

# OPTIONS PAPER ON THE CHILD DEATH REVIEW SYSTEM IN ALBERTA

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#### INTRODUCTION

The Options Paper has been developed as a resource to help guide discussions for the January 28 - 29, 2014, Alberta Child Intervention Roundtable. The Roundtable was announced by Minister of Human Services Manmeet S. Bhullar on January 8, 2014, at the Child Intervention Improvements Media Conference as one of the key milestones in the five point plan for accelerating improvements to Alberta's Child Intervention system.

#### THE FIVE POINT PLAN

The five point plan includes:

- Releasing data on deaths of children known to the ministry, and creation of a robust system to publicly share information on the child intervention system
- Convening experts, policy makers and stakeholders together at the above mentioned Roundtable, to discuss best practices in reviewing child deaths, and striking the right balance between transparency and privacy
- Reconvening representatives from the <u>2010</u>
   <u>Child Intervention System Review</u> panel to work with the <u>Child and Family Services</u>
   <u>Council for Quality Assurance</u> to review progress to date on previous recommendations
- Increasing the focus on using evidence to improve practice by creating a research consortium to help examine and analyze performance and outcomes data and trends and provide advice on improvements over time
- Addressing the root causes of many of the issues that affect the safety and well-being of children, such as poverty, addictions, mental health concerns and family violence

Evidence suggests that up to half of all deaths of children and young people result from non-natural causes. A major proportion of these deaths, which are the result of child abuse and neglect, accidents, suicide, and sudden unexpected deaths in infants are preventable. The background research undertaken in support of the development of the Options Paper documents that the systems and mechanisms used in Child and Family Services in Canada for reviewing and reporting on child deaths vary within and across provinces and territories. Some provincial and territorial jurisdictions publicly report only those child deaths which result from child abuse and neglect, or deaths of children known to child welfare agencies; others focus on a broader public health approach, which entails reports on all child deaths. The two options recommended for consideration in this Paper would address the deaths of all children by all causes.

#### **APPROACH & LIMITATIONS**

A questionnaire survey approach was used that focused on the deaths of children that have been involved with Child and Family Services. The survey was conducted by means of a telephone interview.

#### **APPROACH**

Publicly accessible documents pertaining to child death investigation, review and reporting were examined.

A questionnaire was developed and sent to the provincial and territorial Directors of Child Welfare (DCW) and follow up live interviews were conducted. The questionnaire in its entirety is included (see Appendix 1).

Telephone interviews were conducted from January 10th to 15th, 2014 with follow-up interviews conducted in March 2014.

An international scan of promising practices of child death review and reporting was conducted and thus informed the selection and development of the three case studies. Documentation on child death investigation, review, reporting and data classification was reviewed.

#### LIMITATIONS

The survey was focused on the child welfare sector. Surveys were not conducted with coroners, medical examiners or child advocates.

Non-public information was not provided therefore the research is only based on what exists in the public domain.

Variability in reporting, review and data collection exists from one jurisdiction to another.

The questionnaire targeted the collection of quantitative information; this was supplemented by qualitative material captured during the live interviews and narrative documentation furnished by the jurisdictions.

# JURISDICTIONAL SCAN OF CHILD AND FAMILY SERVICES CHILD DEATH DATA COLLECTION AND REPORTING: NARRATIVE DESCRIPTIONS

The following narratives describe the Child and Family Service child death review and reporting processes in each province and territory. The narratives have been provided by, or are summaries of the telephone interviews with, the respective provincial or territorial government representatives.

#### British Columbia

Children are eligible for services up to the age of 19.

The Coroner reports on all child deaths. Data are shared with the public through a dedicated website (Ministry) and through the Coroner's annual report.

The Coroners Service is in charge of public reporting on all deaths as part of their mandate. The Child Advocate reports every six months on critical injuries and fatalities. The Ministry of Children and Family Development reports on children under the care of Ministry.

The Coroners Service, Ministry of Children and Family Development and the Child Advocate are responsible for collecting child death information. The coroner collects data on all child deaths, the Child Advocate gets information from data generated by the Ministry of Children and Family Development. Some definitions vary from one service organization to the next: for example, an open file does not have the same meaning.

A formal procedure has to be followed every six months. A report is completed, the relevant database is updated, briefing documentation is developed, and the Ministry Communications Section posts the communication on the Ministry website.

#### Alberta

Under Review.

#### Saskatchewan

In Saskatchewan child protection services are provided to a child up to 16 years of age. Services and supports may extend to age 18 and in some cases up to age 21.

Currently the Ministry does not report Child Death numbers publicly, rather, this information is provided to the Advocate for Children and Youth who reports them in their Annual Report. Recently and at the request of media outlets, these numbers have been released publicly. Data are updated on an ongoing basis. The Ministry of Social Services is currently reexamining the Child Death Review process. Vital Statistics reports on provincial numbers of child deaths.

#### Manitoba

Children are eligible for services up to the age of 18, up to age of 21 for the children who are permanent wards. In Manitoba, there is balance between public transparency and confidentiality. Data shared with the public is aggregated and is non-specific. The data are shared in the annual report of the Office of the Chief Medical Examiner, Department of Justice. In 2007, a piece of legislation was written that empowers the Children's Advocate to review the death of a child who was in the care of, or received services from, an agency under this Act within one year before the death, or whose parent or guardian received services from an agency under this Act within one year before the death.

The Chief Medical Examiner and the Children's Advocate are in charge of public reporting. The Chief Medical Examiner is responsible for collecting child death information, the reports child deaths to the Child Advocate.

#### Québec

Children are eligible for services up to the age of 18.

Public reporting and data collection are both under the responsibility of the Coroner. Data are updated once a year. There is no formal protocol respecting public reporting on child deaths: it is done on a case by case basis in each region. One region out of 18 regions and territories has a child death review committee; it reports to the Chief Coroner's office.

#### **New Brunswick**

Children are eligible for services up to the age of 19.

The Coroner's office is in charge of public reporting as well as collecting child death data information. Data are reported by means of investigation reports. The information is also available online, on the Government of New Brunswick website. Data are updated on a per incident base. Those incidents are reported through the Coroner's office as required by a

formal reporting protocol. The Coroner and the Department of Social Development track different elements: the Department of Social Development has a provincial data system that focuses on children receiving services whereas the Coroner looks at all child deaths

#### Ontario

Children are eligible for services up to the age of 16 in Ontario.

The Ministry of Children and Youth Services does not directly public report child death data. An annual report is published by the Office of the Chief Coroner and the Pediatric Death Review Committee is annual report tracks all child deaths. Those documents are made available to the public. The Pediatric Death Review Committee looks at children in care or those who were in care up to 12 months ago. Information is aggregated and individuals cannot be identified. The Office of the Chief Coroner is responsible for public reporting of child deaths.

The Office of the Chief Coroner and the Ministry of Children and Youth Services are responsible for collecting child death information.

#### Prince Edward Island

In Prince Edward Island, the Child Protection Act applies to children up to the age of 18 years. The Department of Community Services & Seniors is responsible for the delivery of Child Protection Services. The Director of Child Protection does not report to the public in regards to the deaths of children receiving Child Protection Services or children in the legal custody and guardianship of the Director of Child Protection. What, if any, investigation takes place will depend upon the circumstances of the death. If, for example, the death is from known, natural causes, it is unlikely that any investigation will take place. If the cause of death or the circumstances surrounding the death are suspect or unusual, then the Coroner's office and/or the Police will be notified for purposes of investigation, as mandated by the Coroners Act and/or the Criminal Code.

The public is made aware of a child death through a

coroner's inquest, if applicable. There is no identification of whether or not the child was a child in care. The Prince Edward Island Child Protection Act does not provide statutory authority for the public release of the identification of a child in the legal custody and guardianship of the Director of Child Protection.

The Director of Child Protection collects data on children in the legal custody and guardianship of the Director. The Child Protection Services policy entitled Death of a Child in the Legal Custody and Guardianship of the Director of Child Protection provides procedures to be followed in the event of the death of a child in care.

Prince Edward Island does not have a Child Advocate.

There has been no reported death of a child in the legal custody and guardianship of the Director of Child Protection in recent years.

#### Nova Scotia

Children are eligible for services up to age of 16 in general, up to age of 19 if the children are in care and can be extended to age of 21 and 24 for educational support.

In Nova Scotia, the Child and Family Services public reporting process is not yet implemented; a preliminary report has been created. Some of it will be made public.

The Office of the Ombudsman is in charge of public reporting. The Department of Community Services is responsible for collecting child death information.

#### Newfoundland and Labrador

Customarily children are eligible for services up to 17. It may be longer depending on the services they receive: 19 if the youth is in an educational program; 21 if in continuous custody.

The Office of the Chief Medical Examiner and the Department of Child, Youth and Family Services are responsible for collecting child death information. The Department notifies the Coroner if a child in care dies.

Child death data are not tracked in a dedicated database, rather information is collected and captured in individual files. Newfoundland does not have a child death data collection system.

The Department of Child, Youth and Family Services is not permitted to reveal identifying information about the death of a child in care. According to Section 52 of the Child and Youth Care and Protection Act, a person shall not publish or make public information that may identify a child, member of the child's family or the foster parents involved in a child protection proceeding.

No children have died in care since the Department was created in 2009.

Confidentiality and Best Interests of the Child

- Due to confidentially reasons, the Department of Child, Youth and Family Services cannot speak about the specifics of any case. Officials can speak to policy and program directions that the government has undertaken but cannot comment on individual cases.
- The departmental position is that it is not in the best interests of any child or youth currently or previously on a Child, Youth and Family Services caseload to have specific identifying information in the public domain.
- Even when some information becomes public it is not in the best interest of any child that is living or deceased to release their personal and sensitive information over which they have no control or ability to give consent.
- While the public may be interested in various issues affecting children in care, it does not have a right to identifying information about a particular child.
   Therefore, the Department does not confirm whether or not it is involved in a case.

#### Yukon

In the Yukon children are eligible for services up to the age of 19 and this may be extended to the age of 24 for children in care. There is no formal process respecting public reporting of child deaths. The Health and Social Services Department is in charge of public reporting; decisions are made at the Ministerial level regarding child death reporting. The process for collecting and reporting child death information is currently being reviewed. A critical incidence policy is at the draft stage (as of January 14<sup>th</sup>, 2014). This policy will advise on how to address child deaths on a case by case basis.

The Coroner's service is responsible for collecting information on all child deaths, whereas the Health and Social Services Department is responsible for children who received services from the Department.

There is no formal child death data collection system. There is a critical incident system that applies to all child deaths. The critical incidence reviews are not made public unless the coroner makes them public.

#### Nunavut

Children are eligible for services up to the age of 16, but services can be provided to children and young adults to the age of 26 (as of April, 2014).

The Department of Family Services is responsible for collecting child death information. The Department reports the information to the public on a case by case basis.

Currently, there is no child advocate in Nunavut. The Coroner's service works with Nunavut Vital Statistics to collect child death information.

There is no formal process for child death data collection and public reporting. A formal policy and procedure manual has been developed. Section 812 of the manual details an internal departmental procedure that must be followed in the event of the death of a child in care. The procedure defines the reporting timelines and the steps to be taken by each member of the case management team (case manager, supervisor, director, etc). The Director must be immediately notified of any child death and a formal investigation must begin within 10 days. A formal report must be provided to the Director of Child Welfare within 30 days of the death.

The Department of Family Services does not proactively share information with the public regarding child deaths, unless there is a specific inquiry from the media.

#### Northwest Territories N/A

# JURISDICTIONAL SCAN OF CHILD AND FAMILY SERVICES CHILD DEATH DATA COLLECTION AND REPORTING: JURISDICTIONAL TABLE

The questionnaire, legend, acronyms and endnotes pertaining to the following tables are found in the appendices 1, 2, 3 and 4

Questionna ire Items	ВС	АВ	SK	МВ	ON	QC			
PUBLIC REPORTING PROCESS									
How is the data reported to/shared with the public?	Dedicated website (Minister/ Coroner)	Annual Report. <sup>1</sup>	Data not reported publicly by Child & Family Services	Chief Medical Examiner <sup>2</sup>	Dedicated website	Coroner			
How often are the data updated?	6 months	Annual Report. Fatality Inquiry reports posted on Justice & Sol. Gen. website	Ongoing, Internal database	Annual	Annual <sup>3</sup>	Annual			
When did the public reporting begin in your jurisdiction?	1996	Public tracking system – under develop- ment.	No public reporting; Tracking death reports since 1992	2000s	1996	Unknown			
Who is in charge of public reporting?	Coroner, Child Advocate	Ministry of Human Servicesfor statistics <sup>4</sup> .  Justice & Solicitor General for Fatality Inquiries.	Coroner, Advocate for Children and Youth	Chief Medical Examiner, Child Advocate	Coroner	Coroner			

Questionnaire Items	ВС	АВ	SK	МВ	ON	QC				
DATA COLLECTION										
Until what age are children eligible for services?	Up to 19	Up to 18 <sup>5</sup>	Up to 16 <sup>6</sup>	Up to 18 <sup>7</sup>	Up to 16	Up to 18				
Which services are responsible for collecting child death information?	Coroner; Dept. of Child and Family Services; Child Advocate	Chief Medical Examiner, Child Advocate, Dept. of Child and Family Services, Other <sup>8</sup>	Coroner; Ministry of Social Services; Advocate for Children and Youth	Chief Medical Examiner; Child Advocate	Coroner; Dept. of Child and Family Services	Coroner				
How common is the language used by the various entities in charge of data collection?	Moderate	High level <sup>9</sup>	High level	Moderate	High level	N/A				
Do you use NASHU as a standard of child death classification?	Yes	NASHU + <sup>10</sup>	Yes	NASHU+	Yes	NASHU + <sup>11</sup>				

Questionnaire Items	ВС	АВ	SK	МВ	ON	QC
What elements are you tracking?	All, child & parent's names and biography <sup>12</sup>	All + <sup>13</sup>	All, + location, agency, If child was in care <sup>14</sup> .	All	Few <sup>15</sup>	N/A <sup>16</sup>
Are these elements made public?	No	No.	No, unless asked	Only aggregate information	No	N/A
Who are the children being tracked in your Child Death Data Collection System (Indirect involvement)?	All, within previous 12 months <sup>17</sup>	Children receiving services, and children in care <sup>18</sup>	All within previous 12 months <sup>19</sup>	All	All, within previous 12 months <sup>20</sup>	None
Who are the children being tracked in your Child Death Data Collection System (Direct involvement?)	All	All <sup>21</sup>	ALL <sup>22</sup>	All	All	None
Is there a formal protocol for public reporting on child deaths?	Formal procedure	Yes <sup>23</sup>	No	Yes	PDRC	No <sup>24</sup>

Questionnaire Items	NB	PEI	NS	NL	YK	NWT	NU			
PUBLIC REPORTIN	PUBLIC REPORTING PROCESS									
How is the data reported to/shared with the public?	Investig- ation reports	Only at Coroner's request	No public reporting	No public reporting	No public reporting	None	No public reporting			
How often are the data updated?	Ongoing	N/A	N/A	N/A	Case by case <sup>27</sup>	Quaterly	N/A			
When did public reporting begin in your jursidiction?	Early 2000s	N/A	In process	N/A	N/A	N/A	N/A			
Who is in charge of public reporting?	Coroner	Coroner	Ombuds	N/A	Dept. of Child and Family Services <sup>28</sup>	Coroner; Dept. of Child and Family Services <sup>29</sup>	Coroner; Dept. of Child and Family Services			

Questionnaire Items	NB	PEI	NS	NL	YK	NWT	NU		
DATA COLLECTION									
Until what age are children eligible for services?	Up to 19	Up to 18	Up to 16 <sup>30</sup>	Up to 17 <sup>31</sup>	Up to 19 <sup>32</sup>	Up to 19	Up to 19 <sup>33</sup>		
Which services are responsible for collecting child death information?	Coroner	N/A	Dept. of Comm. Services	Coroner; Dept. of Child and Family Services	Coroner; Dept. of Child and Family Serv.; Police <sup>34</sup>	Coroner, Dept. Of Child and Family Services, RCMP	Dept. of Child and Family Services		
How common is the language used by the various entities in charge of data collection?	High level	N/A	N/A	N/A	N/A	Moderate	High level		
Do you use NASHU as a standard of child death classification?	NASHU+ <sup>35</sup>	No	No	No	No	Yes	No		

Questionnaire Items	NB	PEI	NS	NL	YK	NWT	NU
What elements are you tracking?	All	None <sup>36</sup>	All	Few <sup>37</sup>	All <sup>38</sup>	Few <sup>39</sup>	All <sup>40</sup>
Are these elements made public?	No	N/A	No	No	No	N/a	No
Who are the children being tracking in your Child Death Data Collection System (Indirect Involvement)	All, within previous 12 months <sup>41</sup>	N/A	See note <sup>42</sup>	See note <sup>43</sup>	None	Yes, All children from age 8 days to 18 years	See note <sup>44</sup>
Who are the children being tracked in your Child Death Data Collection System (Direct Involvement)	All	N/A	All <sup>45</sup>	All	None	Yes, All children from age 8 days to 18 years	All
Is there a formal protocol for public reporting on child deaths?	Yes	No	No	No	No	No	No

#### **TWO OPTIONS**

The Options Paper addresses two proposed Options to improve Alberta's review and reporting on child death. Option 1 is focused on possible enhancements to the Child Death Review System as a whole. Option 2 is directed primarily to improvements to the Child Intervention System's response to child deaths.

It is intended to offer policy and operational guidance at a systems level. It does not attempt to furnish a detailed costing of the options or to demonstrate the specific steps involved in addressing specific implementation issues.

The Options are based on the recognition that the rigour, breadth and prevention utility of child death review and reporting systems vary significantly based on:

- whether they are legislation-based
- where the Child Death Review function is located
- level of resourcing
- whether the data collection and reporting is local, regional or provincial in scope, and
- the scope of the child death reporting (age range, all deaths versus child abuse deaths)

#### **OPTION 1**

#### **Provincial Child Death Review Centre**

This option envisages the design, development, and establishment of a provincial centre on child death review. The scope of the Centre would encompass all deaths of children from all causes ages 0-25. With this scenario, Alberta would be the first jurisdiction in Canada to establish and support a provincial child death review centre. The Centre itself would be constituted as separate and independent from the Government of Alberta. The Review Centre would be legally constituted as a not-for-profit, charitable corporation.

Being constituted as an independent Review Centre would reinforce the Government of Alberta's commitment to child death review system that is characterized by transparency, accountability and high standards of professionalism. The legal status of the Centre as a stand-alone, independent, not-for-profit

corporation would contribute to strengthening public and professional confidence in the processes surrounding child death review and reporting. Child death reviews are inherently a local process. Typically review processes are informed by understanding local contexts and resources. These processes characteristically utilize the expertise and experience of local professionals. Child death reviews are, for the most part, focused on individual child deaths and the case-specific variables that may have contributed to or prevented the death. Effective population-wide recommendations for prevention, and accompanying implementation strategies, are best grounded in evidence derived from multiple sources covering a much larger sample of cases. A significant aspect of the proposed Child Death Review Centre would be to examine individual child deaths in the context of a larger sample of other similar deaths.

#### **Legislative Mandate**

To establish its mandate the Centre would require dedicated legal authority. There are a range of complex issues that would need to be taken into account in moving toward the establishment of a child death review centre. They include legal, ethical, privacy and logistical concerns pertaining to the acquisition, retention, expungement, analysis, synthesis and reporting of child death data. The challenges involved would necessitate that the Centre be grounded in specific enabling legislation.

A legislative mandate is an essential feature to be considered in the establishment of a review centre. As part of the background research for this Paper key informant interviews were conducted with international subject experts who have extensive experience in the development and operations of a child death review centre. The key informants uniformly emphasized the need for a strong legislative framework to provide the authority needed to govern all of the key aspects pertaining to collection and use of child death data.

To ensure that the legislation achieves its desire outcomes it is recommended that it be subject to a legislative review within five years of its passage. A legislative review would allow the opportunity to thoroughly examine the efficacy of the legislation while also ensuring that interested parties are consulted regarding its usefulness.

Enabling legislation would provide the legal scaffolding upon which the Review Centre's capacity could be developed. Providing a legislative base would help to ensure that the key functions of the Review Centre are constituted in a coordinated and integrated manner. The notion of "enabling legislation", as referenced here, denotes the legal authority which would provide the authority for subsequent infrastructure and program development. This recognizes that the opportunity to move forward on this important file on the public policy agenda should be seized while conditions are favorable. It also recognizes that complex, multi-disciplinary, cross-sectoral infrastructure development requires significant time, effort, and coordination to realize its full promise.

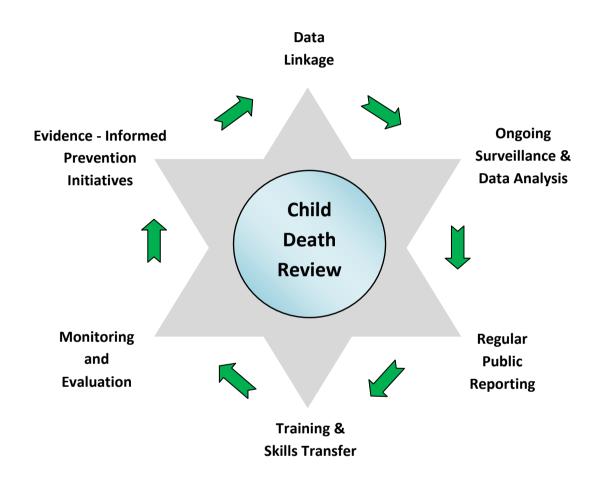
#### **Multi-Dimensional Focus**

The Centre would be multi-dimensional in its reach. The mandate of the Review Centre would be distinguished by the following key functional domains: child death data collection and cross-ministry data linkage; data analysis and ongoing surveillance; child death review training and skills transfer; development and support for child death prevention initiatives; regular public reporting; and, monitoring and evaluation of child death review recommendations and findings. The dynamic interrelationships of the six functions of the proposed Review Centre are presented graphically on Diagram I Child Death Review Centre: Virtuous Cycle and Diagram II Child Death Review Centre: Functional Relationships.

The multi-dimensional focus of the Centre would provide the evidence base, functionality, multi-source data linkages and specialized expertise that a rigorous population-based approach to child death review requires. Importantly, the resources represented in the Centre would, when fully deployed, provide a foundation for evidence-informed prevention work targeted toward multiple sectors and a variety of audiences.

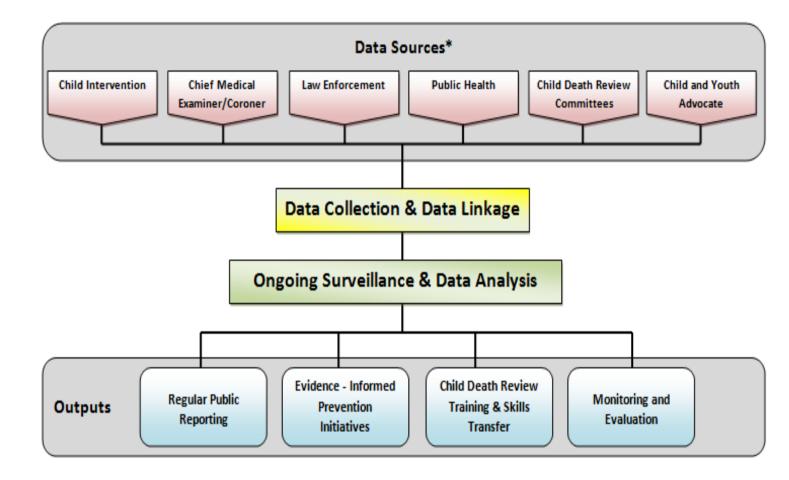
Through the aggregation of relevant information and data, coupled with its analysis and synthesis, trends and patterns in the incidence, etiology and distribution of child death would be more easily identified and interpreted. This in turn can serve to inform relevant policy and program responses and guide and direct coordinated interventions.

# DIAGRAM 1: CHILD DEATH REVIEW CENTRE: VIRTUOUS CYCLE



#### **DIAGRAM 2: CHILD DEATH REVIEW CENTRE:**

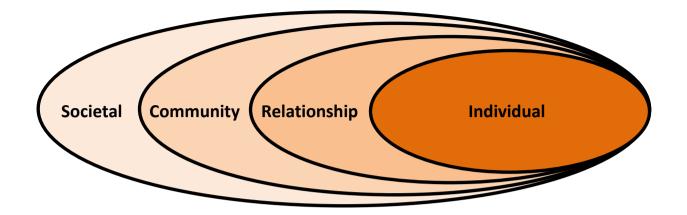
#### **FUNCTIONAL RELATIONSHIPS**



<sup>\*</sup>There may be other data sources.

This capacity coupled with an ecological approach which builds on a rigorous examination of individual, relationship, community and societal variables associated with adverse occurrences will provide a vital resource for improving prevention, case management and intervention responses to child death. The graphic below illustrates the ecological framework, which is adapted from the World Health Organization, can serve to illustrate the relationship between multi-level surveillance of risk and protective factors.

#### **DIAGRAM 3: THE ECOLOGICAL FRAMEWORK**



Source: WHO | The Violence Prevention Alliance (VPA). (2014). *The Ecological Framework*. Available at:

http://www.who.int/violenceprevention/approach/ecology/en/

Currently, child death review systems, in all jurisdictions in Canada are hampered, to varying degrees, by a limited capacity to identify trends and patterns in the incidence and contributing factors leading to child death.

#### **Governance Model**

The governance model for the Centre would be strengthened with multi-sectoral representation, including representation from the government, academic, and not-for-profit sectors.

Multidisciplinary representation in the composition of the Governance Board is important to informing the breadth of vision and mission that the Center should pursue. As a result, multiple perspectives are required in the governance model and should include law enforcement, child welfare, First Nations and Métis representatives, public health, mental health, forensic pathology, and the judiciary. The perspective and understanding that a judicial representative can provide, although often overlooked, is an important adjunct to the multidisciplinarity of the review team.

#### Scope

It is recommended that all child deaths (ages 0-25) from all causes be considered within the purview of the Centre.

#### 1. Data Collection and Cross-Source Data Linkage

Individual child death reviews require accurate, reliable, timely, multi-source data to conduct effective investigations and arrive at helpful findings. The same requirement is true for accurate assessment of the incidence, dimensions, distribution and dynamics of child death at the population-level. The larger task of understanding, documenting and addressing the modifiable risk factors that can lead to child death across the population in general require jurisdiction-wide data collection on all aspects of child mortality. Data linkage across government ministries involved in child deaths is required to effectively advance that goal.

While many governments have graduated to crossministry data linkage in response to public security threats it is still an incipient practice in the area of child death review and data collection. The severity of the issue of preventable child deaths warrants bold initiatives that can effectively address information, data, and knowledge exchange imperatives.

The operational core of the Centre would involve sharing information through multi-system data linkages. Statistical, demographic and epidemiologic data would be derived from the relevant government information systems. Which might include, but would not necessarily be limited to, those housed with: Alberta Human Services (Child and Family Services and Delegated First Nations Agencies), Office of the Child and Youth Advocate, Office of the Chief Medical Examiner, Vital Statistics Office (Service Alberta), public health and criminal justice.

The Child and Youth Data Laboratory (CYDL) situated at the Alberta Centre for Child, Family and Community Research (ACCFCR) is a compelling example of the potential and feasibility for cross-ministry data linkages on children's issues. The data analysis and synthesis work conducted through the ACCFCR bears testament to the power of cross-source aggregation of data on child and youth issues.

The conventional view in many areas of children's services has been that sensitive data pertaining to vulnerable children and youth cannot be, except on an exceptional basis, shared across government ministries or across sectors. That view warrants a reexamination in light of the acknowledged need to share information in a timely manner to better protect children.

Cross-source data linkage affords the opportunity for child mortality data to be contextualized with other epidemiologic reporting on child health and well-being. This can provide a more robust understanding of the opportunities for intervening with at-risk families.

Data linkage across government ministries will enhance the ability to use what is learned in child death research to guide policy, program and practice responses in an evidence-informed manner.

#### 2. Data Analysis and Ongoing Surveillance

Surveillance is commonly understood to include systematic collection, analysis and synthesis, and content evaluation of outcome specific data for the purposes of policy, program development and evaluation. In the context of the surveillance of child death a multiplicity of data sources must be considered: including, public health, law enforcement, child fatality review boards, medical examiner, child advocate, and child intervention.

Comprehensive, cross-system surveillance of child death is needed to strengthen the overall response to these tragedies. Long-term effective prevention strategies on child death require systematic ongoing monitoring of risk and protective factors. In order to inform and guide the adaptation of response systems, a more comprehensive understanding of the contributing factors is required.

A review centre with surveillance and data analysis as a core competence would provide the empirical foundation for a more robust understanding and response to child death. By collecting data from multiple sources (medical examiner, child advocate, police, public health, child intervention, other community services, etc.) a fuller understanding of the dimensions of the various forms of child death, and the specifics pertaining to individual death reviews would be strengthened.

Aggregating child death data can generate many benefits. For example *The National Child Death Review Case Reporting System* in the United States has served to assist organizations in accessing member Review Teams resources for the development and enhancement of local child death review teams. The aggregation of child death data, derived from multiple sources, analyzed over time identifies problems in a way that makes them more amenable to response and remediation. Data aggregation and analysis can serve to identify trends and patterns which can illuminate underlying concerns and risk factors

The adoption of a comprehensive, cross-system approach to child death data collection and reporting can serve to strengthen the case for public investments in this vital area.

There are currently a number of valuable and important public services addressing child deaths in Alberta. However, critics have alleged that the child death review system is fragmented and piecemeal. What is clear is that there is a need for improved child death data collection, aggregation, classification, analysis and reporting. Improvements in those areas would facilitates improvements in intervention, investigation and assessment.

It should be recognized, for example, that the rates of child fatalities due to maltreatment vary considerably depending upon the definitions, classifications, methodologies and data sources used. Those variations lead to different rates as reported by different response systems. This in turn can create confusion and impede a shared cross-disciplinary understanding of the issues under consideration. Common definitions, classification schemes, taxonomies, and reporting protocols are required to ensure data completeness, coherence and cross-disciplinary analysis. In absence of those common understandings and practices mismatches and

common understandings and practices mismatches and disconnects between service providers are likely.

The challenge of classification across disciplines and across systems is profound and far-reaching. Child deaths from maltreatment can be underreported due to misclassified or inadequate information exchange between professionals tasked with investigation.

Historically, the Vital Statistics section of government in jurisdictions across Canada have often failed to adequately document the full significance of maltreatment in child deaths. A provincial child death review centre could provide the mechanism to address these challenges through its mandate on data collection and analysis, training and skills transfer, and monitoring and evaluation.

By focusing on modifiable risk factors the Centre could inform prevention programs at the local, regional and provincial levels. The availability of local data coupled with provincial data on child deaths can provide the foundation for community engagement, public awareness and local/regional prevention activities.

Community engagement involving elders, professionals, volunteers and other concerned citizens is a tremendous resource for advancing the prevention agenda. The availability of the resources resident in a provincial child death review centre should serve to strengthen the engagement of local decision makers and municipal authorities by furnishing them with the evidence and tools to adapt to their prevention needs.

#### 3. Child Death Review Training and Skills Transfer

This Option envisions a training function situated within the Review Centre. This training function would draw on the expertise, experience and insights of professionals and partners. Its focus could include, but not necessarily be limited to; law enforcement, public health, pathology, medicine, social work, and include child advocates, crown attorneys, medical examiners and coroners, elders, and community leaders.

Child death review training is required so that the various professionals, para-professionals, community members, and others involved in child death review can understand each other and communicate effectively. The development and implementation of a cross- disciplinary child death review curriculum would strengthen knowledge sharing and fuel a common vision.

The training curriculum would be made available to all key stakeholders and would serve to create a common frame of reference for understanding child death response and investigation. The curriculum should include child abuse and neglect nomenclature, policies, protocols and practice information, relevant legislation, medical frameworks, investigative techniques, multidisciplinary team strategies, privacy and cultural

considerations, documentation and communication requirements, and necessary technical, software and information technology training.

The cross-disciplinary training model would serve to meld the existing knowledge base and support the transfer of essential knowledge and skills. It would provide a coordinated approach that would help minimize negative impacts on families, communities and care workers that can arise from multiple and uncoordinated reviews. The synergy that is created by having different mandates represented in the Review Centre will allow the child death review community to collaborate in a more meaningful way that serves to keep the best interests of the child in mind.

#### 4. Initiate Child Death Prevention Activities

It is not enough to learn from the deaths of children - as a society we must act on that knowledge to prevent future tragedies. That is the essence of the evidence-informed support function for the proposed Review Centre.

Once the Review Centre is fully deployed it would provide ready access to a vast repository of evidence, knowledge and instrumentation. Fortified with analytic capacity, the mandate for surveillance, and tasked with child death review training and skills transfer the Review Centre would be ideally situated to support prevention initiatives. Typically this sort of action research at the national-level is undertaken collaboratively by universities, non-government organizations and advocacy centres. Currently there is limited capacity at the provincial/territorial level which fosters evidence-informed support for child death prevention.

It is recognized that most child death review teams do not have the resources to develop and conduct prevention campaigns. The Review Centre would be the first facility in the country to provide targeted outreach to communities across the jurisdiction in an effort to support regional and local prevention initiatives.

By understanding the risks which contribute to child mortality, we can be guided in determining the most significant opportunities for prevention. Evidencebased knowledge can galvanize public education campaigns (e.g. safe sleeping, shaken baby, suicide prevention, safe storage of firearms etc.). This information can also strengthen early detection and intervention efforts with high risk families.

This important work must be undertaken in partnership with communities, local governments, universities and non-government organizations.

Key aspects of the prevention initiative function across Alberta would be to:

- 1. coordinate improvement processes (e.g. continuous quality improvement) for partners;
- 2. nurture collaborations with violence and injury prevention, community safety and Aboriginal partners;
- 3. strengthen prevention strategies across the Province; and,
- 4. identify, coordinate, monitor and report on the strategies implemented by multi-sector partners.

#### 5. Public Reporting

Recent media attention in Alberta on the issue of child death reporting has highlighted concerns about the transparency and completeness of the reporting processes. In addition to those concerns criticism has been leveled regarding the quality of the information and data which has been shared. The view has been expressed that child death data is difficult to access, insufficient, incomplete and fragmented. This commentary has generated debate about the adequacy of the current reporting structures and the need for a reappraisal of current practices. The status quo carries the risk of inadvertently undermining confidence in the child intervention system.

It should to be recognized that governments, across Canada, are being asked to provide a higher level of transparency and accountability in the provision of all public services. There is an emerging tension between the public's appetite for greater transparency and government's responsibility to provide services with due regard to privacy, confidentiality and procedural fairness. In the area of child death reporting, in particular, public institutions must learn to reconcile the competing demands between the call for enhanced transparency and the imperative to observe procedural

fairness and maintain the integrity of the investigative processes.

Public reporting is best linked directly to the data analysis and surveillance function. In that regard there are clear synergies to be realized by situating the various functions outlined in this Paper in a single organization like a child death review centre.

Regular, fulsome, accessible public reporting on all child deaths, by all causes, ages 0-25 would be a sensible, achievable and appropriate improvement. It is noteworthy that this approach reflects the spirit and orientation of Alberta's Social Policy Framework. Regular public reporting on all child deaths by all causes will provide added transparency to a complex subject. It will also demonstrate a commitment to giving the public, the media, and professional audiences the information they require to help prevent future incidents.

There is merit in situating the public reporting function in an not-for-profit, independent entity like the proposed Child Death Review Centre. The need for transparency and system accountability can be addressed through improved child death reporting. Being separate from the public services involved in child death review contributes to the reality and perception of transparency, independence and objectivity.

Key elements to consider including in an annual child death review report are:

- Executive Summary capturing overall child mortality data, findings and recommendations
- Annual child mortality data by volumes and rates for all child deaths
- Review Team findings for all deaths by key indicators collected with the case report tool(s)
- Child mortality data with volumes and rates by manner and cause of death
- Annual data within a ten-year trend where available
- Description of cause of death
- Proven preventative interventions and identification of available prevention resources
- Breakdowns by age, race, ethnicity and gender
- Key risk factors identified through the review process

- Actions taken as a result of local and jurisdictionwide reviews
- Recommendations directed to senior and local level government officials
- Recommendations from parents and caregivers

(adapted from: Michigan Public Health Institute, National Center for Child Death Review, Fall 2013 Newsletter. Keeping Kids Alive. www.childdeathreview.org/aboutus.htm)

Regular aggregate reports should be made accessible in multiple formats (web-based, hardcopy reports, media summaries etc.) and targeted toward multiple audiences. Simplicity is paramount so that the reports are accessible and easily understood.

## **6.** Monitoring and Evaluation of Child Death Review Findings and Recommendations

Effective prevention strategies and approaches must take account of the errors, omissions, oversights, system failures and other problems identified and documented in child death reviews.

It is important to build on the findings, recommendations and conclusions contained in individual child death reviews. Similarly, the recommendations and findings originating from other child death review systems (Chief Medical Examiner, Child and Youth Advocate, Child and Family Services Council on Quality Assurance, Child and Family Services Council on Quality Assurance: Expert Review Panel, Fatality Review Board, and Child Intervention) must be tracked, monitored and evaluated with respect to their implementation.

Monitoring and follow-up of recommendations will contribute to public and professional confidence in the responsiveness of the child death review system.

It is important that every reasonable effort be made to track the recommendations and findings that emerge from the different aspects of the overall child death review system. A core aspect of the monitoring and evaluation function should be to track the frequency with which certain recommendations emerge.

Associated with this function is tracking whether or not recommendations have been considered and moved

into action. In essence, the monitoring and evaluation function is intended to ensure that child death review recommendations do not "fall between the cracks".

Communities affected by the tragedy of a preventable child death expect that the recommendations that emerge will be considered and, where practicable, translated into action. An effective monitoring and evaluation mechanism will contribute to the development of a more responsive, preventative child death review system. The key attributes of this function would be to:

- collect, aggregate, and synthesize all recommendations derived from the various review sources.
- 2. develop and maintain a tracking system that addresses the status of the recommendations and findings.
- 3. identify avenues of inquiry and research regarding recommendations requiring further elucidation to translate them into action.
- 4. establish and operate a knowledge transfer mechanism that proactively disseminates the monitoring and evaluation results to the appropriate authorities, services, and other interested parties.
- 5. develop system-based indicators to document, measure and evaluate progress towards identified positive outcomes.

The monitoring and evaluation function is critically important to the process of benefiting from child death reviews.

#### **STRENGTHS**

- Promotes prevention focus through pro-active data usage, knowledge mobilization and development of evidence-informed prevention initiatives.
- Public reporting mandate that emphasizes consistency, completeness, and accessibility of the data.

- Child mortality data contextualized with other epidemiologic reporting on child health and well-being.
- Evidence-informed child death research to guide policy, program and practice responses.
- Addresses the need to examine the individual child death in the context of population-based research.
- Supports the development, through data linkage and analysis, of a more robust capacity to assess and understand the risk factors which contribute to child death.
- Provides cutting edge data linkages across government ministries and agencies.
- Could generate mission critical information and data to key actors in a timely manner to strengthen the responsiveness of the child death system.
- Provides a comprehensive approach that builds on existing capacities.
- This approach is consistent with the governmental responsibility to ensure that child mortality data and reporting is done in a manner that respects the demands of confidentiality, privacy and promotes responsible data usage.

#### **LIMITATIONS**

- Like all significant enhancements to public services the Review Centre would require time to develop.
- To optimize its potential the Review Centre would require a legislative mandate.

#### **CONSIDERATIONS**

 Given the significant child death infrastructure which already exists in Alberta it would be particularly important to incorporate and build upon existing capacities to augment the systems response and avoid duplication.

- It is important to identify that a child death review centre constituted along the lines of what is proposed could be established with a reasonable level of resourcing.
- There is a need to reconcile the tension between the public's demand for increased transparency in child death reporting while respecting the confidentiality issues pertaining to children receiving child intervention services.

#### **OPTION 2**

### **Consortium of Government Ministries, Academic and Not-for-profit Partners**

Option two is directed primarily toward the Child Intervention System rather than the overall Child Death Review System.

Option two is based on the formation of a cross-sectoral Consortium comprised of key government ministries, academic, and not-for-profit organizations who share a common focus to assist in strengthening the child intervention response to the deaths of children ages 0 to 22 from all causes.

The unifying vision would be for a consortium constituted to advance knowledge exchange, provide training and skills transfer, provide information for prevention activities, and provide monitoring and evaluation focused on the child intervention (child and family services) system .

The overarching goal of this Option is to preserve the structures that exist and strengthen the areas where a high impact can be made through additional system improvements. The effort to enhance the child intervention response to child deaths should complement the engagement strategy articulated in Alberta's Social Policy Framework.

#### 1. Training and Skills Transfer

It is recognized that substantive enhancements to the Child Intervention response to child death entails equipping those professionals working on the front-line with the best intervention training, knowledge, access to prevention resources and programming. A defining focus of the Consortium would be training and skills transfer across the Child Intervention System, including relevant partner organizations with a clear objective of supporting and informing professionals who intervene with high-risk families.

This emphasis on training and skills transfer would be intended to complement the significant positive work that has been done, and is currently being done, on quality assurance initiatives.

Child death response training is needed to ensure that child intervention specialists have the skills, knowledge, and preparation to deal with these cases. Related to this is the need to ensure that the training is ongoing and widely available so there is always a cadre of professionals trained up and skilled in addressing child death. The creation and use of a cross-disciplinary child death response and review curriculum would advance knowledge sharing and support common standard of practice.

All key stakeholders should enjoy access to the specialized training curriculum. Aside from the expected instructional benefits this approach would help to nurture a shared frame of reference for understanding child death response and investigation. Topics to be addressed would include: identification of child maltreatment; policies, protocols and practice information; relevant legislative, medical, and investigative concepts; cultural considerations; and case management and case recording techniques.

#### 2. Information for Prevention Activities

Central to the design of the Consortium would be the development and strengthening of partnerships among key prevention stakeholders. Partnerships across sectors can provide the basis for effective information sharing to promote child safety campaigns and other types of prevention activities.

The Consortium would provide the evidence that could be used by community-based organizations and other interested parties to undertake prevention work. The Consortium's role would be to supply the information, evidence and knowledge in an effort to support prevention work by others. This approach recognizes the principle that meaningful change in attitudes, public awareness and changes in behaviour require support and promotion at the community level.

The partners represented in the Consortium model would be well located to exercise a leadership role in developing the prevention information and knowledge for use by other actors in public education campaigns. There are many lessons to be learned from the progress that has been made in child injury prevention. Those lessons need to be adapted for a host of initiatives on child death prevention. To that end the Consortium could play a significant role as a leading source of evidence and knowledge and as knowledge mobilization platform to support prevention efforts.

# **3.** Documenting and Tracking Child Death Review Recommendations

There is a need to ensure that the lessons learned through child death reviews are documented, aggregated and tracked. The documentary and tracking function is important to ensure that the findings, recommendations, problems and errors uncovered in the course of child death reviews are not overlooked or forgotten. Importantly, when recurrent risk factors are identified in the course of child death reviews it is essential to document and address those concerns. This function would provide a basis for promoting changes to better protect children and youth.

A consistent effort to strengthen public and professional confidence in the Child Intervention System's response to child deaths must include a rigorous commitment to documenting, aggregating and tracking this information. The Consortium working across the government, academic and not-for-profit sectors could enhance this function in a way that would serve the dual imperatives of transparency and accountability.

The development and youth of a tracking mechanism would assist in determining the implementation status of child death review recommendations focused on child intervention services.

#### **STRENGTHS**

- These changes could be implemented in a reasonable time frame.
- These proposals would not require major new expenditures.

- A key attribute of this approach is that the key actors are already well situated to put these recommendations into effect. The recommendations if fully implemented would be compatible with existing mandates and operational frameworks.
- The Consortium, comprised of academic, notfor-profit and government partners, would be well-situated to address the child intervention need for inter-disciplinary child death training, and to document the implementation of recommendations pertaining to the Child Intervention System.
- Bridges the gulf between government and nongovernment sectors through meaningful collaboration focused on training, prevention and recommendation tracking.
- Involvement of non-government and academic partners could strengthen confidence in the Child Intervention System's response to child death.
- Skills transfer and training initiatives developed and delivered across sectors and across disciplines will enhance a common understanding of the child intervention challenge.
- The documenting and tracking function will underpin child intervention improvements in child death review while helping to identify pressure points in the child intervention system that require further enhancements.

#### LIMITATIONS

- These proposed improvements require a change management strategy that takes into account system behaviour, the need for a skills transfer strategy, and a practical implementation framework.
- It should be noted that these proposals, even if fully implemented, might have only marginal visibility and may not satisfy the appetite for immediate positive change.

- The proposals represent significant improvements but they may not be sufficient to answer the demands for fundamental change.
- These proposals represent an incremental approach to change and are not intended to constitute a fundamental restructuring of the Child Intervention System.

#### **CONSIDERATIONS**

- The Consortium could be governed by a Board of Directors representing the three sectors at the core of the model, the public, academic and the not-for-profit sectors.
- The multi-disciplinary nature of child death review should be reflected in the composition of the Board of Directors. First Nations and Métis representatives, public health, mental health, social work, forensic pathology, paediatrics are some of the important perspectives that should be considered for representation on the Board.

## TWO OPTIONS: COMPARATIVE TABLE

Options	Option #1	Option #2
Structure	Legally constituted, not-for-profit provincial child death review centre	Consortium of not-for-profit, academic and government partners
Governance	Governed by a Board of Directors with multi-sectoral representation	Governed by a Board of Directors with multi-disciplinary representation
Scope of coverage	0-25 deaths of all children by all causes	0-22 deaths of all children by all causes
Legislation	Legislation based	Not legislation based
Focus	Overall Child Death Review System	Child Intervention System primarily
Functions	<ol> <li>Data Collection and Data Linkage (data sharing, protocol development, data interface)</li> <li>Data Analysis and Ongoing Surveillance (trend and pattern identification, multi-source data analysis and synthesis)</li> <li>Training and Skills Transfer (cross-discipline training, curriculum development)</li> <li>Initiate Evidence-Informed Prevention Initiatives (initiate and co-lead public education campaigns, knowledge to practice initiatives)</li> <li>Regular Public Reporting</li> <li>Quality Improvement Monitoring and Evaluation (focused on the overall child death review system, cross- system compliance measures, efficacy and efficiency studies, development of outcome measures, evaluative process indicators, tasked with evaluating improvements in practice)</li> </ol>	<ol> <li>Training and Skills Transfer (skills development)</li> <li>Information for Prevention Activities (information and knowledge development)</li> <li>Documenting and Tracking Child Death Recommendations (focused on Child and Family Services)</li> </ol>

#### **CASE STUDIES**

#### **CASE STUDY 1: NEW ZEALAND**

#### NAME OF ORGANIZATION

Child and Youth Mortality Review Committee

#### **MANDATE**

Established committee to review deaths of children and young people aged 28 days to 25 years to advise on how to reduce the number of preventable deaths in the future by:

- 1. Monitoring the number and types of deaths that occur among New Zealand children and young people over time
- 2. Providing education about how mortality reviews are useful
- 3. Interacting with community and organizational networks
- 4. Collecting information from all relevant sources that will identify ways to prevent deaths both locally and nationally
- 5. Conducting investigations into particular types of child and youth deaths
- 6. Producing an annual report outlining data and making recommendations for actions that will reduce child and youth deaths in New Zealand
- 7. Advocating for any improvement of health and social services for children and young people that will reduce deaths.

#### **STRENGTHS**

A key strength of the New Zealand model is that the National Committee makes policy recommendatitions. The system is further enhanced by the following features:

- Strong legislation that mandates information sharing
- Collecting a standard set of information
- Information is made available to local review meetings and is provided in varying formats

- Data includes ethnicity
- Reviews are designed to identify national trends and patterns of illness, incidents and accidents leading to death which may indicate where health, education, social or environmental systems are not functioning to protect children and young people

#### LIMITATIONS

- Some local review committees have more members from health than other disciplines which may result in an overly focus on public health
- Maintaining the system is time consuming
- Information shared is non-specific

Recommendations made from the Committee to the Government of New Zealand:

There is a need for leadership in these matters.
 Governments and those working with children and youth must actively identify and address barrier to inter-agency communication and working together.

#### **CASE STUDY 2: UNITED KINGDOM**

#### NAME OF ORGANIZATION

Child Death Overview Panels of Local Safeguarding Children Boards

#### **MANDATE**

Through a comprehensive and multidisciplinary review of child deaths, the Child Death Overview Panel aims to improve the understanding of how and why children die and use the findings to take action to prevent future child deaths and more generally to improve the health and safety of the children.

The United Kingdom has been doing child death reviews for many years. Legislation was introduced following a critical report in 2003 authored by The House of Commons Health Committee regarding the high profile case of Victoria Climbie. Lord Laming noted in this report that *The Children Act of 1989* was good legislation but poorly followed and enforced.

Some of the sweeping changes related to the Victoria Climbie Inquiry Report include new procedures and further application of *the Children Act* 2004. According to the Community Care website on assessment of child protection, one of these changes arising from the Climbie case includes the integrated children's computer system where information is tracked and collected.

Death review processes follow a national framework approach.

It is mandated that all child deaths, up to 18 years, are reviewed. In the case where a child is under 28 days, deaths are reviewed to gain insight into prevention measures unless the child was stillborn or the pregnancy ended in legal termination.

Child Death Overview Panels are in place to conduct reviews. There are centralized national guidelines and regulations that have standardized the approach to conducting child death reviews. Training and knowledge exchange is also in place. Training includes best practices, responding to child deaths, investigations of child deaths and prevention. The review process is in place to promote transparency and prevention. Data are centralized through the oversight of the Department of Education. Once a year, the data are reported on to the public through the Government of the United Kingdom website.

#### **STRENGTHS**

- There are national markers for good practice even though this is a local review process
- Collaboration is built into the process with expert representation
- All child deaths, except for still-born children are reviewed
- Parental/caregiver education and support is a part of the process
- Multi-sectoral medical, child protection, public health, community health and justice representation is built in
- Data collection and data sharing is mandated

- Process is legislation based and has been reviewed and is updated periodically
- Data from child death reviews are drawn upon to improve Public Health

#### LIMITATIONS

- There is a directive on how to collect, analyze and report data by means of a template through the Department of Education, but usage of the template is not mandatory.
- The child death review data are collected at a national level, or a local level; but there is a need to also collect data on a regional level.

#### **CASE STUDY 3: UNITED STATES**

#### NAME OF ORGANIZATION

National Center for Child Death Review

#### **MANDATE**

The National Center for Child Death Review is a resource center for state and local child death review programs, funded by the US Department of Health and Human Sciences. It promotes, supports, and enhances child death review methodology and activities at the community, state, and national levels.

#### **HISTORY**

The deaths of all children up to age 17, which are due to external causes, are reviewed by a Child Fatality Review Team (CFRT).

- Members include representatives from:
  - o Criminal Justice
  - o Child Protection
  - o Medical system
  - Medical examiners
  - o Public health
- Team acts as a peer review function
- Sharing of information and expertise
- Prevention campaigns are generated by teams
- Promotes data linkages for example

California has set up a data linkage system of matching health, vital statistics, criminal justice data and fatal child abuse and neglect reports"

- Data for each state is made publicly available at a central location
- 39 states release annual reports to the public about child deaths, 18 states do not have legislation making this a requirement

#### **STRENGTHS**

- National in scope
- Collaborative
- Rich source of data
- Information sharing
- Transparent
- Prevention focus
- Multidisciplinary expertise
- Multi-source linkage seen in some states

#### **LIMITATIONS**

- Preparing the report on child death review findings can be difficult and time consuming
- Not all states have legislation to release public reports (39 do, 18 do not)

#### CONSIDERATIONS

The case review of a child's death can often catalyze local and state action to prevent other deaths. It is important to systematically collect data and report on the findings from reviews over time. It is also important to compare review findings with child mortality data from vital statistics and other official records.

When data from a series or cluster of case reviews are analyzed over time, significant risk factors or patterns in child injury and safety can be identified. The collection of findings from case reviews and the dissemination of findings can help:

- Local teams gain support for local interventions
- Child Death Review teams review local

findings to identify trends, major risk factors and to develop recommendations and action plans for state policy and practice improvements

- Child Death Review teams match review findings with vital records and other sources of mortality data to identify gaps in the reporting of deaths
- Child Death Review teams use the findings as a quality assurance tool for their review processes
- Child Death Review teams and states use the reports to demonstrate the effectiveness of their reviews and advocate for funding and support for their child death review program
- National groups use state and local child death review findings are used to push for national policy and practice changes

# APPENDIX 1: JURISDICTIONAL AND FAMILY SERVICES CHILD DEATH DATA COLLECTION AND PUBLIC REPORTING: QUESTIONNAIRE

1. How is the data reported to/shared with the public?

## **PUBLIC REPORTING PROCESS**

a. Through a dedicated website

c. Through investigation reports

b. Through case studies

d. None of the above e. All of the above

t.	Other please specify
	2. How often are the data updated?
a.	Annually
b.	Quarterly
c.	Every 6 months
d.	Other please specify
	3. When did public reporting begin in your jurisdiction?
a.	1980s
b.	1990s
c.	2000s
d.	2010s
	A state to the decree of a latter or a state 2
	4. Who is in charge of public reporting?
	Coroner/Medical Examiner
	Department of Children and Family Services (Child Welfare)
c.	Child Advocate
d.	Police/Law enforcement
e.	Other please specify
	5. Is there anything else you would like to share with us about the public reporting
	process in your jurisdiction?

# **DATA COLLECTION**

	6. Until what age are children eligible for services?
a.	Up to 16
b.	Up to 18
c.	Up to 19
d.	Other please specify
	7. Which services are responsible for collecting child death information?
a.	Coroner/Medical examiner
b.	Department of Children and Family Services (Child Welfare)
c.	Child Advocate
d.	Police/Law enforcement
e.	Other please specify
	8. How common is the language used by the various entities in charge of data collection?
0	No common language
0	Very little common language
0	Few common language
0	Moderate level of common language
0	High level of common language
0	9. Do you use NASHU as a standard of child death classification? NASHU stands for:
0	<ol> <li>Do you use NASHU as a standard of child death classification? NASHU stands for: Natural, Accidental, Suicide, Homicide, Undetermined.</li> </ol>
0	<ol> <li>Do you use NASHU as a standard of child death classification? NASHU stands for: Natural, Accidental, Suicide, Homicide, Undetermined.</li> </ol> Yes
	<ol> <li>Do you use NASHU as a standard of child death classification? NASHU stands for: Natural, Accidental, Suicide, Homicide, Undetermined.</li> </ol>

### 10. What elements are you tracking?

	Yes	No	Made public? (yes or no)
Name of Child			
Date of Birth of child			
Dute of Birth of child			
Gender			
Ethnicity			
Children served by			
the agency			
Cause of death			
Age of child at death			
Name of alleged			
perpetrator			
Relationship with			
alleged			
perpetrator			
Deceased child's			
siblings			
Does the child have			
siblings?			
Do you track Name, Date of Birth, etc?			
Date of Birtil, etc.			
Other 1:			
Other 2:			
Other 3:			
Other 4:			
Other 5:			
Other 6:			
Other 7:			

## 11. Who are the children being tracked in your Child Death data collection system?

INDIRECT INVOLVEMENT		
	Yes	No
No prior involvement with Child & Family Services		
Child over 18 at time of death		
Closed Files		
Child who received services in the past but had a closed file at the time of death		
Child who was in care and returned home and had a closed file at		
the time of death		
Child whose family member(s) received support services in the		
past whose file was closed at the time of death		
DIRECT INVOLVEMENT		
	Yes	No
Open Files		
Child in Care		
Child receiving services at home		
Child whose family member(s) were receiving support services at the time of death		
Child whose need for protection was investigated at the time of death		

## 12. Is there a formal protocol for public reporting on child deaths?

- o Yes
- o No

# **CONCLUSION**

13. Is there anything else you would like to share with us today?

# APPENDIX 2: JURISDICTIONAL SCAN OF CHILD AND FAMILY SERVICES CHILD DEATH DATA COLLECTION AND REPORTING: LEGEND AND ACRONYMS

#### **LEGEND**

A. The elements tracked include the following:

- Name of child
- Date of birth of the child
- Gender
- Ethnicity
- Children served by the agency
- Cause of death
- Age of child at death
- Name of alleged perpetrator
- Deceased Child's siblings

B. Indirect Involvement refers to the following:

- No prior involvement with Child and Family Services
- Child over 18 at time of death
- Child who received services in the past but had a closed file at the time of death
- Child who was in care and returned home and had a closed file at the time of death
- Child whose family member(s) received support services in the past at the time of death

C. Direct Involvement refers to the following:

- · Child in care
- Child receiving services at home
- Child whose family member(s) were receiving support services at the time of death
- Child whose need for protection was investigated at the time of death

#### **ACRONYMS**

NASHU **N**atural is any death that is not

the result of an external injury.

Accidental is any death resulting from an external injury that is considered unintentional.

**S**uicide is any death due to self

induced external injury.

Homicide is any death due to an external injury intentionally caused by someone else other

than the deceased.

**U**ndetermined is any death for which the cause is unknown.

OCME Office of the Chief Medical

Examiner

# APPENDIX 3: CHILD AND FAMILY SERVICES PUBLICATION PRACTICES PERTAINING TO THE DEATH OF A CHILD IN CARE

Publication bans against revealing the identity or identifying information regarding the death of a child receiving child welfare services are intended to protect the privacy of the child and family.

Information on publication bans was not obtained relating to Yukon, Northwest Territories and Nunavut.

Province	Does Child and Family Servion make identifying information child death's public? (Q10)
British Columbia	No
Alberta	No
Saskatchewan	No
Manitoba	Only aggregated information
Ontario	No
Quebec	No
New Brunswick	No
Nova Scotia	No
Prince Edward Island	No
Newfoundland and Labrador	No

# PUBLICATION BAN ON RELEASING IDENTIFYING INFORMATION ON THE DEATH OF A CHILD

The publication ban is a contentious issue that has generated passionate debate. It is a complex issue which must be addressed carefully. Amendments to or repeal of the ban could have unfortunate ramifications for the families directly affected by it. Children and families involved with the child intervention system could be adversely impacted by changes to the current practice.

The debate regarding whether to preserve, amend or repeal the publication ban usually references one or more of the following issues: lack of transparency; lack of accountability; the public's right to know; preserving confidentiality; and, the best interests of the child. It is important to recognize that these issues due not necessarily warrant equal weight or apply in the same way to all cases. The right to know, for example, may apply to non-identifying aspects of a child intervention case and the right to confidentiality might apply to identifying aspects of the same case.

Concerns have been expressed that the publication ban, as it is currently stands, contributes to the perception of a lack of transparency. A related concern is that the ban has, over time, undermined efforts to ensure the accountability of the child intervention system. There is also a perception by some commentators that the publication ban has been misused as a "shield", in effect protecting the child Intervention system from critical review and examination.

When a child involved with the child intervention system dies there is a need for accountability. However, there is a need to reconcile the demand for accountability with the longstanding requirement to treat with confidentiality identifying information about children receiving intervention services.

Children and families who receive child intervention services have a right to have their matters treated with confidentiality. The principle of confidentiality, with respect to identifying information about the recipients of child intervention services, is longstanding, well-established, internationally observed and foundational to the professional ethics of child welfare. To depart from this principle would invite risks that should be carefully weighed. If identifying information, like the name and

photograph of a deceased child, is no longer treated confidentially this may deter some people from availing themselves of vital services that are needed to ensure the protection of children.

This is analogous to the confidentiality frame that characterizes the health care system. Publicly sharing confidential medical information about children is inconceivable except in the most exceptional circumstances.

Revealing the identity of a deceased child, who was in care, could generate adverse attention to the surviving family members including siblings who might also be in care. The concern has been expressed that repealing the publication ban could stigmatize surviving siblings and other family members.

Those concerns notwithstanding there may be instances when the publication ban should be lifted or relaxed. Currently, the Office of the Statutory Director for the Child, Youth and Family Enhancement Act is empowered to make the decision to uphold, relax or lift the ban. The concerns noted above regarding transparency and accountability suggest that the decision making authority may be best situated outside the Ministry.

The authority to make decisions on the release of identifying information about a deceased child could reside with an independent, impartial third party, such as the Office of the Information and Privacy Commissioner of Alberta.

#### **APPENDIX 4: ENDNOTES**

- Non-identifying written response available on Alberta Human Services Website if there has been an external review (OCYA, CQA, Expert Panel, and Fatality Inquiry). The Fatality Inquiries Act requires that a written report is made available to the public. The ministry provides a written public response to each report (see: http://humanservices.alberta.ca/abuse-bullying/17189.html)
- <sup>2</sup>The OCME is submitted to the Minister of Justice in which the annual report has a specific chart for children based on calendar year and another chart based on fiscal year.
- 3 Not through the Ministry
- <sup>4</sup> The Fatality Inquiries Act requires that a written report is made available to the public. The ministry provides a written public response to each report (see: <a href="http://humanservices.alberta.ca/abuse-bullying/17189.html">http://humanservices.alberta.ca/abuse-bullying/17189.html</a>)
- 5 Additional supports may be provided between 18 and 22.
- Age protection is up to 16 but able to provide support services up to 18 and extended services up to 21
- <sup>7</sup>Up to 21 for voluntary support services which can be offered to children who are/were Permanent Wards
- The Office of the Chief Medical Examiner (OCME), Fatality Review Board, Child and Youth Advocate (OCYA), Council for Quality Assurance (CQA), Ministry staff (Statutory Director, department staff, regional delivery staff (see: <a href="http://humanservices.alberta.ca/abuse-bullying/17189.html">http://humanservices.alberta.ca/abuse-bullying/17189.html</a>)
- <sup>a</sup> The Ministry utilizes the same language / classifications as the OCME.
- <sup>10</sup> Uses the OCME classifications Natural, Accident, Suicide, Homicide, Unclassified, Undetermined and Pending. Medical (includes congenital anomalies, health conditions and disease); Accidental; Undetermined (may include Sudden Infant Death Syndrome); Suicide; Homicide; and Pending (see: <a href="http://humanservices.alberta.ca/abuse-bullying/17189.html">http://humanservices.alberta.ca/abuse-bullying/17189.html</a>)
- International Statistical Classification of Diseases and Related Health Problems (ICD-10-CA)
- Except name of alleged perpetrator and relationship with alleged perpetrator.
- Worksite, name, child ID#, DOB, DOD, agency notification to Ministry, manner of death, cause of death, OCME confirmation (y/n), racial origin, band affiliation, legal status, placement type, family violence history, family violence in the incident, reported to the OCYA, OCYA status, reported to CQA, Expert Panel (y/n/members), fatality inquiry called (y/n), chronology / report status.
- <sup>14</sup> Name of alleged perpetrator, relationship of alleged perpetrator and the child's siblings are in the reviews.
- Only gender, cause of death (made public if necessary), Age of child at death
- 16 Coroner does the tracking
- <sup>17</sup> Does not track prior involvement at all with Child and Family Services

- <sup>18</sup> Children receiving services: screening, safety phase assessment, family enhancement, supervision order, Support and Financial Assistance Agreement (18-22)
- 19 Does not track prior involvement at all with Child and Family Services
- <sup>20</sup> Does not track prior involvement at all with Child and Family Services
- 21 http://humanservices.alberta.ca/abuse-bullying/17189.html
- <sup>22</sup> Death is tracked and an Initial Review is completed in cases where an in-depth review is not completed.

Policy does not depend on the manner/cause of death.

- 23 Annual Report.
- 24 Case by case approach in each region
- 25 Preliminary report is being created.
- 26 Unless inquired by Media
- 27 It is on a case by case basis. Each case would be determined if it will be reported publicly.
- 28 Per Deputy Minister's request
- Although there is no public reporting requirement, the Minister of Health and Social Services may authorize a report. The NWT Coroner Service may order a public inquest or issue a Report of Coroner, with recommendations.
- <sup>30</sup> Up to 19 if in care, extended to 21 if needed be, and up to 24 for educational support
- 31 Could extend services: 19 if in educational program, 21 if in custody
- 32 Post care until the age of 24 as long as they were in case before the age of 19
- 33 Provide services to children and young adults up to age of 26 as of April 2014
- 34 The Department only tracks the children in care, whereas the Coroner and Police are responsible for tracking all children's deaths
- <sup>25</sup> Tracks deaths details by the following categories: Natural, Accidental, Intentional by self, Intentional by others, Medical, Unknown
- <sup>36</sup> There have been very few deaths in PEI. The tracking is for all children in care. Policy is created in case it happens.
- Name of child, Date of birth, Gender, Children served by the Agency, cause of death, family composition, background information on incident. Note that these items are tracked in individual files, not in databases.
- 38 In the Critical Incident Review Policy
- <sup>59</sup> Element vary from case to case, but all cases include name, sex, ethnicity, date of birth and cause of death.
- 40 Does not track name of alleged perpetrator
- 41 Does not track prior involvement at all with Child and Family Services
- <sup>42</sup> Only for children who received services in the past but had a closed file at the time of death
- <sup>43</sup> Only to child who was in care and returned home and had a closed file at the time of death
- 44 Only if a child whose family member(s) received support services in the past whose file was closed at the time of death and child who was in care
- <sup>45</sup> Only for the ones under protection—policy 78 only applies to children who are currently receiving child protective services and die as the result of child abuse.

#### **OBJECTIVES OF CHILD DEATH REVIEW**

- Accurate identification and uniform, consistent reporting of the cause and manner of child death
- Improved communication and linkages among local and provincial/territorial agencies
- Improved agency responses to investigation of child deaths
- Strengthening agency responses in protecting siblings and others in homes where a child has died
- Improved investigation and prosecution of child homicide
- Enhanced provision of services to children, families, care providers, and community members
- Identification of blockages and systematic issues contributing to the death of children
- Identification of risk factors and trends in child deaths
- Advocacy for prevention-focused improvements in legislation, policy and practices and expanding preventive health and safety efforts
- Increase public awareness of and advocacy for societal issues affecting the health and safety of children

Source: Covington, T. M., Foster, V., & Rich, S. K (eds.). (2005). *A Program Manual for Child Death Review*. Michigan: National Center for Child Death Review. Available at: http://www.childdeathreview.org/finalversionprotocolmanual.pdf

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