19-YEAR-OLD ERNIE

An Investigative Review

ocya
OFFICE OF
THE CHILD AND
YOUTH ADVOCATE
ALBERTA

JANUARY 2017

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THE CHILD AND
YOUTH ADVOCATE
ALBERTA

Under my authority and duty as identified in the *Child and Youth Advocate Act* (*CYAA*), I am providing the following Investigative Review regarding the death of a 19-year-old young man who had received Child Intervention Services within two years of his passing. Consistent with Section 15 of the *CYAA*, the purpose of this report is to learn from this sad circumstance and recommend ways of improving Alberta's child intervention system.

This is a public report that contains detailed information about children and families. Although my office has taken great care to protect the privacy of the youth and his family, I cannot guarantee that interested parties will not be able to identify them. Accordingly, I would request that readers and interested parties, including the media, respect this privacy and not focus on identifying the individuals and locations involved in this matter.

In accordance with the *CYAA*, the names used in this report are pseudonyms (false names). Finding an appropriate pseudonym is difficult because a young person's name is part of who they are. However, it is a requirement that my office takes seriously and respectfully. In this situation, his foster mother who cared for him for most of his life, has chosen the name, Ernie.

Ernie was a young man of First Nation heritage who became involved with Child Intervention Services shortly after birth. He had significant disabilities and was totally dependent for his care. When he reached adulthood, support services were transitioned from Child Intervention Services to the Persons with Developmental Disabilities program. Ernie had no involvement with Family Support for Children with Disabilities because of his involvement with Child Intervention Services.

This review highlights the importance of seamless transitions in service delivery between child welfare and adult disability systems, continuity of relationships and incorporating the voice of a young person in decision-making. It is my sincere hope that the recommendations arising from this review will be acted upon to improve services for Alberta's children and youth.

[Original signed by Del Graff]

Del Graff
Child and Youth Advocate

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EXECUTIVE SUMMARY

Alberta's Child and Youth Advocate ("the Advocate") is an independent officer reporting directly to the Legislature of Alberta, deriving his authority from the *Child and Youth Advocate Act* (*CYAA*). The Advocate has the authority to conduct investigations into systemic issues related to the death of a young person who had received Child Intervention Services within two years of their passing.

Ernie (not his real name)[1] was a young man of First Nation heritage who was severely disabled and died from an obstructed bowel. Prior to his passing, Ernie was moved from his long term foster home to a group home for adults with disabilities. Although the Terms of Reference for this review did not identify cultural connections as a potential systemic issue, the Advocate recognizes that Ernie would have benefited by being more connected to his cultural heritage and traditions.

The information gathered through this Investigative Review revealed two issues related to children and families involved with Child Intervention Services.

1. Easing transitions from child intervention to adult disability services

Navigating service delivery systems can be challenging. When child intervention was involved with Ernie, he had a single caseworker who was responsible for making decisions. When Ernie transitioned to adult disability services, he had multiple workers who had distinct roles, responsibilities and decision-making powers. There are structural differences between Child Intervention Services and the adult disability service system (that includes Assured Income for the Severely Handicapped and Persons with Developmental Disabilities) that can pose challenges and create confusion during the transition process.

2. Voice of a young person

The United Nations Convention on the Rights of the Child (UNCRC) states that a young person's opinion must be considered in decisions that affect them. For disabled youth who are unable to voice their thoughts and opinions, it is imperative to include those closest to them who know them well and put their best interests forward. In Ernie's circumstance, this was his foster mother, Maggie. She was critical to ensuring that Ernie's thoughts and feelings were known and considered.

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[1] All names throughout this report are pseudonyms to ensure the privacy of the young person and family.

To address these issues and to help improve the effectiveness of Alberta's services to children, the Advocate makes **two recommendations**:

Recommendation 1

The Ministry of Human Services should develop processes to ensure that consistent services and supports are in place when young people transition from Child Intervention Services to the adult disability system.

Recommendation 2

The Ministry of Human Services should ensure that the voice of the young person is included in case planning. If a young person is unable to voice an opinion, caseworkers need to access all avenues to ensure that the young person's rights, interests and viewpoints are considered.

INTRODUCTION

The Office of the Child and Youth Advocate

Alberta's Office of the Child and Youth Advocate ("the Advocate") is an independent officer reporting directly to the Legislature of Alberta. The Advocate derives his authority from the *Child and Youth Advocate Act* (*CYAA*).[2]

The role of the Advocate is to represent the rights, interests and viewpoints of children receiving services through the *Child, Youth and Family Enhancement Act*[3] (the *Enhancement Act*), the *Protection of Sexually Exploited Children Act*[4] (*PSECA*), or from the youth justice system.

Investigative Reviews

Section 9(2)(d) of the *CYAA* provides the Advocate with the authority to conduct Investigative Reviews. The Advocate may investigate systemic issues arising from the death of a child who was receiving child intervention services within two years of their death if, in the opinion of the Advocate, the investigation is warranted or in the public interest.

Upon completion of an investigation under this section of the *CYAA*, the Advocate releases a public Investigative Review report. The purpose is to make findings regarding the services that were provided to the young person and make recommendations that may help prevent similar incidents from occurring in the future.

An Investigative Review does not assign legal responsibilities, nor does it replace other processes that may occur, such as investigations or prosecutions under the *Criminal Code of Canada*. The intent of an Investigative Review is not to find fault with specific individuals, but to identify key issues along with meaningful recommendations, which are:

- prepared in such a way that they address systemic issue(s); and,
- specific enough that progress made on recommendations can be evaluated; yet,
- not so prescriptive to direct the practice of Alberta government ministries.

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[2] *Child and Youth Advocate Act*, S.A. 2011, c. C-11.5.

[3] *Child, Youth and Family Enhancement Act*, RSA 2000, c. C-12.

[4] *Protection of Sexually Exploited Children Act*, RSA 2000, c. P-30.3.

It is expected that ministries will take careful consideration of the recommendations, and plan and manage their implementation along with existing service responsibilities. The Advocate provides an external review and advocates for system improvements that will help enhance the overall safety and well-being of children who are receiving designated services. Fundamentally, an Investigative Review is about learning lessons, rather than assigning blame.

ABOUT THIS REVIEW

The Advocate received information that 19-year-old Ernie passed away from a bowel obstruction. He had involvement with Child Intervention Services within two years of his death.

Ernie's child intervention records were thoroughly reviewed by the investigative staff from the Office of the Child and Youth Advocate (OCYA). The Advocate determined that an Investigative Review was warranted and the Ministry of Human Services was subsequently notified.

Terms of Reference for the review were established and are provided in Appendix 1. A team gathered information and conducted an analysis of Ernie's circumstances through a review of relevant documentation, interviews and research. The team also met with Ernie's long-term foster mother, Maggie.

A preliminary report was completed and presented to a committee of subject matter experts who provided advice related to findings and recommendations. The list of committee members is provided in Appendix 2. Committee membership included an Elder and experts and academics in the field of disability services.

About Ernie and his Family

Ernie was a 19-year-old young man of First Nation descent. He was the youngest of 10 children. He sustained a brain injury when he was an infant and was severely disabled.

He had a mischievous sense of humor and enjoyed listening to music, singing and drumming. One of Ernie's favorite daily activities was listening to his radio and dancing, which was an activity he enjoyed with Maggie and with his other caregivers. He loved the water and being outdoors and Maggie often used a bubble bath to sooth him at the end of the day. He had a special doll that he would always hug and kiss goodnight. In his last year, Ernie was recognized as student of the month at his school.

Ernie was brought into government care when he was approximately two months old and had minimal involvement with his birth family. When Ernie was six years old, his father died by suicide. Seven years later, his mother passed away from an addictions-related illness.

Ernie lived with Maggie from infancy until he was 17 years old. She attempted to keep Ernie connected to his family by sending photographs and supporting visits between Ernie and his older brother. Maggie was a single parent who was a caregiver to many. She looked after her adult daughter, who had a significant brain injury, and her elderly mother. She fostered other special needs children and adopted one of her foster daughters. Ernie surpassed developmental expectations in Maggie's care. Maggie's mother taught him to walk with the aid of a walker and he learned to use simple verbal cues to express his needs. Many of the professionals who worked with Ernie viewed Maggie as his mother.

Ernie did not qualify for supports from the Family Support for Children with Disabilities (FSCD) program because he was receiving services from child intervention.[5] When he turned 18 years old, Ernie was moved to a group home for adults with disabilities. Maggie continued to maintain a relationship with Ernie after his move. He came home for visits and holidays and Maggie advocated to ensure his needs were met. He lived in the group home for about 18 months before he passed away.

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[5] Both programs fall under the umbrella of the Ministry of Human Services and accessing both at the same time is contrary to policy.

HISTORY OF INVOLVEMENT WITH CHILD INTERVENTION SERVICES

Ernie was prenatally exposed to street drugs and prescription medications. When he was about one month old, he suffered a severe brain injury and was admitted to hospital. He was placed on a ventilator for over a week and required a gastrostomy tube (G-tube).[6] Ernie required constant supervision because there were concerns that he would stop breathing. His parents were unable to provide for his medical needs.

Ernie was apprehended[7] while in the hospital. Maggie, Ernie's future foster parent, first met him while her adult daughter was receiving treatment in the same hospital. Maggie saw that Ernie had few visitors. She was drawn to him and asked for permission to spend time with him. She had received training to care for her daughter and believed that she could use this knowledge and training to help Ernie. She became a foster parent so that she could care for him.

When Ernie was four months old, he was discharged from hospital and placed with Maggie. Approximately four months later, a Permanent Guardianship Order[8] was granted and Ernie lived with Maggie until he was 17 years old.

Ernie's primary diagnosis was Quadriparetic Cerebral Palsy.[9] He also had a heart condition, visual impairments and a slow progressive loss of kidney function.

When Ernie was about nine months old, the family moved to a city so that Ernie would have access to a specialized medical team. He was enrolled in a specialized school and surpassed expectations for his development. Ernie learned to say some two and three word phrases to ask for what he wanted and learned to use a standing frame. From a young age, Ernie banged his head and hit himself in the face. Maggie learned that these cues were how he communicated his discomfort or need for something. The behaviours were better managed as she became adept at understanding him.

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6 A tube inserted through the abdomen that delivers nutrition directly to the stomach.

7 The Director has reasonable and probable grounds to believe that the child is in need of intervention according to the *Child, Youth and Family Enhancement Act* and removes the child from the care of the guardian.

8 An Order in which the court awards guardianship of the child to the Director on a permanent basis. The child is in the care of the Director and remains in an approved placement.

9 A subset of spastic cerebral palsy that affects both arms and legs.

When Ernie was seven years old, the family returned to Maggie's home community. They moved a few more times, but Ernie adjusted to the change as long as Maggie was there. He was comfortable at home and appeared at ease with those he was familiar with and trusted. Maggie found it difficult to access respite because Ernie became inconsolable when he realized she was not there. Eventually, a family was found who devoted time to build a relationship with him and they became his regular respite providers.

Elementary school staff were challenged to support Ernie. This changed when he entered high school because the educational staff appeared more comfortable with Ernie and he in turn, became comfortable with them.

During adolescence, Ernie began to display aggressive behaviours towards Maggie and others. The service team believed that he would require ongoing intensive care beyond what Maggie could provide because of his significant needs, size and medical issues. His motor skills were deteriorating and he would eventually be confined to a wheelchair and require lifts. When Ernie was 16 years old, he was referred to the Persons with Developmental Disabilities (PDD)[10] program. Planning started toward a specialized group care placement where he could remain into adulthood. Maggie and child intervention staff agreed that the transition needed to be slow because Ernie did not cope well with change, as seen by an increase in his frustration through banging his head and hitting himself.

Ernie's transition to group care occurred over the three months prior to his 18th birthday. There were immediate concerns about medication management and his diet in the group home. Although Ernie had a G-tube, he primarily ate his food. When he was stressed or ill, Ernie refused to eat and the G-tube was used. During the transition, Ernie's self-injurious behaviours increased, leaving significant bruises. There were quality of care concerns reported that included three incidents of missed medication and lack of staff training in his medical care. The concerns were reported to a child intervention unit specializing in the assessment/investigation of placement resources. The matter was closed at intake with the recommendation that Ernie's caseworker follow up with the facility to ensure that the issues were resolved.

Maggie had regular contact with Ernie. She voiced her concerns to the group home staff and the caseworker about his increased injuries and the care he received. She also attended his medical appointments and was involved in the placement investigation by giving her insight into Ernie's situation.

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[10] PDD funds programs and services to help adults with developmental disabilities be a part of their community and live as independently as possible. In 2015, PDD joined Family Support for Children with Disabilities under one umbrella to form Disability Services.

On Ernie's 18th birthday, a Child Intervention Services manager signed a Support and Financial Assistance Agreement (SFAA)[11] on Ernie's behalf, so they could continue to assess his care in the group home. It was agreed that Maggie and her adult daughter would apply for joint guardianship and report any concerns to Child Intervention Services.

Ernie continued to struggle. He was accustomed to Maggie's care. He was not in school because there were difficulties locating a program that could meet his needs. Additional medication was prescribed to help calm his anxiety. Ernie's physician suggested that Maggie could care for Ernie with additional support and that he should be returned to her care, but he remained in the group home. Four months after moving, a school program was secured. Ernie started slowly, attending a couple of hours a day which gradually increased to full days.

There was ongoing disagreement between Maggie, who was seen as his mother, and the group home staff on how to best care for Ernie. He continued to hurt himself; his diet was a concern and he lost weight. It was suggested that Maggie not be as involved in Ernie's care because he was so attached to her. Facility staff felt Ernie would settle better if Maggie visited less.

Maggie indicated that she was no longer able to become Ernie's guardian. She continued to administer Ernie's Assured Income for the Severely Handicapped (AISH)[12] funds on his behalf. Four months after his 18th birthday, Child Intervention Services' involvement ended after it was confirmed that the group home had implemented strategies to address the concerns regarding Ernie's care. An application to the Office of the Public Guardian and Trustee (OPGT)[13] was made; however, a Public Guardian Representative was not yet appointed.

AISH and PDD were in place. Ernie remained in the group home and Maggie saw him regularly. Five months after child intervention involvement ended, a Public Guardian Representative was appointed. Two months later, a new PDD coordinator was assigned.

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[11] An agreement with a youth to continue to receive supports and financial assistance from the ages of 18 to 24.

[12] AISH provides financial and health-related assistance to eligible adults with a disability.

[13] The Office of the Public Guardian (OPG) and the Office of the Public Trustee (OPT) merged on April 1, 2014, to form the Office of the Public Guardian and Trustee (OPGT). The OPGT provides decision-making mechanisms for individuals who are unable to make personal, non-financial decisions for themselves.

Ernie after Child Intervention Services Involvement Ended

Ernie received one-on-one attention from his group home staff. He attended school and had regular outings to the park, a shopping mall and to the movies. He visited with Maggie both at his group home and at her home. Although, Maggie continued to have concerns about Ernie's nutritional needs, he regained some of the weight he had initially lost when he left her home.

After his 19th birthday, Ernie was taken to the hospital three times because he was not feeling well. He was treated for constipation. Medical professionals noted that he was at risk for reoccurrence. During the last admission, his breathing became rapid and he was moved to the Intensive Care Unit (ICU). He had exploratory surgery which revealed necrosis[14] of both the small and large bowel. The surgeon ended the procedure and Ernie was returned to the ICU for palliative care.

The next day Ernie passed away with Maggie by his side.

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[14] The death of most or all of the cells in an organ or tissue due to disease, injury, or failure of the blood supply.

DISCUSSION AND RECOMMENDATIONS

The Terms of Reference identified **two systemic issues:** the monitoring of placements for youth who transition to adult services; and, the voice of disabled young people in planning their future. Through the review process these have been incorporated into the following:

1. **Easing transitions from child intervention to adult disability services**
   Monitoring of placements for disabled youth who transition to adult services
2. **Voice of a young person**
   The United Nations Convention on the Rights of the Child (UNCRC) states that a young person's opinion must be considered in decisions that affect them.

Easing Transitions from Child to Adult Disability Services

Navigating service delivery systems can be challenging. The availability and sharing of information is key to making the transitions between child intervention and adult disability systems successful. A measure of success is the coaching and support for family members to enable them to make the best possible decision for their loved one.

Disability services encompasses AISH, PDD, the OPGT and agencies that provide the frontline services. In relation to child intervention and adult disability services, there are key differences that include:

- How relationships are developed
- Differences in expectations related to client contact
- Differences in practice and how services are accessed, organized and managed
- How placement concerns are reported

When child intervention was involved with Ernie, his caseworker was his sole decision-maker. His caseworker knew him, was aware of his needs and visited Maggie's home on a regular basis. Maggie was given supports to care for Ernie and she knew that his caseworker was her one point of contact for anything related to Ernie's care.

When Ernie transitioned to adult disability services, he had multiple workers who had distinct roles, responsibilities and decision-making powers. AISH provided financial support for his basic needs. He had group home staff who managed his day-to-day care and a public guardian who made decisions on his behalf. A PDD coordinator assessed and established the services and a PDD contract specialist ensured that accreditation standards were met.[15]

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[15] Certification for agencies occurs every three years.

Once services are established, PDD coordinators meet to review client needs and progress on an annual basis. PDD caseloads can reach 150 clients[16] and it is difficult for workers to build relationships with their clients. Young people and their families, like Ernie and Maggie, coming out of a system where roles and decision-making authority are distinctly defined, can have difficulties with adult service delivery. This might result in their needs not being fully explored and supported, which could result in a reluctance to engage in the transition process.[17]

In the United Kingdom, transition planning and review occurs at intervals and involves all of the practitioners providing support to the young person and their family.[18] A formal sharing of duties acknowledges that no one person can take on all of the responsibility. In this circle of care, it is imperative that roles, responsibilities and decision-making authority are clearly identified so that families know who to contact to address concerns.

During the first year that Ernie was in the group home, there were a number of government and agency staff involved. Maggie was overwhelmed by the number of people and was confused about who made what decisions. Research indicates that clear communication about roles and responsibilities, processes, funding and timelines can help to minimize miscommunication and frustration when young people are transitioning to adult services.[19]

Structures and supports can significantly diminish when a young person begins to access the adult disability system. An example is how placements are monitored and concerns are addressed. Child Intervention Services requires that group home staff submit Critical Incident reports when there are issues like missed medication and injuries. An investigation can be initiated requiring the agency to address the concerns and report their progress. Outcomes can range from minor fixes to closure of the home.

In the adult system, these concerns are left primarily to the agency to address. There is limited external oversight on progress made to alleviate the concerns. Families or guardians can raise their concerns with the agency and bring them to the attention of PDD for resolution or ultimately remove their loved one and find another placement.

In 2013, the Government of Alberta took steps to transform the PDD program. As part of this process, indicators for success were developed. Families would receive information easily, have relationships with PDD staff and have confidence in the quality of service, while PDD staff would have clear, meaningful roles allowing them to be involved with individuals and families.[20] Implementation is ongoing.

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[16] Information obtained through the Investigative Review process.

[17] National Institute for Health and Care Excellence, 2016.

[18] National Institute for Health and Care Excellence, 2016.

[19] National Institute for Health and Care Excellence, 2016.

[20] Government of Alberta, 2014.

In September 2015, the Ministry of Human Services began an engagement process to examine the standards of safety for individuals receiving supports through PDD. Feedback from stakeholders consistently indicated a need to develop a relational aspect to PDD service delivery along with open communication.

The final report was released by the Government of Alberta in October 2016 with 11 recommendations under 5 broad areas:

- Persons with Developmental Disabilities Program
- Staff Training and Education
- Accreditation Standards for Agencies
- Safety Codes Act Interpretation
- Other Ideas to Support Safety

Of particular relevance to Ernie's circumstances are recommendations that improve certification and education of staff, increased supports for individual and family advocacy and meaningful communication between PDD and the disability community. The Advocate supports all of the recommendations contained within the report which is available at: **http://www.humanservices.alberta.ca/documents/PDD-standards-consultation-recommendations-report.pdf**.

Transitioning from a child welfare system to an adult-serving disability system is a significant adjustment for young people. While funding sources and program structures change, their needs for stability, consistency and attachment remain consistent. The goal should be to shape systems to fit individuals' needs.

Recommendation 1

The Ministry of Human Services should develop processes to ensure that consistent services and supports are in place when young people transition from Child Intervention Services to the adult disability system.

Voice of a Young Person

The United Nations Convention on the Rights of the Child (UNCRC) states that a young person has a right to an opinion, to be listened to and receive and express information in a variety of ways.[21] This right applies equally to young people with disabilities and is included in the United Nations Convention on the Rights of Persons

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[21] United Nations, 1989.

with Disabilities (UNCRPD).[22] Participation in decision-making only happens for a small number of disabled youth; those who are the most able to communicate.[23] Adults need skills, training and knowledge to engage those young people who are less able to communicate so that they can be involved in decision-making. This must include listening to those close to the young person who have their best interests in mind. Literature refers to this inclusion as "ethics of care."

Ethics of care are founded in relationships that consist of at least two people—the "one-caring" (in this instance, Maggie) and the "cared-for" (Ernie), and doing what is morally right for a person. The one-caring considers the viewpoints and needs assessment of the cared-for, and acts in a way that promotes their well-being.[24] Two criteria must be met for the ethics of care to have force:

1. The relationship with the other person must exist (or have potential to exist); and,
2. This relationship must have the potential to grow into a mutually caring one.[25]

Maggie cared for Ernie almost his entire life. Those who knew them, knew that Maggie was his mother and she cared for him like he was her own child. Ernie flourished beyond expectations in her care. When he was 16 years old, planning for adult disability services was initiated. It was felt that Maggie would have difficulty caring for Ernie into adulthood because of his size, increasing needs and her age. Ernie needed a slow and deliberate transition to a group home. Although he could not speak, Ernie tried to let people know that he was not happy with the change. The uncertainty and disruption of his routine and surroundings was stressful and he expressed his distress through banging his head and refusing to eat or drink.

Maggie was able to hear Ernie despite his inability to verbalize his concerns. In 2002, Ruddick wrote, "…to grow, flourish, survive and endure illness, disability and frailty, each individual requires a caring relationship with significant others who hold that individual's well-being as a primary responsibility and a primary goal." Maggie's primary goal was Ernie's well-being and she made his interests her own. In order to meet Ernie's needs, service providers had to carefully consider what Maggie was saying.

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[22] United Nations, 2006.

[23] Franklin & Sloper, 2006.

[24] Ethics of Care, 2016.

[25] Ethics of Care, 2016.

Engaging disabled youth in decision-making happens in part, through the acknowledgement of the continuity of their relationships. It begins with identifying significant relationships and then supporting them. If we do not include ethics of care in service delivery for disabled young people, we risk not hearing their voice and losing their involvement in decision-making. This exclusion may result in their abilities being overlooked and their capacity being underestimated; which may lead to increased adult control and further disempowerment.[26]

Recommendation 2

The Ministry of Human Services should ensure that the voice of the young person is included in case planning. If a young person is unable to voice an opinion, caseworkers need to access all avenues to ensure that the young person's rights, interests and viewpoints are considered.

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[26] Mitchell, Franklin, Greco & Bell, 2009.

CLOSING REMARKS FROM THE ADVOCATE

Ernie was young man with significant disabilities who enjoyed life. He loved to dance and listen to music and would laugh when he teased his caregivers. Ernie loved being outdoors in his community. He had a profound impact on the people around him, and our condolences are extended to those who knew and loved him.

I want to thank all those who spoke with us and shared their insight into Ernie's life and experiences. Many young people in the child welfare system do not experience the stability that Ernie had in Maggie's care. He was lucky to have her and we know that she feels fortunate to have had him in her life.

This Investigative Review identified a number of challenges between the child welfare system and the adult disability system. Better transitions are needed for young people when they reach adulthood. Furthermore, young people must have a voice in decisions that affect them. Those who are particularly vulnerable because of a disability, cannot be treated as though they have nothing to tell us. It is up to us to find the ways to listen.

This review must result in meaningful change for young Albertans with disabilities. Government needs to take notice and act on my recommendations so that young people like Ernie, have a more positive outcome.

[Original signed by Del Graff]

Del Graff
Child and Youth Advocate

APPENDICES

APPENDIX 1: TERMS OF REFERENCE

Authority

Alberta's Child and Youth Advocate ("the Advocate") is an independent officer reporting directly to the Legislature of Alberta. The Advocate derives his authority from the *Child and Youth Advocate Act* (*CYAA*). The role of the Advocate is to represent the rights, interests and viewpoints of children receiving services through the *Child, Youth and Family Enhancement Act*, the *Protection of Sexually Exploited Children Act* or from the youth justice system.

Section 9(2)(d) of the *CYAA* provides the Advocate with the authority to conduct Investigative Reviews. The Advocate may investigate systemic issues arising from the death of a young person who received child intervention services within two years of their death if, in the opinion of the Advocate, the investigation is warranted or in the public interest.

Incident Description

The Advocate learned that 19-year-old Ernie passed away after surgery. Child Intervention Services had ended their involvement within two years of his death. At the time of his passing, Ernie was receiving supports through the Assured Income for the Severely Handicapped and Persons with Developmental Disabilities. He was living in a group home for adults with disabilities.

The decision to conduct an investigation was made by Del Graff, Child and Youth Advocate.

Objectives of the Investigative Review

To review and examine service and supports provided to Ernie and his family specifically related to:

- The voice of disabled young people in planning their future
- Monitoring of placements for disabled youth who transition to adult services

Scope/Limitations

An Investigative Review does not assign legal responsibilities, nor does it replace other processes that may occur, such as investigations or prosecutions under the *Criminal Code of Canada*. The intent of an Investigative Review is not to find fault with specific individuals, but to identify and advocate for system improvements that will enhance the overall safety and well-being of children who are receiving designated services.

Methodology

The investigative process will include:

- Examination of critical issues
- Review of documentation and reports
- Review of Enhancement Policy and casework practice
- Personal interviews
- Consultation with experts as required
- Other factors that may arise for consideration during the investigative process

Investigative Review Committee

The membership of the committee will be determined by the OCYA Director of Investigations and the Advocate. The purpose of convening this committee is to review the preliminary Investigative Review report and to provide advice regarding findings and recommendations.

Chair: Del Graff, Child and Youth Advocate

Members: To be determined but may include:

- An expert in child and youth disabilities
- A specialist in the area of child intervention best practices
- An expert in specialized placements

Reporting Requirement

The Child and Youth Advocate will release a report when the Investigative Review is complete.

APPENDIX 2: COMMITTEE MEMBERSHIP

Del Graff, MSW, RSW (Committee Chair)

Mr. Graff is the Child and Youth Advocate for the Province of Alberta. He has worked in a variety of social work, supervisory and management capacities in communities in British Columbia and Alberta. He brings experience in residential care, family support, child welfare, youth and family services, community development, addictions treatment and prevention services. He has demonstrated leadership in moving forward organizational development initiatives to improve service results for children, youth and families.

Elder Colleen Mustus

Elder Mustus is from the Sturgeon Lake Cree Nation. She is fluent in Cree and grew up immersed in her traditional lifestyle. She has worked as a social worker and Aboriginal awareness consultant for several years. Elder Mustus currently works as a program manager with the Nechi Institute.

Lori Adamchick, MEd

Ms. Adamchick has a Masters of Education Degree with a specialization in Community Rehabilitation and Disability Studies from the University of Calgary. Ms. Adamchick has worked in the field of disabilities for close to 40 years in a variety of roles including Executive Director of a human service organization providing individualized supports to children and adults with developmental disabilities. As the Executive Director of Family Initiatives, Ms. Adamchick has been involved in a 10-year partnership with Child and Family Services Regions, working with parents with developmental disabilities or children at risk or involved with Child Intervention Services.

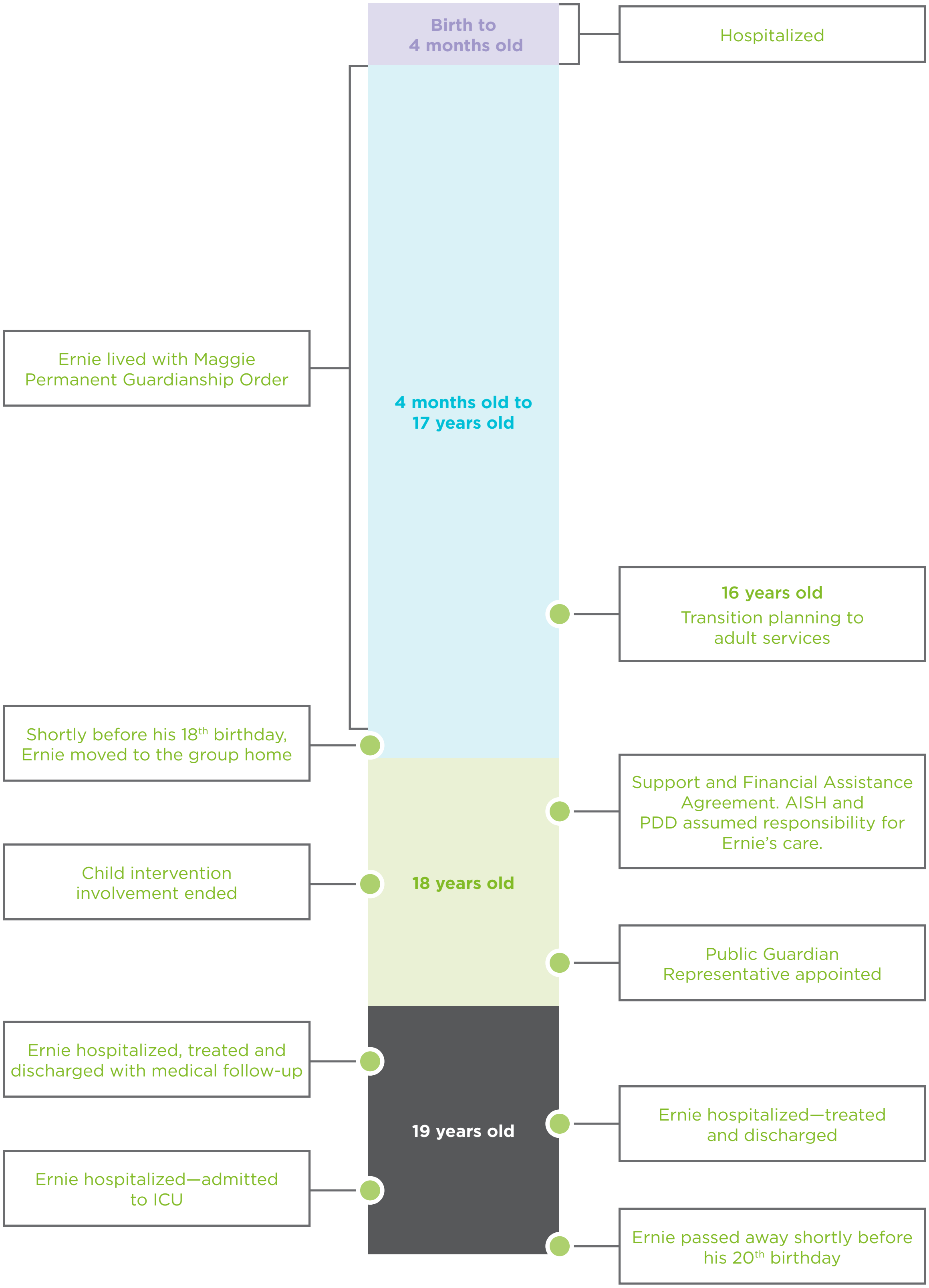
David McConnell, PhD

Dr. McConnell is a Professor and the Director of the Family and Disability Studies Research Initiative at the University of Alberta. His research focuses on the nexus between family, life-long disability and human service systems. He is Chair of the International Association for the Scientific Study of Intellectual and Developmental Disability Special Interest Research Group on Parents and Parenting. He has conducted research on decision-making in child welfare matters and co-authored numerous scientific papers.

Ann Nicol, MSW

Ms. Nicol is the Chief Executive Officer for the Alberta Council of Disability Services (ACDS). The goal of ACDS is to ensure quality service delivery for individuals within Community Disability Services. Before taking over as CEO for ACDS, she was the Executive Director of a national human service organization with programs for children and adults, including outreach, consulting, residential and vocational services. She is a sessional instructor in the Faculty of Social Work at the University of Calgary.

APPENDIX 3: SUMMARY OF SIGNIFICANT EVENTS



Birth to 4 months old

Hospitalized

4 months old to 17 years old

Ernie lived with Maggie
Permanent Guardianship Order

16 years old
Transition planning to adult services

Shortly before his 18th birthday, Ernie moved to the group home

18 years old

Support and Financial Assistance Agreement. AISH and PDD assumed responsibility for Ernie's care.

Child intervention involvement ended

Public Guardian Representative appointed

19 years old

Ernie hospitalized, treated and discharged with medical follow-up

Ernie hospitalized—treated and discharged

Ernie hospitalized—admitted to ICU

Ernie passed away shortly before his 20th birthday

APPENDIX 4: BIBLIOGRAPHY

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