



Report to the Minister of Justice and Attorney General Public Fatality Inquiry

WHERI	EAS a Public Inqu	iry was held a	at the	Provincial Court of Alberta
in the	City (City, Town or Village)	of	Edmonton (Name of City, Town, Villag	in the Province of Alberta,
on the	25 th	day of	January	, <u>2010</u> , (and by adjournment
on the		day of),),
before	The H	onourable Le	o J. Wenden	, a Provincial Court Judge,
into the	death of		A.O.	
	(Name in F	ull)		(Age)
of		Alberta (Residence)		and the following findings were made:
Date ar	nd Time of Death	:	Feb	ruary 17, 2008
Place:	Stollery Child	ren's Hospit	al, Edmonton, Alb	perta
("cause Diseases and publi	, Injuries and Causes shed by the World He	e medical causes s of Death as la		to the International Statistical Classification of the inational Conference assembled for that purpose es Act, Section 1(d)).
Severe	gastroenteritis.			
("manner	r of Death: of death" means the erminable – The Fatal			ral, homicidal, suicidal, accidental, unclassifiable
Natural.				

Report – Page 2 of 2

	ces under which Deat I pages 1 to 3.	th occurred:	
Recommend See attached	lations for the prever I page 4.	ntion of similar de	eaths:
DATED	August 11, 2010	,	
at	Edmonton	, Alberta.	
			Leo J. Wenden A Judge of the Provincial Court of Alberta

Report – Page 1 of 4

Introduction

This is the report on the Fatality Inquiry into the death of A.O. (the child).

He passed away February 17, 2008, at the Stollery Children's Hospital, Edmonton, Alberta ("Stollery").

The immediate cause of death was severe gastroenteritis. The other significant condition was a neuro-degenerative disorder.

The manner of death was natural.

In terms of evidence presented at the Fatality Inquiry, in addition to the three witnesses who testified, inquiry counsel filed two volumes of documents that set out the history of the child's contact with *Children's Services of Alberta* (Children's Services) and the Stollery in a detailed and complete way.

The Child Care Unit

Children's Services became involved with the child on 2004-12-07. The placement intake screening report specified that A.O. "was brought into care as his parents are not able to meet his needs". The report continued as follows:

Special needs include a degenerative brain disease ... severe seizure disorders... A.O. is one years old, though as developmentally at a newborn stage... His condition will not improve as his disease is degenerative, and at the rate he has been progressing, A.O. is not expected to live to be two years old."

Rita Holzer - Caseworker

On February 7, 2005, the child became subject to a *Permanent Guardianship Order*, and was under the care of Children's Services. At the Fatality Inquiry, Ms. Rita Holzer testified on behalf of Children's Services. She was his case worker from April 2007, until the date of his death on February 17, 2008.

Ms. Holzer said that her responsibilities were to ensure that the foster placement was appropriate, that the child received whatever medications or equipment that he needed, and that she visit him at least once every three months.

The child was in the foster care of David and Lenette Noack. Ms. Holzer described their home as large and very clean. She said that the foster parents were very knowledgeable and that they gave the child excellent care.

From the review of his file, Ms. Holzer said that the child was extremely ill, had continuous seizures, and had to be fed through a tube because he could not be fed orally. She said that he did not walk or crawl.

He received equipment and drugs that were not available through Children's Services' budget. As an example, she recalled him getting a chest percussor, a vibrator for the chest which serves to loosen phlegm and mucous. As well, he was provided with a very expensive drug used to break down phlegm and mucous. Both of these items required special funding and managerial authorization, which was always granted in relation to the child.

Lenette Noack - Foster Mother

Lenette Noack testified at the inquiry. She was the sole foster mother that the child had during his lifetime. She had extensive fostering experience, having started fostering children in 1990; since then, she had fostered extremely medically fragile children. At the time that she testified, there were five medically fragile children in her home, which is located on forty acres of land. She, her husband, and a full time nanny lived there.

Report – Page 2 of 4

The child came into her care when he was eleven months old. From the start, it was evident that he had many medical problems. He needed many seizure medications, and he aspirated all the time. When she took him into her care, he had to be fed by a gastric tube as he was unable to keep food down. She noted that he was developmentally delayed and was unable to crawl, roll over, or grasp toys. Contrary to the initial assessment, he could see and could hear. According to Ms. Noack, he loved music. Over the months he developed from a baby into a little boy who was capable of interacting with his foster parents.

She did acknowledge, and testify to, his many serious medical problems. He had to be suctioned, and this consisted of having a tube put down his throat in order to pull out mucous. Depending on the state of his lungs, he might have to be suctioned four or five times an hour, up to several times a day. He had "very severe suction needs"; [Transcript, page 24]. He was fed from a gastric tube, which meant that he was hooked up to a device which contained a formula. At the start, he was unable to tolerate any food and would throw up. However, with the passage of time, he acclimatized.

He had no motor control. Ms. Noack put him on a program designed to teach him to lift his head, something that he was able to do somewhat.

Another severe medical problem that he had was that he was very susceptible to pneumonia, and had to be hospitalized several times. Ms. Noack said that when the child was hospitalized, either she, her husband, or the nanny stayed with him all the time.

He was also subject to seizures. The seizures were brief, but followed one upon the other in fairly rapid succession. If there were three seizures within an hour, he was given a sedative. If he had a seizure while sedated, something which happened occasionally, he was given a rectal valium, which generally worked. The many seizure medications that he was on slowed down the seizures, but never totally controlled them. When the seizures were particularly severe, he had to be taken to emergency and given intravenous injections of drugs that would control the seizures.

The seizures were brought under control in November 2007. Many different drugs had been tried, but none were capable of permanently controlling the seizures. Ms. Noack testified that the Neurologist said that the child had reached the limit so as far as seizure medications were concerned. The Neurologist suggested that he be placed on a diet called the Ketogenic diet, an extremely strict diet that controls intakes of carbohydrates, sugar, and starch; protein was the key component. Ms. Noack said that the diet was complicated to prepare and that it called for precise measurements. She described the result of the diet on the child as being "a miracle" and "the most amazing thing" she ever saw.

Her related evidence included the following:

"Coming from a kid who seizures every day and was choking, and was on oxygen and within the first week was completely weaned off one of the seizure meds. The second week we started weaning him off the second seizure med and by that time he was completely off the second seizure med [he] had no seizures, he had no trouble swallowing, we didn't require suction at all, and he was off oxygen. His lungs were clear ... he was alert because he wasn't so drugged up from all the seizure medication"; [Transcript, page 27, lines 4-15].

Ms. Noack testified that anything that either she or Dr. McGonigle requested through Children's Services was always granted. The social workers were very supportive and always did their best to accommodate requests that were made on behalf of the child. She said that he received top notch care from Children's Services. She described Dr. McGonigle as "the best" and as being very supportive.

She enrolled the child in the *Wetaskiwin Early Education Centre* ("Centre"). He attended there for two years, although from time to time, he missed attending because of his hospitalization. She said the Centre was very accommodating. He had a one-on-one teacher's assistant who was trained to aid with all of his medical needs; that is: how to suction the lungs; regulate the flow of oxygen; and administer necessary medication, etc. The Ketogenic diet that he was on, and the fact that he was no longer on seizure medication made a world of difference. He was able to interact with the students at the Centre. According to Ms. Noack, all of the children liked him and would bring him toys, hold his hand and generally, spend time with him. She expressed the belief that "... although he doesn't move and doesn't talk ... his eves

Report - Page 3 of 4

were expressive and his smile so infectious that he loved people ... and people loved him" [Transcript, page 35 lines 8-9].

He had to be immunized to attend the Centre. There were difficulties attendant upon his immunization. Ms. Noack was able to stabilize him. Regrettably, he contracted viral pneumonia and once again there were intravenous treatments, and these resulted in more seizures. He also had a severe case of diarrhea that could not be stopped. He developed a severe diaper rash. As well, his lungs were not clearing up and food was not being processed.

After discussing the situation with Dr. McGonigle, a PICC line was inserted into him. This, however, did not result in any improvement in his condition. The device was inserted on a Tuesday and he died the following Sunday. Ms. Noack was with the child this entire time. In her view, everything that could have been done in an attempt to save his life had been done, and there was nothing more that could have been done.

Dealing with the question of visitation by the biological parents, Ms. Noack stated that throughout the period she fostered the child, she set up visits for the parents at various locations. These were always cancelled by the parents. The Saturday before his death, the biological parents came to see him, and the mother visited with the child.

Dr. McGonigle - Pediatrician

Dr. McGonigle, who is a pediatrician, testified at the inquiry. The child was in his medical care from the age of eight months. The doctor testified to the severe medical problems that faced the child. He had:

- (1) a severe abnormality of the brain that had its start when he was in the womb and for which there was no treatment;
- (2) difficulty with his lungs;
- (3) severely delayed development; and
- (4) severe seizure disorder.

Dr. McGonigle stated that all that could be done for the child was to support life sustaining functions, i.e., feeding, breathing, and give him medications to control his seizures. These seizures were controlled in November 2007 when he was placed on a Ketogenic diet, and it appeared as if he had stabilized. However, he had to be hospitalized in January 2008, as a result of viral pneumonia. His homeostasis was disrupted by the virus and he never recovered. He was showing signs of multi-system failure, had difficulty swallowing, and over time, his lungs became damaged.

The autopsy's pertinent findings were:

- severe pneumonia;
- lungs full of inflammation; and
- severe, extensive damage to the brain.

The child lived as long as he did because of the excellent physiotherapy that he received.

Dr. McGonigle had this to say about the care that the child received from Ms. Noack:

"So I look after a number of kids that the Noack's care for, their foster kids and adopted children. I am truly impressed, and I am not easily impressed, by the care that they provided their children... I think that Lenette Noack is probably the best foster mother in Alberta, and I say this without question because she is extremely caring. She loves these children, she is knowledgeable she brings the children appropriately, seeks care for them, when they need care, follows through absolutely with suggestions that are made, and recommendations that are made medically... supports these kids emotionally, mentally, physically and spiritually. I just can't say enough about how good of care these kids received, or that [the child] received in this home. I can say without

Report – Page 4 of 4

question that [the child] would not have lived as long as he did if he hadn't been in that foster home"; [Transcript, page 40 lines 25-30].

And commenting upon the care the child received, the Doctor stated: "I think he lived as good a life as he could live and received rather exemplary care, which is why he lived as long as he did..." [Transcript, page 39, line 27].

He said that the care that the child received "only contributed to his life"; [Transcript, page 43, line 3].

Dr. McGonigle noted that the child responded to touch, music and a soothing voice. He testified that the child could communicate with the foster mother who "lived heart to heart with him" [Transcript page 44, line 2] and that "this child had every opportunity to live the best life he could for as long as he could..." [Transcript page 44, line 18-19].

Section 53 (2) of the *Fatality Inquiries Act* ("Act") states: "(2) A report under subsection (1) may contain recommendations as to the prevention of similar deaths."

In this case, an investigation into the death of A.O. clearly shows that his death was solely attributable to the physiological circumstances in which he found himself at birth. There were no external circumstances that contributed to his death. Indeed, the evidence heard at this Inquiry clearly show that A.O. received excellent care from all with whom he came into contact while in the care of Children's Services, particularly that received from Ms. Noack, his foster mother.

The evidence revealed that the child experienced a brief, remarkable improvement of his quality of life upon becoming stable when placed on the Ketogenic diet. This continued until such time as he was given immunizations as part of a routine process to attend a public facility. This ultimately led to fatal complications as a result of viral pneumonia, an illness which had affected the child during earlier periods of his short life.

The evidence is clear that both physiotherapy and the exceptional dedication, care and love that Ms. Noack provided served to extend the child's life considerably beyond the short period that was articulated in the placement screening report. Without his foster mother, he would not have had the opportunity to improve on the Ketogenic diet and attend the Centre, and thereby interact with other children to the extent that Ms. Noack described during her testimony. Sadly, this child had little chance to thrive from the outset, due to the physiological abnormalities which were present at birth. His foster mother managed to make a significant contribution to both heightening the quality and extending the duration of the child's life.

As there was nothing that could have been done to prevent the sad end result in this case, no recommendations are appropriate under s. 53(2) of the Act.