



January 17, 2020

Statement regarding HB 2438

Dear Madam Chairman Susan Concannon and members of the committee,

My name is Susanna Joy and I am joined by my colleague Esther Shaw. We are staff at the National Center for Fatality Review and Prevention (National Center), which is a program of the Michigan Public Health Institute (MPHI). First, we want to thank you for welcoming us to Kansas to provide testimony on House Bill 2438, related to the state child death review board. It is an honor to be with you today.

The National Center is funded in part by the Health Resources and Services Administration (HRSA) which is part of Health and Human Services. At a national level, child death review (CDR) is when a multidisciplinary group of professionals come together to understand the risk factors and circumstances surrounding the death of a child. I like to think of CDR team meetings as putting together a puzzle in three steps. The first step is to tell the story. We do this by reviewing records of a child that has died in order to gain an understanding of how systems function to identify both strengths and gaps. Once the story is told and clarified, the team uses the data to identify risk factors and circumstances for prevention. This is the second step; and the final step is to catalyze prevention. Prevention is the reason for this work.

The National Center is charged with supporting all aspects of fatality review. We tend to break this down into two categories, technical assistance and data. I'll talk first about the technical assistance aspect of our work. We provide a variety of technical assistance from site visits, to virtual training, phone/email consultation, listserv management, a quarterly newsletter, written products like our program manuals and guidance documents, and our new training modules. Basically, if a team asks for support, our goal is to provide it or link them to it.

The second category of our work is to manage the National Fatality Review-Case Reporting System, which is commonly called the Case Reporting System. The Case Reporting System is a free, web-based data system for fatality review teams. The Case Reporting System contains a unique set of data, not available elsewhere. Currently, there are 45 states using the Case Reporting System and we are working to onboard three additional states. The Case Reporting System was developed in 2004 by a work group of national partners. The first version was launched in 2005 and we are currently supporting version 5. The National Center releases an updated version every 18-24 months.

The goal of the Case Reporting System is to collect aggregated, de-identified information on risk and protective factors surrounding child deaths to inform and support prevention. It is organized by cause of death, and significant effort is put into reducing users' data entry burden. When a user indicates that a child died in a drowning, for instance, only questions related to drownings and water safety appear. There are a few exceptions to this: users entering data can select if the death was sleep-related, a suicide, or a result of child abuse and neglect, regardless of cause of death. Additionally, some questions

are filtered on/off, depending on previous answers users provide. Infants have additional questions and some questions are removed for children who never left the hospital.

States who use the Case Reporting System sign a data use agreement. The data use agreement outlines the protections and utilizations of the data. States retain rights to their data. This means, each state can define, what, if any, de-identified cases are shared with approved researchers. Data from the Case Reporting System have been used in many peer-reviewed journal articles including many on child maltreatment, infant safe sleep, suicide, and unintentional injury. One example is a study that looked at all child abuse and neglect deaths in the Case Reporting System. The findings of this study confirmed that as a result of child death review, states expand their knowledge of child abuse and neglect deaths which improves the ability to do prevention work (Palusci, Covington 2014).

States also control what information they enter into the Case Reporting System. This allows each state to enter the amount of information that is most appropriate for them. The Case Reporting System is housed within our organization and has never experienced a data breach. There is no charge for using the Case Reporting System, as it is funded by HRSA. Each state only has access to their own data. Furthermore, there are several permission levels that can be used within a state. This allows very specific tailored access.

As I said earlier, the Case Reporting System contains a unique set of information that has been used throughout the US to drive prevention efforts that have improved the health and safety of many communities.

Thank you for the opportunity to appear before the committee today. We would be happy to answer any questions the committee members may have.

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Palusci, V. J., & Covington, T. M. (2014). Child maltreatment deaths in the U.S. National Child Death Review Case Reporting System. *Child Abuse and Neglect*, 38(1), 25–36. Retrieved from <https://doi.org/10.1016/j.chiabu.2013.08.014>