a cornerstone of the CDRT process. However, stakeholder engagement is a particular challenge for CM surveillance because of the sensitive nature of data involved and the different perspectives of public health and child welfare on CM. Moreover, public health agencies typically do not have the authority, capacity, or resources to spearhead CM stakeholder engagement efforts on their own. Child maltreatment–related activities have historically been the responsibility of child welfare and law enforcement agencies. Effective partnerships between all key stakeholder agencies are essential not only for surveillance but also for establishing a continuum of supportive, protective, and prevention services.[20]

Here, we describe the experiences of and lessons learned by the 3 state health agencies in building collaborations and partnerships with multiple stakeholders for CM surveillance and their implications for public health practice.

Methods

In December 2006, after a competitive selection process, 3 state health agencies (California, Michigan, and Oregon) were chosen to field a model CM mortality surveillance system developed by the evaluation team, CDC, and a team of experts in CM.

To evaluate the experiences of the 3 CM surveillance systems, the evaluation team conducted a site visit to each of the 3 states to gather the perspectives of diverse system stakeholders. During these site visits and follow-up calls, the evaluation team members conducted individual and group interviews with project staff and partners including those from law enforcement, CPSs, the medical community, and child welfare advocacy groups. The key informants selected for the interviews were participants in the review process, key users of findings from the review process, and/or represented agencies providing data to the review process. Selection of specific individuals and agencies for interviews was based on the evaluation team's familiarity with each of the program over its development as well as consultation with project coordinators. A total of 35 interviews were completed and each lasted 30 to 60 minutes. Interviews were guided by a semi-structured discussion guides tailored to the position and background of the stakeholder. The interviews were tape recorded with the permission of the key informants.

The goal of the analysis was to identify patterns and themes in the transcripts that would inform our understanding of the factors and conditions that promoted or hindered stakeholder engagement. We prepared transcriptions of the interviews from the recording and notes of each interview and using content analysis—"a systematic, replicable technique for compressing many words of text into fewer content categories based on explicit rules of coding"[21]—coded the text in QSR International's NVivo 8 software.[22] Two analysts reviewed each coded transcript to promote consistency and reliability. They discussed any discrepancies in the coding and came to a mutually agreed-upon resolution. The procedures for carrying out the coding were consistent with established methods for ensuring the validity, reliability, and replicability of qualitative research.[23] The research protocol for the evaluation was submitted to the RTI, International institutional review board and deemed exempt.

Lessons Learned

The experiences of California, Michigan, and Oregon in implementing the CDC model approach for CM surveillance yielded a number of important lessons learns for engaging stakeholders, which we summarize in the following section. Illustrative quotes are presented in Table 1.

CDRTs serve as an infrastructure for engaging stakeholders in CM surveillance

Key informants in each state noted that a defining feature of their surveillance system was multidisciplinary membership of their CDRTs. Professionals from many disciplines contribute important perspectives to the death review. They build a collective understanding of each death that would be difficult to achieve if each member were addressing the death solely from the perspective of his or her own discipline. The multidisciplinary approach made standardization of reviews more difficult and states struggled to achieve it, but stakeholders acknowledged that surveillance (and reviews) required both standardization and multidisciplinary participation.

In addition to their professional expertise, multidisciplinary stakeholders provide one another with access to information and data (through formal and informal channels) that were critical to the surveillance process. For example, law enforcement representatives on the CDRT provided documentation vital to review of the death. When these stakeholders left, their loss impacted the functioning of the team.

Engagement of a diverse set of stakeholders is necessary for the development of a CM surveillance system

As displayed in Table 2, we found in all 3 states a diverse mix of stakeholders from public health, medicine, social services, and law enforcement who contributed to 1 or more functions of CM surveillance. Several types

TABLE 1 ● Lessons Learned and Illustrative Stakeholder Quotes

Lesson Learned	Illustrative Quotes
CDRTs serve as an infrastructure for engaging stakeholders in CM surveillance.	"We have a significant MUA (Memorandum of Understanding and Agreement) for CDRT. It talks about membership and purpose, authority, meetings, ground rules, and procedures." (public health stakeholder) "The work with CDR (Child Death Review) keeps them [team members] engaged. They understand power of working with multidisciplinary group, see all sides of things. They're used to professional debate without getting hackles raised, turf issues have never been a problem. It's because of CDR, that going to CM review was kind of natural." (law enforcement stakeholder)
Engagement of a diverse set of stakeholders is necessary for the development of a CM surveillance system.	"We have doctors on [the state team] and other attorneys on [the state team] but they bring a unique perspective coming from their different disciplines. So, in terms of engaging in the process, they are learning from it and changing their focus and how they do their jobs too." (public health stakeholder)
Public health can play multiple roles in the engagement of stakeholders for CM surveillance.	"We have the connection to Vital Stats; DHS (Department of Human Services) does not. If they need something from Vital Stats we get it for them because we have that connection. . .. When you talk to [DHS official] he'll tell you that DHS gets information they wouldn't otherwise get." (public health stakeholder) "They [Department of Health] have been champions in keeping the focus on science based decisions, not emotion based decisions. They are good at looking at the science. They had a technical assistance team, they sent someone to the local meetings and that was helpful because some of what we struggled with at the local meetings, that technical person could answer and now we don't have that person. And I think they kept things more organized and gave members a sense that you can speak your mind." (CDRT stakeholder)
CM surveillance requires active and sustained engagement with child welfare stakeholders.	". . .without CPS we may not get the background on the family and it would be a different discussion." (CDRT team member) "CPS ultimately looked to us to provide counts to them. We had to develop a whole new set of partners when we lost funding. An individual in our agency who was against CM surveillance has recently retired and has replaced with interim DHS person who is in support of it." (public health stakeholder)
Codifying relationships promotes accountability and sustainability.	"We plan to have a cooperative relationship with the Department of Public Health and have a MUA. We plan on continuing to be an active participant in state CDR and state council." (CPS Stakeholder)
Legislation can facilitate but not guarantee stakeholder engagement.	"Teams compose themselves. CPS is not mandated to be on the teams. There is no directive that has given counties an emphasis to be on teams. We are hands off." (CPS stakeholder) "We are mandated to send reports to the governor and the state assembly and all folks who have responsibility with CM- all CDRT teams, managers. The state council is mandated but CDRTs are not mandated. But if a CDRT exists, it is mandated to submit reports. At first I had no authority over CDRTs. Now with [public health colleague] help teams get paid to submit reports which in a sort of odd way connect us to those teams. But there is no formal process." (criminal justice stakeholder)
Public health stakeholders need to build a case for surveillance to non-public health stakeholders.	"Having an online web-based system has been a motivator for small teams to see a way to collect data. They can use the data right away for their reports. Before they were saying—"Why are we collecting this data? It is not helping us. And now we are saying, here it is and here is how you can use it. We are seeing an increased willingness and capacity to help us." (public health stakeholder)
System-level changes for CM surveillance require the support of stakeholders with decision-making authority.	"I am blessed to work where I work and to be surrounded by supervisors and colleagues who support the work I do. I continue to miss work and go to meetings because I want to and because my bosses support what I do. I am very, very lucky." (law enforcement stakeholder)

(*continues*)

TABLE 1 ● Lessons Learned and Illustrative Stakeholder Quotes (*Continued*)

Lesson Learned	Illustrative Quotes
	"Our workgroup is a significant time commitment. When you're going through in a very dissecting manner four inches of reading material that isn't something you can do right away—I don't do that on work time. I do that at home but my current employer allows me to participate in this; it requires the tolerance of my colleagues to know that sometimes twice a month I have to leave town. . .. as long as they tolerate that I will remain involved in the process." (physician stakeholder)
Public health can facilitate stakeholder engagement by streamlining and coordinating the CDRT and data collection processes.	"We have changed the process. . . What we do now is request the whole case file and put it in chronological order, make copies and number all the pages, and people get 3 weeks to review the case before they come in to the workgroup meeting. So now you're getting the case in its totality, not just your section—like if you're law enforcement you're not just looking at the police report. That really puts the case into perspective. We're organized; everything is there [no missing information]." (public health stakeholder)
Obtaining buy-in "or use commitment" from the CDRT members regarding the content and application of a standard CM definition is foundational to stakeholder engagement.	"Central to having a good data source is having people understand and buy in the case definitions to be used there. So they have to be practical, feasible and realistic to local teams." (public health stakeholder)

Abbreviations: CDRTs, child death review teams; CM, child maltreatment; CPS, child protective service.

of stakeholders were instrumental in defining and characterizing the nature, magnitude, and scope of CM or collecting and accessing data; we deemed these stakeholders critical to the assessment function of a CM surveillance system. Other stakeholders participated in the CM surveillance system mainly by informing child injury prevention efforts (eg, Safe Kids Coalitions, consumer advocates) and CM policy and program development. However, in these 3 states, a potentially important stakeholder—schools—was not as prominent as other stakeholders in CDRTs and state councils that developed CM programs and policies.

Public health can play multiple roles in the engagement of stakeholders for CM surveillance

Our evaluation revealed a diverse range of public health roles in CM surveillance among the 3 states. These roles ranged from active involvement in training and staffing of state and local CDRT teams and promoting statewide CM policy to periodic analysis of available CDRT data. The major factors determining the extent of public health agency engagement were the existence of legislative authority to access data specifically for CM surveillance purposes and the appropriation of state resources for CM surveillance.

CM surveillance requires active and sustained engagement with child welfare stakeholders

A particular challenge in all 3 states was gaining the endorsement of the human service agency responsible for CPS. Public health stakeholders reported that they devoted considerable time and effort to engaging their child welfare stakeholders because accessing CPS data for surveillance activities rested heavily on the strength of that partnership.

Codifying relationships promotes accountability and sustainability

Informants placed a high value on personal, collaborative relationships with colleagues in stakeholder agencies; however, memoranda of agreement, data-sharing agreements, and other types of contractual vehicles were necessary to ensure the exchange of data and the commitment of agency resources to CM surveillance activities.

Legislation can facilitate but not guarantee stakeholder engagement

None of the 3 states had explicit guidelines for stakeholder engagement, but all had some form of legislation that had created state CDRTs with mandated participation from key agencies and reporting requirements. Even with this structure, frequent turnover or low attendance at meetings hindered the establishment of productive and sustainable relationships among members in some CDRTs. Time and travel to attend meetings also limited participation.

Public health stakeholders need to build a case for surveillance to non–public health stakeholders

A few stakeholders perceived limited benefit to their agency from their participation in CM surveillance

TABLE 2 ● Child Maltreatment Surveillance Stakeholders in 3 States and Their Roles

	CM Surveillance Role(s)	
Stakeholder Type	Assessment	Policy and Program Development
Local and state public health officials (typically from the injury division)	X	X
Vital registrar	X	
Child protective services official	X	X
Medical professional	X	X
Forensic pathologist	X	
Hospital administrator		X
Home visiting nurse, social worker		X
Child advocacy center representative		X
Safe kids coalition advocate		X
Local and state law enforcement officer	X	X
Medical examiner	X	
Prosecuting attorney		X
Probation officer		X
Family court officer		X
Highway patrol officer		X
Consumer protection agency official or advocate		X

activities and even perceived a cost in terms of more work for their agencies. Law enforcement and child welfare agency stakeholders in particular saw less value in compiling and classifying cases because they were able to effect a change in policy or procedures on the basis of information obtained from a review of a single case. In contrast, CM surveillance compiles data to reveal patterns that have significance for prevention and intervention. A number of stakeholders agreed that the potential for surveillance data to impact CM deaths and morbidity offered the most compelling case for engagement with public health. In California, CM data revealed that a high proportion of cases of CM death also had a special health care need(s). This finding was used to amend the training of CPS personnel to focus more intensively and specifically on the needs of families of children with special health care needs.

System-level changes for CM surveillance require the support of stakeholders with decision-making authority

In all 3 states, stakeholders could name 1 or 2 champions whose longstanding passion and commitment to the issue of CM had been instrumental in raising awareness and establishing programs and policies. But the less visible personalities, the "foot soldiers" were able to participate in CM-related efforts (often on their own personal time) because they had the support of their organization or agency. The local CDRTs in particular could not have functioned without the endorsement and support of each member's agency because the reviews often required time and travel away from work. Moreover, an agency policy or regulatory recommendation was more likely to be realized if the agency had a representative on the CDRT who had informed the recommendation and was in a favorable position to promote it to the agency's leadership.

Public health can facilitate stakeholder engagement by streamlining and coordinating the CDRT and data collection process

Key informants emphasized the high burden of (largely volunteer) time spent preparing for and participating in a CDRT meeting. In Michigan and California, reducing the level of burden was an important means of keeping stakeholders engaged. The project team in Michigan established a process for compiling, collating, and organizing the case documents and sending them to team members well in advance of the CDRT meetings. In California, a regional coordinator provided similar technical and logistical support to local CDRTs. California also established an online system to transition the submission of data from local CDRTs from paper to electronic forms. At one time, Oregon also had a state-level team that provided training and technical assistance to the local CDRTs.

Obtaining buy-in "or use commitment" from the CDRT members regarding the content and application of a standard child maltreatment definition is foundational to stakeholder engagement

Law enforcement and child welfare agencies have specific definitions of CM, which largely overlap. Developing a consensus among CDRT stakeholders on a standard case definition for surveillance purposes was challenging and the states were not able to achieve it during the project period. Nonetheless, stakeholders recognized that a consensus definition would greatly enhance the utility of the CDRT because the final determination of a case could meet the data requirements of all the participating stakeholders. CDRT stakeholders are more apt to support a surveillance system that uses case definitions that conform closely to their understanding of CM and those of their agency.

Implications for Public Health Practice

The state public health agencies funded by CDC to develop and implement a statewide system for CM surveillance demonstrated the critical role stakeholder engagement plays in those efforts. Each of these states represents a unique model of CM surveillance implementation with varying levels of state-level resources, structures, and processes. Yet, a common theme for all 3 states was the necessity of devoting considerable time and effort to engaging partners largely outside of public health to obtain data, interpret the results, and shape public policy and programs. Four key implications for public health practice can be drawn from the lessons learned regarding stakeholder engagement:

1. Effective engagement will require public health practitioners to become knowledgeable about the reporting requirements, agency priorities and data needs of their partners to understand where differences exist and how common ground can be achieved. Most constituencies can agree on the goal of preventing CM. Thus, recognizing the utility of CDRTs for supporting a broad range of purposes (including but not limited to surveillance) that can lead to the prevention of CM would be an essential first step in bridging organizational differences in priorities and culture.
2. Because resources devoted to CM surveillance are limited and state expenditures for public health and social services have been further constrained by the recent economic downturn, leveraging resources judiciously and efficiently among multiple stakeholders is imperative. Child maltreatment surveillance is a team effort that calls on the technical expertise and resources of numerous non-public health stakeholders for case definition, data acquisition, and program and policy development. Public health practitioners should actively seek opportunities to build on existing CDRTs and Child Health Advocacy Centers, and partner with other local and statewide child abuse and injury prevention initiatives to share existing resources and identify new ones. Electronic health records, as a case in point, could yield detailed clinical data on cases under review and greatly enhance the timeliness and accuracy of data elements needed for surveillance.
3. Public health practitioners will need to demonstrate the tangible benefits of CM surveillance to a diverse set of stakeholders. Over time, if the utility of CM surveillance data can be evidenced in new and enhanced prevention funding, policy and regulatory changes, reduced health care expenditures, and ultimately in fewer CM deaths and morbidity, then the engagement of all critical stakeholders is likely to be more self-sustaining.[24]
4. Centers for Disease Control and Prevention can facilitate state-based stakeholder engagement efforts through renewed support of CM surveillance activities such as training and technical assistance for local CDRT reviews that build the capacities of diverse stakeholders to work effectively toward the goal of building a sustainable CM surveillance system.

Although the 3 states did not establish a final set of common definitions, data sources, and standards for CM surveillance through this particular project, stakeholders reported multiple benefits resulting from the project. The states gained a better appreciation for the complexity of integrating the perspectives of multiple stakeholders into a common definition of CM and a deeper understanding of the risk factors for fatal CM. They obtained enhanced guidance for prevention and intervention initiatives. Finally, each state established stronger working relationships across allied agencies that would continue the developmental work initiated by the project. States considering or currently undertaking CM surveillance can glean useful insights from the experiences of these 3 states and apply them to their own efforts to engage stakeholders.

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