Ministerial Roundtable:
Investigations and Reporting of Deaths and Serious Injuries

Summary Report

April 2014

Executive Summary

On January 28 and 29, 2014, 13 experts, 91 in-room participants and 475 on-line participants gathered for two days to discuss how the investigation and reporting of child deaths in Alberta should be improved.

There was strong consensus that the following conditions should support full and meaningful investigations into the deaths and serious injuries of children in Alberta:

- All deaths of all children should be reviewed.
- The child death review process should be structured, standardized, thorough and transparent.
- There should be an orientation to prevention in the investigation of child deaths.
- Culturally relevant knowledge and expertise must be included in the investigations and the healing processes. As the majority of the deaths of children in care involve Aboriginal children, Aboriginal knowledge and expertise must be represented.

1. General recommendations for investigations into deaths of all children

It was proposed that a process of reviewing child deaths could be built within the current system through an overall "paediatric death review committee". This review committee, comprised of expert nominees from the major agencies, frontline groups and Aboriginal communities would have overall responsibility for the review of all child deaths. The committee would ensure that the review into a child's death was conducted by the most appropriate independent agency or office, without undue interference from the committee. The goal of the review committee would be to ensure all deaths are investigated thoroughly, producing comparable and meaningful data, while allowing for each agency to operate with a great deal of autonomy.

Six critical success factors for a meaningful child death review system were proposed:

1. Legislative authority
2. Structured, standardized, thorough and transparent processes
3. Full, confidential disclosure by all participants in a review/investigation
4. Improved access to information by participating offices/agencies
5. Fair, equitable and appropriate timeliness of investigations and reporting
6. Consideration of the full history of a child - understanding the broader context of a death, not just the physical circumstances.

It was also strongly recognized that there is a very real and personal impact of child deaths on individuals, families and communities. This needs to be considered in how reviews are conducted and reported.

The process and results of investigations and reviews need to be communicated publicly on a consistent and timely basis. The goal of reporting is to be open, transparent and accountable to the public, families and communities involved. By mandate, the paediatric death review committee would produce an annual report that would report on all deaths; identify trends; and discuss (without providing identifying information) specific cases.

Through its coordination function, the paediatric death review committee would be able to:

a. Improve rigour, transparency and thoroughness of all aspects of reviews and reporting
b. Identify and close gaps in the good work that accountable organizations currently perform
c. Coordinate the approach in order to ensure efficiency, effectiveness and timeliness
d. Coordinate the approach in order to minimize the negative impacts on families, communities and care workers that can arise from multiple and un-coordinated reviews.

Currently, recommendations from inquiries and reviews are seen to lack accountability. Participants identified a need for a strong and independent assurance mechanism whereby the implementation of recommendations arising from child death reviews would be monitored, reviewed and reported upon.

While serious injuries are considered to be important to review, as they include “near misses” that can inform prevention and may be early indicators of the risk of death, there are several challenges in reviewing serious injuries. These include includes a lack of agreement on what constitutes a serious injury and the different organizations that are currently involved in injuries versus those involved in death reviews. Further discussion about how best to review the serious injuries to all children is required.

2. Specific recommendations for investigations into deaths of children receiving child intervention services.

It was clearly established in the Roundtable that, within an overall child death review system, the deaths of children receiving child intervention services are a subset of all deaths and there are specific dynamics and players involved that need to be considered.

The review of deaths of children in care typically requires involving a broader range of people than other child deaths. This may include birth families, siblings and other children in the home, child intervention workers, foster families and kinship caregivers, communities and agencies. While the role and context of these people needs to be included in the review, it also is important to recognize that the tragedy of the death also affects these people and that healing must be supported.

The need to support cultural perspectives in child death reviews and reporting was acknowledged as key to ensuring effective investigations and clear communication. Given the higher than average rate of interventions in Aboriginal families, Roundtable participants considered it essential to have a strong Aboriginal presence and perspective in the review process – at all levels.

It was felt that current investigations, which lack a clear prevention mandate, place extraordinary pressure on the frontline child intervention workers; discourage honest communication; and diminish the grieving and healing process. Participants agreed that frontline child intervention workers must receive support at difficult times. A thorough and compassionate plan for debriefing family, ministry and agency staff, as well as caregivers, was deemed necessary in every investigation.

Reporting on the deaths of children in care needs to identify the positive - what was working - as much as it identifies the failings. Some participants expressed concern that a purely medical-centred approach to child death reviews might be too narrowly focused and that an ecological, strengths-based model would be more appropriate. Knowledge of system strengths as well as weaknesses will help sustain the system and encourage best practice by frontline child intervention workers.

3. Recommendations about information disclosure and the publication ban

The Roundtable expressed a near universal concern regarding the lack of information currently shared, both specific and aggregate. A fair, open, transparent and balanced reporting of aggregate data conducted in a timely fashion and consistently released to the public was seen to be required.

The timely release of aggregate data, with the intent to prevent and educate, was strongly supported. Possible changes to the publication ban were more widely debated. Despite the complexity of the issues, there was unanimous agreement that the ban must be amended to allow for better holistic investigation and improvement of the deficiencies in the care system.

There was strong, but not universal, consensus that the decision to release information about a child's death should strongly consider the child's wishes and be made by the family. While clear in principle, it was acknowledged that the process to determine whether information should be released would be complex. A process to determine the criteria and principles around this decision-making, and an assessment of potential impacts, was considered achievable.

The youth participants expressed a strong belief that all children should be treated equally regardless of whether or not they are in care. They did not want their identity diminished after death as the result of a publication ban. The youth also recognised that revealing their identity/revealing that they were children in care was a very personal opinion and would vary from individual to individual.

A clear framework must be established with respect to the release of information and specific criteria to govern the release of information. Some suggested principles by which decisions to make information public are made include:

- The best interests of the child
- The child's right to determine the release of their information /family rights
- The community's interests
- The public's interests
- Accountability and transparency of the system
- Potential for prevention of similar tragedies.

Background and Method

Albertans want to be confident that its government is doing everything it can to protect and nurture Alberta's most vulnerable children. When tragic incidents occur, Albertans need to be assured that the system of care and protection is following the right processes and publicly reporting the right information.

The Honourable Manmeet S. Bhullar, Minister of Human Services, hosted a Child Intervention Roundtable on January 28 and 29, 2014 in Edmonton. Convening the Roundtable was intended to bring experts, service delivery agency representatives and community partners together to have a focused discussion about Alberta's current investigation processes for children who die or who are seriously injured, and how this information is reported to the public.

The format of the two-day event included facilitated discussions by small groups representing various perspectives on the issue of investigations and public reporting. These discussions were observed by a larger group of about 91 attendees who also had an opportunity to participate in discussions within small group settings. The event was webcast to allow for participation by Albertans who were unable to attend the event in person. There were approximately 475 webcast participants.

Purpose

To engage Roundtable participants in the discussion of the following questions:

1. What supports a full and meaningful investigation into the death or serious injury of a child in Alberta?
2. What additional steps should be taken to improve investigations when it involves a child receiving child intervention services?

3a. What information should be available about:

- The death of or serious injury to all children?
- The death of or serious injury to a child receiving child intervention services?

3b. What changes should Alberta consider with respect to the *Child, Youth and Family Enhancement Act*'s publication ban?

Expert Panel Participants

Question 1 and Question 2	Question 3
Dr. Ada Bennett Deputy Medical Officer of Health Office of the Chief Medical Officer of Health	Mr. John Archer President Alberta Legislature Press Gallery
Dr. Lionel Dibden Director, Child Adolescent Protection Centre Chair, Child and Family Services Council for Quality Assurance	Dr. Ada Bennett Deputy Medical Officer of Health Office of the Chief Medical Officer of Health
Mr. Del Graff Child and Youth Advocate Office of the Child and Youth Advocate	Ms. Jill Clayton Commissioner Office of the Privacy Commissioner
Dr. Anny Sauvageau Chief Medical Examiner Office of the Chief Medical Examiner	Dr. Lionel Dibden Director, Child Adolescent Protection Centre, Chair, Child and Family Services Council for Quality Assurance
Mr. Gordon Phaneuf Executive Director Child Welfare League of Canada	Mr. Del Graff Child and Youth Advocate Office of the Child and Youth Advocate
Dr. Jennifer Macpherson Clinical Assistant Professor - Dept. of Pediatrics, University of Calgary Executive Member, Child and Youth Maltreatment Section, Canadian Pediatric Society	Dr. Anny Sauvageau Chief Medical Examiner Office of the Chief Medical Examiner
Dr. Eric Wasylenko Associate John Dossetor Health Ethics Centre, University of Alberta	Mr. Gordon Phaneuf Executive Director Child Welfare League of Canada
	Dr. Eric Wasylenko Associate John Dossetor Health Ethics Centre, University of Alberta
	Ms. Colleen Wilson Executive Director Alberta Press Council
	Faven Youth
	Monique Youth
	Samantha Youth

Investigations in Child Deaths and Serious Injuries

Discussion Question:
What supports a full and meaningful investigation into the death or serious injury of a child in Alberta?

All deaths, all children

There was near universal agreement that it is important to review all deaths of all children. This ensures that there is a context to understand the deaths of children in care.

A child death review process should be structured, standardized and thorough, and look at all deaths including homicides, suicides, accidental deaths, natural deaths and unclassified or undetermined deaths.

While the Office of the Chief Medical Examiner currently reviews aspects of all deaths, it was agreed there is a need to more broadly and comprehensively review all child deaths and that a new structure/process is required.

Prevention orientation

It was important to participants that there be a prevention orientation in the investigation of child deaths – the emphasis being on what can be learned to prevent future deaths rather than an emphasis on finding fault or blame in an individual death.

> "There's a tendency in child death to get into a culture of blame as opposed to a culture of improvement and accountability. Sometimes that holds us back because we're frozen in that moment of a tragedy that has occurred and we lose sight of the larger picture. We need to go back and look dispassionately at what went wrong in the system, not to assign blame, but to see how can this reoccur, how did this come to pass? That we do when we do the review population-wide, when we look at the province as a whole."
>
> Dr. Lionel Dibden

Serious injuries

Serious injuries are considered to be important to review as they include "near misses" that can inform prevention and may also be early indicators of the risk of death. These reviews may be an essential part of the prevention orientation of a child death review system.

> "You can't escape the fact that injury, particularly severe injury, is a call for help and has to be part of the conversation." Dr. Ada Bennett

There are challenges in reviewing serious injuries:

- There is not a shared understanding or definition of what constitutes a serious injury.
- There may be essential players in a child death investigation, such as the Office of the Chief Medical Examiner, who might not be involved in a serious injury investigation.

There was strong agreement that further discussion is required on the review of serious injuries and whether these reviews can be integrated into a child death review system.

Elements of a child death review system

A meaningful review system would consist of a number of components:

Understanding the context

In order to fulfill a mandate of prevention, understanding the context of the death, including the events and environment that preceded the death, be included in the reviews.

Context includes the individual environment, the family, the community and the society. All are essential components of a meaningful review. In particular, participants agreed that it's very important to recognize Aboriginal knowledge and Aboriginal expertise in investigation, and in the healing processes.

Clear, transparent and standardized reviews

> "Simple things like improving access to information while maintaining appropriate privacy are paramount to supporting an adequate and thorough investigation."
>
> Dr. Jennifer MacPherson

To facilitate systemic analysis, reviews must be clear, transparent and conducted in a consistent manner, regardless which agency/office is conducting the review.

It was acknowledged that there is not a common standard of data reporting across Canada and comparisons between jurisdictions is difficult.

The initial investigations must be thorough and complete to enable a review committee to be able to determine whether further reviews are required.

Principles

> "Principles can drive a more considerate and responsive system." Dr. Lionel Dibden

In designing a child death review system, eight principles were discussed:

- Transparency
- Impact
- Attentiveness
- Accountability
- Understanding
- Clarity
- Dignity
- Data and the full context of the death.

Not: Fear → Fault → Blame, as this situation creates paralysis and prevents transparency and accountability.

Structure

It was proposed that a process of reviewing all child deaths could be built within the current system, which had a strong level of vocal support during the Roundtable. However, there was consensus that the communication touch points between organizations are lacking and that these need to be reviewed, defined and formalized. This could be achieved by the creation of a new paediatric death review committee which would include broad representation from relevant expert representatives. This review committee would oversee all reviews into child deaths to ensure the quality of the review and to gain relevant information for future prevention.

Currently, the Office of the Chief Medical Examiner – which operates at arms length from the government – has an existing mandate to review all deaths and was discussed as a potential existing structure within which a paediatric death review committee could be located.

This committee would not interfere with the independence of any office/agency to conduct a review, but through the wise collaboration of the members, the committee would ensure that all deaths are reviewed in the most appropriate manner by the most appropriate office. A proposed benefit of this process is that it would reduce the duplication of reviews that exists today.

> "We should also be careful to not create a system that duplicates so much that it becomes more costly to Albertans." Dr. Anny Sauvageau

Membership of this review committee was proposed to include (but not be limited to):

- Office of the Chief Medical Examiner
- Office of the Chief Medical Officer of Health
- Office of the Child and Youth Advocate
- Child and Family Services Council for Quality Assurance
- Aboriginal communities
- Community of frontline child intervention workers.

The legislated role and independence of any of the offices and agencies involved would not be limited by the work of the paediatric death review committee.

Critical success factors

Experts and participants identified six critical success factors for a meaningful child death review system:

Legislative authority

Legislative authority is seen to be essential to ensure all deaths are reviewed and that recommendations arising from those reviews are implemented. This is supported by best practices from the United Kingdom, the United States and New Zealand.

Strong legislation would include providing a prevention orientation to the child death reviews, and legislative authority to the paediatric death review committee and the organizations conducting the reviews.

Transparency

Reviews of child deaths should be conducted and reported in a manner that is structured, standardized, thorough and transparent.

Full, confidential disclosure

While everyone is concerned about rigorous information sharing, strong legislation also ensures that information sharing can occur without accusations. Legislation supports a culture where everyone involved feels confident they can share information without recrimination (e.g., a statutory shield). This is also supported by a prevention mandate for reviews.

Improving access to information

Even where the right to access data exists today, it can be a time - and labour - intensive process for agencies/offices to access the information they need to conduct reviews.

More meaningful reviews will require the right of access by review bodies, as well as the infrastructure to be able to access the data in a timely and cost-effective manner. Barriers to sharing information need to be removed.

Timeliness

The timeliness of investigations and reporting should be fair, equitable and appropriate to the circumstances. For example, in cases where there is potential risk to others, an investigation may need to be expedited. In other circumstances, the timing of the investigation may take into account the needs of grieving families and communities.

Full history

Considering the full history of a child contextualizes many aspects of the child's life that may have a bearing on the circumstances of his or her death.

There were mixed opinions about the use of external consultants to help investigations. Some participants promoted them for increased transparency; others advised against using external consultants for cost and efficiency reasons.

Minimizing impact

Honouring the dignity of the people involved

> "We need to really be careful to honour the personhood of this neonate or infant or child or youth. When we think about what we're focused on in investigations, it seems to me that we need to cultivate an attitude that the investigation pays attention to at least three things – the dignity of the individual person that we're addressing in the investigation, secondly the dignity of the particular family and community – and community is defined largely and in smaller terms – and thirdly we need to understand that this work is crucial to helping avoid other tragic circumstances, which many people have talked about today."
>
> Dr. Eric Wasylenko

Sensitivity training for all persons investigating and reviewing deaths was recommended, so that they are aware of impact on those involved.

Reporting

The process and results of investigations and reviews need to be communicated publicly on a consistent and timely basis. The goal of reporting is to be open, transparent and accountable to the public and to the families and communities impacted.

It is considered essential that with every death review, the report identifies what went wrong, what is the pattern, what is the trend and how to move to action to make corrections and improvements.

By mandate, a paediatric death review committee should produce an annual report that would report on all deaths, identify trends, and discuss (without providing identifying information) specific cases. Within this report, deaths could be broken down into relevant subsets, including children in care, Aboriginal children, and other groups that may be of interest, such as children with disabilities and children who identify as sexual or gender minorities.

It was also felt that data should not be limited to quantitative/systemic analysis as narrative data can also provide insights not possible in a systemic review and serves to honour the children involved.

> "In all of our actions, we need to make sure that the voice of the child is heard. And so whether we're talking about external reviews, whether we're talking about care and support for caregivers, for workers, et cetera, whether we're talking about the decisions that may happen after a child passes, we need to make sure that we keep the child's voice as a central consideration."
>
> Del Graff

Independent assurance

Currently, recommendations from inquiries and reviews are seen to lack accountability – there is no organization with the responsibility or authority to document, follow and track recommendations to ensure they are implemented or, if they are not implemented, to assess why.

Participants identified a need for a strong assurance mechanism whereby the implementation of recommendations arising from child death reviews could be reviewed and reported upon. It was further proposed by participants that this function should be independent from government and distinct from a paediatric death review committee.

It also was noted that recommendations may be external to Alberta Human Services and other agencies/Ministries should be included in the assurance mechanism.

A further mandate of this assurance role would be to resolve conflicting recommendations and prioritize recommendations for implementation.

Canadian Paediatric Society Recommendations

Experts and participants expressed support for the paper published by the Canadian Paediatric Society (CPS), "The Importance of Child and Youth Death Review (CDR)" (2013). This paper recommends that a comprehensive, structured and effective CDR program be initiated for every region in Canada, with systematic reporting and analysis of all child and youth deaths and the ability to evaluate the impact of case-specific recommendations. The CPS recommends that CDRs should have:

- **Broad representation** from the regional chief medical examiner, law enforcement, child protection services, local public health and the crown attorney, as well as a pediatricians, family physician and/or other health care provider. As required, on a case-by-case basis, other participants may include agencies with relevant involvement or knowledge (e.g., emergency medical services, school officials, child care providers, clergy or domestic violence representatives).
- **Structured processes** and a reporting protocol to identify emerging trends in and causes of serious injury or mortality, and pathways for implementing effective policies and programs to address prevention efforts.
- **Linkable databases**. For meaningful data collection, consolidation and dissemination, more systematic data collection, including surveillance and data-sharing, would generate and support national programs and policies, as needed.
- **An evaluative mechanism** would determine the effectiveness of CDR follow-up and recommendations.
- **Designated financial support from all levels of government**.

This paper can be found at http://www.cps.ca/documents/position/importance-of-child-and-youth-death-review.

Clarity of reviews

Many participants identified a concern that review processes are confusing and often misunderstood. Families and all others involved in a review would benefit from a clear understanding of the review process and intent.

Ensuring that families and communities affected by deaths are informed of the outcomes of investigations can be an important part of the healing process.

Ecological model

In the breakout sessions, some groups expressed concern that a purely medical-centred approach to child death reviews might be too narrowly focused and that an ecological, strengths-based model would be more appropriate.

> The ecological model places the child at the centre and identifies families and a strong network of services and programs as significant factors that support the child's development. A strengths-based approach looks for opportunities to complement and support existing strengths and capacities as opposed to focusing on and staying with the problem or concern. The problem and the person are distinct, but the problem is not minimised.

Terminology

Some participants took exception to the word 'investigation' as it implies that someone failed – a "review" is considered to be a less judgemental and more constructive term.

Participants also expressed concern that focusing on the "cause of death" is too limiting, it implies the immediate cause, rather than the longer-term effects that built the "context" of death.

Other children

While much of the Roundtable discussion focused on children in care and Aboriginal children, there are other distinct groups of children that should be included in a paediatric child death review system, including children with disabilities who represent significant portions of the population at large and of children in care, and children who identify as sexual or gender minorities.

Special Considerations for Children Receiving Child Intervention Services

Discussion question

What additional steps should be taken to improve investigations when it involves a child receiving child intervention services?

It was clearly established in the Roundtable that within an overall child death review system, the deaths of children receiving child intervention services are a subset of all deaths and there are specific dynamics and players involved that need to be considered.

Aboriginal community involvement

Experts and participants recognized that because the majority of deaths of children in care involve Aboriginal children, it is essential that there be a strong Aboriginal presence and inclusion of Aboriginal perspectives in the review process – at all levels.

- There needs to be an understanding of the community context as well as the child and family context.
- Aboriginal communities need to be strongly considered in the healing process.
- Delegated First Nation Agencies (DFNAs) and Band councils need to be involved where appropriate.

Specific concerns were raised in the Roundtable about the overall circumstances of Aboriginal children in care and it is hoped that systemic reviews would contribute to the improvement of this serious issue.

Reporting back to Aboriginal communities should include statistics on child deaths by treaty, for chiefs/bands to take action.

Child death reviews and reports need to support cultural perspectives to ensure effective investigations and clear communication.

Concerns were expressed that there was not sufficient Aboriginal representation at the Roundtable, particularly on the Expert Panel. The concept of an Aboriginal Expert Panel Roundtable was encouraged and would be welcomed. First Nations, Métis, and Inuit leaders should be encouraged to attend, as they play an important role in the health of their communities.

Broader range of direct involvement

The deaths of children in care involve a broader range of people than other child deaths. These include birth families, siblings and other children in the home, child intervention workers, foster families and kinship caregivers, communities and agencies. While the role and context of these people needs to be included in the review, it also is important to recognize that the tragedy of the death also affects these people and that healing must be supported.

Frontline worker engagement

It was felt that current investigations, which lack a clear prevention mandate, place extraordinary pressure on frontline child intervention workers, discourage honest communication and diminish the grieving and healing process.

It was felt that there was too much downward pressure on frontline workers. They do not have the supports that, for example, the police have, nor do they have the opportunity to step back for a while and take a break. Frontline child intervention workers must receive support at difficult times.

Contact with family

A thorough and compassionate plan for debriefing family and caregivers is necessary. This debriefing plan would include:

- A single point of contact who has full information, to prevent the family from being bombarded with information from multiple sources.
- Each agency clearly understanding their role.
- Protocols that ensure follow-up support to other children in the home, family, staff, etc. This process may happen informally now but may need to be formalized and standardized to help move everyone through tragedy.
- Understanding of a community's requirements at a time of investigation and death is essential.
- Investigations could, and should, consult other family members as they are often the best source of more considered fact and opinion.
- Follow-up with families, siblings, etc., even when files close. Staff try to do it now but this needs to be placed in regular practice. Staff should be encouraged to keep relationships. Parents don't forget about their children after they die. Government as guardians should not either.

Beyond the scope of a specific review, participants expressed concerns about the overall relationship with the family. Specifically, it was suggested that before an incident happens, contact with the family of a child in care should occur regularly as a matter of course, at least once a month, to ensure family continues to feel involved in the child's upbringing. Without this regular contact, distrust builds in the family so that when an incident occurs, sides have already been formed and blame is immediate. In addition, children in care should be consulted regularly, in accordance with their age and development to ensure their well-being and to plan for services and supports provided to them.

> "It is not the child's fault." Roundtable participant

Currently the child intervention system is highly stigmatized, which promotes secrecy, shame and embarrassment. This needs to change to promote more openness.

Reporting

Reporting on the deaths of children in care needs to identify what did work as much as it identifies what did not work in order to sustain the system and encourage the work of the frontline child intervention workers.

Information disclosure and the publication ban

Discussion Questions

What information should be available about:

- **The death of or serious injury to all children?**
- **The death of or serious injury to a child receiving child intervention services?**

What changes should Alberta consider with respect to the *Child, Youth and Family Enhancement Act*'s publication ban?

Current information insufficient

> "There has to be improvement in the practice of sharing factual information on a consistent basis. This is essential." Colleen Wilson

Participants and experts expressed a consistent concern regarding the lack of information currently shared, both specific and aggregate.

A fair, open, transparent and balanced reporting of the facts conducted in a timely fashion and consistently released to the public is required.

Aggregate data release

There is an overwhelming desire for the release of aggregate data. The data must be released on a consistent basis and be transparent, including: the number of children in care, the number of injuries, and the number of deaths.

The intent of releasing information should be to prevent other deaths/injuries, fix current issues, help others involved in the system, and educate the public.

> "The issues and the problems that are being talked about yesterday and today have very real consequences for real people, and I think that it's sometimes easy to forget that when we get all caught up in what we can or can't do." Commissioner Jill Clayton

Communication

There is a consensus to ensure that the release of information is determined by:

- Keeping in mind the best interests of the child and their family
- Keeping in mind the best interests of society as a whole – will the information prove to have an educational and/or preventative value?

> "In addition to a balance between privacy and the right to information, what needs to be added is the concern around privacy and the best interest of the child. That's not a secondary principle. It's not a derivative principle. It's a primary principle, and that's not an opinion, that's a statement of fact…. The best interest of the child, that precept is one that defines us as a caring society, and we can't compromise that." Gordon Phaneuf

A strong desire exists for:

- Clarity
- Transparency
- Accountability.

Publication ban

There is a desire to lessen the restrictions of the publication ban. Participants did not want a complete removal of the ban, nor did they want the ban to remain as restrictive as it currently is. Despite the complexity of the issues, there was unanimous agreement that the ban must be amended to allow for better holistic investigation and improvement of the deficiencies in the care system.

A consensus exists that, regardless of whether or not the child or youth's information is released, it is important to release details of the situation (with the intent of educating and preventing) and to release the information regarding the investigation (whether on a case-by-case basis or in aggregate data).

Although complicated, it was generally felt that the release of specific details regarding the child as a person should be left to the family to decide. The release of details pertaining to the death or injury, however, must be released to the public.

> "We need to balance the privacy of vulnerable people with our need as a society to learn and access community wisdom. We also may need to balance the components of dignity for these people. Dignity is about privacy, but it's also about voice, about legacy, about personhood." Dr. Eric Wasylenko

There was a strong opinion expressed from the media members of the expert panel that the burden of proof on the publication ban should be on the part of those who wish to enforce the ban rather than those who wish full disclosure.

> "Disclosure should be the rule; secrecy the exception. And in each case, when secrecy is believed to be necessary, it must be justified." John Archer

There was a strong opinion expressed by some of the medical community that the telling of the "story" should not require the identification of the individuals involved.

These last two perspectives remained unresolved in the Roundtable, but there was agreement that the current publication ban was too restrictive.

Reinforcing stigmatization

Some participants believed that it is important to refrain from focusing on the label "children in care" when releasing information to reduce the stigmatization associated with being in care.

Balancing interests

A balance must be established between the child or youth, their family, and society. Specifically, the release of information must take into account the best interests of all parties involved.

- This includes balancing the personal lives of the family members involved with the need to improve the system.

Identity

The youth representatives expressed a strong belief that all children should be treated equally regardless of whether or not they are in care. They did not want their identity diminished after death due to a publication ban.

> "I believe that the protection of vulnerable populations is incredibly important. But I also believe that individuals have the right to both anonymity and self-determination. It is imperative that we uphold privacy, but we also promote transparency. We need to ensure that the privacy policy is serving the purpose of protection for the right reasons. It is not necessary to be exploitive towards children and families of children who have died in care; but it is necessary to disclose failures of the system to protect children."
>
> Samantha

> "Is there a reason why the children in care are unidentified? Are they any less important than the children who are not?" Faven

The youth also recognized it is a personal choice to release information that a) reveals their identities, and b) reveals that they are in government care. For some, these revelations are unwanted; for others, they were seen as necessary.

Family-centred decision making

There was strong, but not universal, consensus that the decision to release information about child deaths should strongly consider the child's wishes and be made by the family.

While clear in principle, it was acknowledged that the process by which this would be determined would be complex:

- Family structures are complex and varied. A clear definition of "family" must be established – which may be determined on a case-by-case basis.
- Defining family should consider the child or youth's individual definition of their family.
- Complex family relationships may make it difficult to secure family consent.
- There may be processes in place with children in care to help them identify their wishes for disclosure. Use of consent forms – signed by the individual – to indicate their decision to have their name/information withheld or to give the right to make it public. Child intervention workers may also have a role to play in securing or providing consent.

Equality

All children should be treated equally, regardless of whether or not they are in care. Youth, in care or not, should have the rights to voice, memory and care.

There was debate as to whether releasing the individual's name and photo is essential, or whether their story (made anonymous) is sufficient. A large majority believed that the release of the information surrounding the situation was critical; however, they were undecided as to whether the child's name was required to fully inform the public about the situation.

Minimizing impact

We must be aware of how the release of information may impact others. Specifically, the release of information should not cause harm to:

- The child or youth involved
- The family, specifically their siblings
- The frontline workers, foster parents, kinship caregivers and/or group care staff

- The other children who may have resided within the same home.

Principles-based privacy legislation

A clear framework must be established with respect to the release of information and specific criteria to govern the release of information.

Defining the purposes of sharing information is essential. The purpose will lead to a clear set of principles by which decisions to make information public are made. Some suggested principles include:

- The best interests of the child
- The child's/family's right to determine the release of their information
- The community's interests
- The public's interests
- Accountability and transparency of the system
- Potential for prevention of similar tragedies.

There was interest in having an external third party serve as a mediator to negotiate the decision pertaining to the release of information.

> "We've heard very eloquently how each situation can be different. There are situations that lots of us would not be able to imagine. It's really important that we have a process that gets to honour the voices that we've all talked about that are important, that attends to the values of each individual and their families." Dr. Eric Wasylenko

As part of the legislation development process, a comprehensive national and international review of information release practices should be used to inform best practices, and a continued network of sharing of best practices should be implemented.

Appendix – Participant List

EXPERTS

OFFICE OF THE CHILD AND YOUTH ADVOCATE

Mr. Del Graff
Child and Youth Advocate

OFFICE OF THE CHIEF MEDICAL EXAMINER

Dr. Anny Sauvageau
Chief Medical Examiner

OFFICE OF THE CHIEF MEDICAL OFFICER OF HEALTH

Dr. Ada Bennett
Deputy Medical Officer of Health

OFFICE OF THE INFORMATION AND PRIVACY COMMISSIONER

Ms. Jill Clayton
Commissioner

OFFICE OF THE INFORMATION AND PRIVACY COMMISSIONER

Ms. Marilyn Mun
Assistant Privacy Commissioner

CHILD WELFARE LEAGUE OF CANADA

Mr. Gordon Phaneuf
Executive Director

COUNCIL FOR QUALITY ASSURANCE

Dr. Lionel Dibden
Director, Child Adolescent Protection Centre

CANADIAN PAEDIATRIC SOCIETY

Dr. Jennifer MacPherson
Clinical Assistant Professor - Dept. of Paediatrics
University of Calgary

ALBERTA PRESS COUNCIL

Ms. Colleen Wilson
Executive Director

JOHN DOSSETOR HEALTH ETHICS CENTRE, UNIVERSITY OF ALBERTA

Dr. Eric Wasylenko
Associate

ALBERTA LEGISLATURE PRESS GALLERY
Mr. John Archer
President

PARTICIPANTS

ALBERTA CENTRE FOR CHILD, FAMILY AND COMMUNITY RESEARCH
Ms. Robyn Blackadar
President and CEO

CHILD AND YOUTH DATA LAB
Dr. Xinjie Cui
Director

OFFICE OF THE CHILD AND YOUTH ADVOCATE
Ms. Terri Davies
Director, Legal Representation

OFFICE OF THE CHILD AND YOUTH ADVOCATE
Ms. Jackie Stewart
Sr. Manager

FAMILY DEATH REVIEW COMMITTEE
Dr. Allen Benson
Chair

FATALITY INQUIRY BOARD
Mr. Don McDermid
Chair

CHAIR LOCAL 006, AUPE
Ms. Melanie Metcalf
Chair

FAMILY DEATH REVIEW COMMITTEE
Ms. Robyn Scott
Regional Manager

ALBERTA ASSOCIATION OF SERVICES TO CHILDREN AND FAMILIES
Mr. Jim Pritchard
President

ALBERTA ASSOCIATION OF SERVICES TO CHILDREN AND FAMILIES
Ms. Rhonda Barraclough
CEO

ALBERTA FOSTER PARENT ASSOCIATION
Ms. Katherine Jones
Executive Director

CHILD AND YOUTH CARE ASSOCIATION
Ms. Carmen Roberts-Kowalchuk
President

CANADIAN ACCREDITATION COUNCIL
Mr. Calvin Wood
CEO

COUNCIL ON ACCREDITATION
Mr. Richard Klarbeg
President and CEO

COMMISSION ON ACCREDITATION OF REHABILITATION FACILITIES
Ms. June Korbisser

ALBERTA ASSOCIATION FOR COMMUNITY LIVING
Mr. Bruce Uditsky
CEO

TREATY 6
Ms. Rose Lameman
Child and Family Service Coordinator

TREATY 6
Mr. Wally Sinclair
Senior Advisor

TREATY 7
Ms. Bobbi Herrera
Child and Family Service Coordinator

TREATY 7
Ms. Connie Bigplume
IGR Coordinator

TREATY 8
Ms. Arlene Thunder
Child and Family Service Coordinator

MÉTIS SETTLEMENTS GENERAL COUNCIL
Ms. Debbie Gauchier
Representative

MÉTIS NATION OF ALBERTA
Ms. Kelsey Bradburn
Metis Child and Family Coordinator

MÉTIS NATION OF ALBERTA
Ms. Sarah Parker
Intergovernmental Relations

MÉTIS CHILD & FAMILY SERVICES AUTHORITY MANITOBA
Ms. Billie Schibler
Chief Executive Director

ALBERTA COLLEGE OF SOCIAL WORKERS
Ms. Lynn King
Executive Director and Registrar

ALBERTA COLLEGE OF SOCIAL WORKERS
Ms. Lori Sigurdson
Manager, Professional Affairs

ZEBRA CHILD PROTECTION CENTRE-EDMONTON
Mr. Bob Hassel
CEO

SHELDON KENNEDY CHILD ADVOCACY CENTRE
Ms. Bonnie Johnston
CEO

ALBERTA CHILDREN'S HOSPITAL
Dr. Ian Mitchell
Professor, Department of Paediatrics

MOUNT ROYAL UNIVERSITY
Dr. Peter Choate
Assistant Professor of Social Work

MCGILL UNIVERSITY
Dr. Nico Trocme
Professor of Social Work

UNIVERSITY OF CALGARY
Dr. Jackie Sieppert
Dean - Calgary Faculty of Social Work

UNIVERSITY OF CALGARY
Dr. Jean Lafrance
Associate Professor, Faculty of Social Work

UNIVERSITY OF ALBERTA
Dr. Wayne MacDonald
Program Manager, Government Studies

UNIVERSITY OF ALBERTA

Dr. Kristopher Wells
Director, Institute for Sexual Minority Studies and Services

UNIVERSITY OF NEW BRUNSWICK

Dr. Kathleen Kufeldt
Adjunct Professor

CHILD AND FAMILY SERVICES COUNCIL FOR QUALITY ASSURANCE

Ms. Claudia Ponce
Executive Director

CHILD AND FAMILY SERVICES COUNCIL FOR QUALITY ASSURANCE

Dr. Eva Cardinal
Elder and CFS-CQA Member

Ms. Loretta Bellerose
Elder Liaison

CHILD AND FAMILY SERVICES COUNCIL FOR QUALITY ASSURANCE

Former Staff Sergeant Kent Henderson
Edmonton Police Service

CHILD AND FAMILY SERVICES COUNCIL FOR QUALITY ASSURANCE

Dr. Gayla Rogers
Professor and Provost Fellow University of Calgary

CHILD AND FAMILY SERVICES COUNCIL FOR QUALITY ASSURANCE

Judge Marlene L. Graham PCJ
Provincial Court of Alberta

CANADIAN ALLIANCE TO END HOMELESSNESS

Mr. Tim Richter
President and CEO

EDMONTON POLICE SERVICE

Sergeant Gary Willits

CALGARY POLICE SERVICE

Superintendent Sat Parhar

CALGARY POLICE SERVICE

A/Staff Sergeant Jas Kainth

ROYAL CANADIAN MOUNTED POLICE

Mr. George Stephenson

KTC CHILD AND FAMILY SERVICES
Ms. Erica Jagodzinsky
Executive Director

LESSER SLAVE LAKE INDIAN REGION COUNCIL
Ms. Debbie LaRiviere
Director

BLOOD TRIBE PROTECTIVE SERVICES
Ms. Shannon Soop
Director

KASOHKOWEW CHILD WELLNESS SOCIETY
Ms. Carolyn Peacock
Director

INVITED GUEST
Phil Goodman
Advisor

PREMIER OF ALBERTA
Premier Alison Redford, QC
MLA for Calgary-Elbow

MEMBER OF ALBERTA LEGISLATIVE ASSEMBLY
Kerry Towle, MLA Innisfail-Sylvan Lake
Wildrose Official Opposition Critic for Human Services and Seniors

MEMBER OF ALBERTA LEGISLATIVE ASSEMBLY
Rachel Notley, MLA Edmonton-Strathcona
Alberta New Democratic Party

MEMBER OF ALBERTA LEGISLATIVE ASSEMBLY
Dr. David Swann
Alberta Liberal Party

MEMBER OF ALBERTA LEGISLATIVE ASSEMBLY
Dr. Raj Sherman, MLA Edmonton-Meadowlark
Alberta Liberal Party

HUMAN SERVICES
Honourable Manmeet Bhullar
Minister

HUMAN SERVICES
Honourable Sandra Jansen
Associate Minister of Family and Community Safety

HUMAN SERVICES

Honourable Naresh Bhardwaj
Associate Minister of Services for Persons with Disabilities

HUMAN SERVICES

Mr. David Morhart
Deputy Minister

HUMAN SERVICES

Ms. Lana Lougheed
Chief Strategy Officer

HUMAN SERVICES

Ms. Lori Cooper
Chief Delivery Officer

HUMAN SERVICES

Ms. Susan Wismer
Chief Corporate Counsel

HUMAN SERVICES

Mr. Mark Hattori
ADM, Child and Family Services Division

HUMAN SERVICES

Mr. Bryce Stewart
ADM, Policy Coordination and Community Engagement

HUMAN SERVICES

Ms. Karen Ferguson
ADM, Early Childhood and Community Supports

HUMAN SERVICES

Ms. Susan Taylor
ADM, Family Violence Prevention and Homelessness Supports Division

HUMAN SERVICES

Dr. David Rideout
Regional Director, Central Alberta Child and Family Services

HUMAN SERVICES

Mr. Jon Reeves
Regional Director, Calgary and Area Family Services

HUMAN SERVICES

Mr. Rick Flette
Regional Director, Northwest Child and Family Services

HUMAN SERVICES

Mr. David Wilson
Regional Manager, Edmonton and Area Child and Family Services

HUMAN SERVICES

Mr. Elden Block
Director, *Child, Youth and Family Enhancement Act*

HUMAN SERVICES

Mr. Fred Anderson
Director, Child and Family Services Division

HUMAN SERVICES

Ms. Joni Brodziak
Director, Child and Family Services Division

HUMAN SERVICES

Ms. Antonella Soria
Assistant Director, Legislative Services

HUMAN SERVICES

Ms. Leann Wagner
A/Executive Director, Strategic Policy Initiatives

HUMAN SERVICES

Ms. Paulette Rodziewicz
Executive Director, Family Violence Prevention and Homelessness Supports Division

HUMAN SERVICES

Ms. Yvonne McFadzen
Executive Director, Data Development & Evaluation

ALBERTA HEALTH

Honourable Fred Horne
Minister

ALBERTA HEALTH

Dr. Michael Trew
Chief Mental Health Officer

ALBERTA HEALTH

Silvia Vajushi
Executive Director Community Health

ALBERTA JUSTICE AND SOLICITOR GENERAL

Mr. Tim Grant
Deputy Minister of Justice and Deputy Solicitor General

ALBERTA JUSTICE AND SOLICITOR GENERAL

Ms. Erin Skinner
Barrister and Solicitor

ALBERTA INNOVATION AND ADVANCED EDUCATION

Steve MacDonald
Deputy Minister

SERVICE ALBERTA

Ms. Cathryn Landreth
ADM, Open Government

SERVICE ALBERTA

Ms. Cheryl Naundorf
Director, Policy and Governance

YOUTH

Ms. Monique
Ms. Faven
Ms. Samantha

GOVERNMENT OF SASKATCHEWAN

Ms. Natalie Huber
Executive Director, Program and Service Design
Ministry of Social Services