

CHILD DEATH REVIEW, THE EXPERIENCE IN THE UNITED STATES

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Children are not supposed to die. The Child Death Review process as developed in the United States is an organized regional and national system that attempts to understand each child's death and to draw conclusions from that discovery to develop technology, policy, or legislation that can hopefully reduce the re-occurrence of deaths. At least 50% of child deaths are preventable. This review article outlines the process in the United States and discussed its implications for Croatia.

Descriptors: INFANT DEATH, CHILD DEATH, PREVENTION OF CHILD DEATH

"A simple child,
That lightly draws its breath,
And feels its life in every limb,
What should it know of death?"

William Wordsworth

The Article

Children are not supposed to die. Especially in the modern western society of Europe and the Americas. Children, of course, in every society, do die. The major causes are accidents and trauma; infectious disease, cancer, gastroenteritis now being rare causes of death. In the United States, 41% are transport accidents, 15% are drowning, 14% are intentional, 7% are from fire, and 4% are from falls. At least 50% of deaths from accidents and trauma are preventable (1).

A review of child death from injuries in Croatia from 2012 shows that there are 11 deaths per 100,000 children (21st out of 28 European countries). Particularly high death rates in Croatia, compa-

red to the rest of Europe, are pedestrian deaths (2,3/100.000; car passenger safety (8,6/100.000); scooter / moped (highest rate in Europe at 2,15/100.000); and water safety at 2,15/100.000 (2).

Over the past 20 years in the United States, a very formal regional and national process has been developed to review the deaths of children in an effort to look for patterns of death or risk factors that could be understood and perhaps prevented. The entire focus of the process, called Child Death Review (CDR) Teams, is on increasing understanding about the deaths and finding potential solutions for prevention. The intent is not to find fault, or to label blame. The process is universal to all deaths and requires, in fact, mandates communication and collaboration amongst the various agencies involved in child health and child death. As stated in the mission of the CDR, "may their deaths bring a measure of meaning to other children at risk".

The major principle behind the CDR process is a belief that environmental, social, economic, health and behavioral factors impact the risk, manner and investigation of child death. The CDR is straightforward but complex and detailed; collecting all of the information and then using a group think process and a shared responsibility for understanding the data and discovering potential solutions and improvements (3).

There are many objectives to a CDR team be it a regional or national level. These include to obtain accurate identification and uniform reporting of the cause and manner of every death; to improve communication and collaboration among the responsible agencies, to develop and put into action protocols for the investigation of certain child deaths; to identify risk factors and trends in child deaths; to increase public awareness for these issues that affect child health and safety.

More objectives include improving agency response to child victims, to improve delivery of services to children and their families, to identify and advocate for warranted changes in legislation, policy and practices that would decrease risk of harm and improve health and safety.

Much of the tenets for the work relate to the Prevention Matrix public health model. The matrix stresses seven factors that must be addressed for a new prevention approach to be accepted and successful. These factors are: 1) the effectiveness of the proposed plan or intervention, 2) the ease of the implementation, 3) the cost of the intervention, both financial cost and human capital costs, 4) the potential sustainability of the approach, 5) the potential cultural and community acceptance of the effort, 6) the political acceptability of the pro-

posed plan and 7) a detailed understanding of a potential unintended consequences of the proposal.

The spectrum of prevention must attempt to strengthen individual and agency knowledge and skill, promote community education, educate professionals, foster coalitions and networks, change existing practices and protocols, and influence policy and, if necessary, legislation.

A CDR team is developed by the organizer working to be inclusive in the invitations of potential team members. The organizer can come from any agency or field but must be committed and passionate about the work and be patient and resilient. This works does not spring into action immediately. It takes time and slow ground work. Agencies that do not currently trust each other, are not suddenly going to change their work patterns. These teams at the start often arise by gradual education and slow growth of an initial task force of agencies that are ready to change, the early adopters to the new approach. In the United States, the CDR process spread after a slow beginning by having state legislators mandate the teams and the protocols and demand a yearly report of progress and recommendations. Ultimately the best start is a pilot in a ready to change environment, developing important understandings of mechanisms and possible solutions, and demonstrating the value of the work to the rest of the community, the community health, welfare and police agencies, and then ultimately to formal recognition by the legislative process.

Example of CDR team members in the USA include the medical examiner, law enforcement, public health, social services, pediatrics and health care, emergency services, schools, day care, mental health, and parents and community advocacy groups. These teams all share common guiding principles that help orchestrate their actions: 1) deaths and serious injuries are sentinel events and markers of health and safety of children, 2) the environmental, social and health factors are multidimensional and there is often a shared responsibility, 3)

the reviews focus on what went wrong and how to fix it and 4) the best reviews are multidisciplinary.

The process demands that as many records and reports be compiled before the review and that each case is reviewed separately and not as part of a predetermined composite. The data sources take time to accumulate, particularly when first starting out. For example, a review of an infant death could require birth records, outpatient records, death certificate, prenatal records, hospital records, emergency department records, social agency records, police reports, home visit reports, and autopsy findings. It is in the compilation and analysis of such a broad range of records and data that allows for new ideas and understandings be take place.

As stated, the review meetings allow for one reporter to present an analysis of one death. Each meeting might allow time for a highlight of all of the deaths and then in depth review of deaths believed to be of concern because of the nature of the death, the risk factors involved, the recurrence of similar deaths previously, or the input from the reporter about concerns or identified solutions.

Over the course of many years, the CDR process has become part of the culture of child death review and accepted and supported by the agencies caring for children. The process still has barriers and weaknesses. Even after many years, interagency collaboration is still not natural to the agencies. The data collection is still arduous and many pieces of data are missing from many of the evaluations. The ability of team to make clear decisions and plans demands a skillful leader, clarity of purpose and vision. The relations to the affected families is often problematic as the families are often looking for blame and fault. The legislative process may not produce the clear recommendations of the team because of competing political realities or cost or acceptance concerns.

The potential solutions to preventable deaths can involve technology, social marketing, and legislative or policy innovations. Technology may be the first to

occur because it provides additional protection without involving major change by agencies or by society. These changes are passive prevention, putting into place barriers or safeguards not previously universal. Examples from the CDR process in the USA include universal and evidence based car seats and protocols for use, seat belts, fences around pools, trigger locks for guns, fire, smoke and carbon monoxide alarms in all homes and businesses, improvements in crib design and child toys, socket covers for electrical outlets. Some of these changes are new technology but more often is the spread through education, social marketing, or legislation for universal use of these valuable and passive safety technology (4).

Legislative and policy innovations have included the back to sleep campaign to prevent sudden infant death, much stricter day care regulations, the elimination of baby walkers and three wheel drive off road vehicles, mandated helmets for scooter and motorcycle driving, mandated bike helmets for bicycle use.

A more detailed list of examples from the CDR focus on infant deaths includes the safe sleep campaigns, improved emergency transport to tertiary care for high risk infants and maternal fetal transfers, establishment of residential substance abuse treatment programs for pregnant mothers, improved coordination among agencies in immunization records and the development of state and national registries for immunization, birth records, and newborn screening, expanded home visiting services and the create cribs for kids program for families living in poverty.

A look at current Croatian laws and policies concerning child health and safety show there there is no legislation regarding smoke detectors, no national regulation for public and private buildings requiring safe design and guardrails, no law for fencing around pools, and use of personal floatation devices, and no national law requiring reduced speed in residential areas (5).

Thus there is clear value of the develop of a regional and national model for multidisciplinary CDR. It would put

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a real time urgent focus on children. It would create a comprehensive portrait of every child death. It would promote professional communication. It would engender respect for families. It would draw lines from qualitative and quantitative data for use for prevention. It would lay out a case for prevention with the right people at the table. It would foster community response to real community problems. It would create opportunities for professional debriefing and broader understanding the infant and child deaths.

Michael Durfee, often seen as the father and chief representative of the CDR team process in the United States, offers that "child death is an opportunity to work together. The major hazard is becoming a political body owned by one agency or profession. Every agency has problems and limitations". Thus the meetings and the process must be inclusive. There needs to a public he-

alth perspective as the foundation for the analyses. There needs to improved links between health, mental health and social agencies. There must be improved ways of gathering information on dangerous adults and with domestic violence.

The CDR process, once established, is never stationary. There are always improvements and innovation. Each era brings with it new challenges, new costs, new political and community priorities, competing agendas, new professionals. In many ways these competing realities only give increased credence to the real and potential value of a formal prevention based multidisciplinary approach to the review and understanding of a region or country's child deaths.

This reviewer hopes this information is useful to Croatian pediatricians and child health providers. The references list many more details about process, formation and structure.

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Sažetak

PREGLED SMRTNOSTI DJECE, ISKUSTVO IZ SJEDINJENIH DRŽAVA

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Djeca ne bi trebala umirati. U Sjedinjenim Američkim Državama je razvijen Pregled Smrtnosti Djece i to je organizirani regionalni i nacionalni sustav kojim se pokušava razumijeti razloge svake smrti djeteta. Iz toga se izvlače zaključci i razvija tehnologija, politike i zakonske pretpostavke koji bi mogli smanjiti učestalost smrti. Najmanje 50% smrti u djece je preventabilno. Ovaj pregledni članak ističe procese u Sjedinjenim Državama i raspravlja o njihovim implikacijama na stanje u Hrvatskoj.

Deskriptori: DOJENAČKA SMRTNOST, SMRTNOST DJECE, PREVENCIJA SMRTNOSTI U DJECE

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