



**Report to the Minister of Justice
and Solicitor General
Public Fatality Inquiry**

Fatality Inquiries Act

WHEREAS a Public Inquiry was held at the _____ Court House
in the _____ Hamlet of _____ Sherwood Park _____, in the Province of Alberta,
(City, Town or Village) (Name of City, Town, Village)
on the _____ 8th day of _____ June _____, _____ 2017 _____, (and by adjournment
year
on the _____ 9th to 12th days of _____ June _____, _____ 2017 _____),
year
before _____ M. M. Collinson _____, a Provincial Court Judge,
into the death of _____ Betty Anne Gagnon _____ 48
(Name in Full) (Age)
of _____ Strathcona County _____ and the following findings were made:
(Residence)

Date and Time of Death: _____ November 20, 2009, found dead shortly after 1746 hrs _____

Place: _____ The Country Boyz Tempo located at 52341 Range Road 214 Sherwood Park, Alberta _____

Medical Cause of Death:

("cause of death" means the medical cause of death according to the International Statistical Classification of Diseases, Injuries and Causes of Death as last revised by the International Conference assembled for that purpose and published by the World Health Organization – *Fatality Inquiries Act*, Section 1(d)).

Blunt head injury

Manner of Death:

("manner of death" means the mode or method of death whether natural, homicidal, suicidal, accidental, unclassifiable or undeterminable – *Fatality Inquiries Act*, Section 1(h)).

Homicidal – Failure to provide the Necessaries of Life (Indirect)

Circumstances under which Death occurred:

Betty Anne Gagnon (Betty Anne) was mentally and developmentally delayed due to oxygen deprivation at birth. In 1980, she was assessed that, although capable of looking after her personal needs, she was in need of supervision at all times, not able to live alone and employable only for sheltered work. She received long-term Assured Income for the Severely Handicapped (AISH). She became legally blind due to glaucoma as well as developed high blood pressure. At the time of her death on November 20, 2009, Betty Anne was a 48-year-old woman who had the mental capacity of a young child.

The AISH payments were controlled and distributed by her father Donald Gagnon (Donald). He was not a formal trustee. She did not have a guardian.

At the time of her death, she was living with her sister, Denise Scriven (Denise) and her brother-in-law, Michael Scriven (Michael). Following Betty Anne's death, Denise and Michael were charged and plead guilty to the criminal offence of failing to provide the necessities of life.

Betty Anne had developed behavioural issues including plugging the toilet, excessive masturbation, wandering off and feces smearing. The feces smearing became extreme; for example, she would mix her feces with water, pour it on herself, pour it on her bed, make holes in the drywall and pour the mixture into the walls through the holes. The home, bedding and Betty Anne required cleaning several times a day. The drywall often needed replacement.

The couple struggled with the demands of caring for Betty Anne while at the same time, they deteriorated into abuse of drugs, paranoia, and depression including suicide attempts. The last few months of Betty Anne's life were tragic. The couple employed abusive, even torturous methods to deal with the behavioural issues. To manage and punish Betty Anne for this behavior, at various times, the couple placed Betty Anne in a locked basement, a dog run in the yard, and a cage in the garage lined with chicken wire and a roof with pointed nails through it to discourage her escape which Michael referred to as her "jail cell". She was also placed in an unheated school bus with no running water or toilet, to sleep, even as temperatures fell below zero.

According to the Agreed Statement of Facts filed in the criminal matter, the couple videotaped their abusive punishment of Betty Anne. On one videotape, Denise is heard spanking Betty Anne between 70 – 75 times. On another, Denise scolds Betty Anne and tells her she will get 57 hits. In that tape, Denise can be heard slapping Betty Anne and Michael can be heard saying, "this is funny" and Betty Anne can be heard crying and screaming. In another, Betty Anne tries to escape her "jail cell" in the garage. Michael watches Betty Anne stand on a table, crawl over the wall, and fall to the garage floor, striking her head hard against the floor. He did nothing to prevent or help Betty Anne.

In one tape dated six days before Betty Anne's death, Denise is wearing rubber gloves and repeatedly slapping Betty Anne's buttocks as Betty Anne is leaning over a makeshift toilet. Denise tells Betty Anne that she has earned 60 slaps for such offences as sleeping all day, not saying good morning and brainwashing Michael by "getting in his head". Michael is heard in the background calling Betty Anne, a "dumbass". Denise lost count at one point and started over. Betty Anne is seen biting her lip and can be heard crying and screaming. Betty Anne is heard to say, "how many more" and "ouch". Denise is heard to tell her to scream loudly. The video has a date of November 14, 2009.

The above examples are only a sampling of the consistently abusive behaviour of the couple towards Betty Anne leading up to her death.

On November 20, 2009, Emergency Medical Services (EMS) located Betty Anne at the "Country

Boyz Tempo” near Sherwood Park and declared her dead on arrival. Denise had driven Betty Anne there from their nearby acreage.

On that day, Betty Anne had been staying in the unheated bus. Denise had given Betty Anne lunch and when she returned later, she found Betty Anne with her pants down, wet with urine and lying on her side. She was having trouble breathing, but was able to talk. Denise went back into the house and told Michael to draw a bath for Betty Anne. When Denise returned to the bus, Betty Anne was clenching her jaw, her breathing was laboured and she was unresponsive. Denise thought she was having a seizure. She tried to force open Betty Anne’s mouth with a funnel and then began CPR. When CPR did not seem to be working, she began to drag Betty Anne to the residence, stopping intermittently to continue CPR. Denise stopped this process briefly to run to the residence to get help from Michael, who then helped her to get Betty Anne into their vehicle to drive Betty Anne to the nearby gas station to meet EMS.

The cause of Betty Anne's death is blunt head injury. As the Medical Examiner noted in her report, the manner is less clear. She could not rule out direct inflicted trauma. The manner of death for the purposes of this report is a fall while left unattended by the couple. At the time of her death, Betty Anne was grotesquely malnourished weighing just 65 pounds. The Medical Examiner noted multiple bruises to her face and body.

Betty Anne’s Background

As a child, Betty Anne lived with her family. Prior to living with Denise and Michael, as an adult, Betty Anne lived in a number of group homes. The following is a chronology:

1989 – 2005

In 1989, she was placed in a private home with Suzanne Jackett (Suzanne) and Sue Thomas (Sue). Suzanne worked (and still does) with disabled persons and she had been asked to become Betty Anne’s supportive roommate.

While Betty Anne lived in their home, Donald received Betty Anne’s AISH payments and paid rent to Suzanne and Sue. The Calgary Developmental Disabilities Resource Centre (DDRC), a Persons with Developmental Disabilities (PDD) funded service, also paid Suzanne and Sue. Out of that money, they paid for groceries, activities, an extra support worker and respite care.

Betty Anne lived in an independent suite above their garage. She attended to daily living activities such as showering, laundry and housework with prompting and some assistance. She was able to participate in supported activities such as going to movies and bowling and working at a car wash and as a dishwasher. She shopped by herself at the local 7/11. She took a bus around on her own until glaucoma left her legally blind.

Betty Anne was known to seek independence. She could be somewhat stubborn, but did not have behavioural issues and there was no incontinence or feces smearing. Donald was actively involved in decision-making and as he lived nearby, visited monthly.

2005

In 2005, Suzanne and her new partner decided to buy a new business and move to Bragg Creek, a rural community outside of Calgary. As it wasn’t close to transit or community activities for Betty Anne, they decided to contact the family to find a new placement for her. As none could be found within 30 days of the proposed move, the family decided she would move in with Denise in Edmonton.

June 2005: Initially, Betty Anne lived with Denise and Michael in Edmonton; however, the couple bought an acreage outside Sherwood Park, near Ardrossan. Prior to making the purchase, Denise inquired about supports in rural Sherwood Park with the Robin Hood Association (Robin Hood), an organization based in Strathcona County that provides services to children and adults with disabilities, to confirm that similar services to Calgary were available in the area.

September 1, 2005: They took possession of the acreage, but the home needed renovations so the move-in date was delayed. While the new place was being prepared, Betty Anne returned to her father's home in Calgary.

October 31, 2005: They moved onto the acreage.

2006

Denise thought that the funding and supports would follow Betty Anne but they did not. Donald continued to get the AISH payments on Betty Anne's behalf. He did not provide any portion of these funds to Denise or Michael for Betty Anne's rent. Instead, he placed those funds in a bank account for Betty Anne and gave Betty Anne money for groceries and clothes from time to time.

June 22, 2006: Denise contacted PDD for intake regarding Betty Anne, seeking support for transportation, day programs at Robin Hood, respite care and outreach.

June 27, 2006: Denise and Betty Anne met with the PDD Community Support Coordinator (CSC) Val Bacon (Val), who advised that PDD doesn't pay for family members to provide care and support.

July 7, 2006: PDD sent a letter to Donald approving Betty Anne's application for day support programs.

July 14, 2006: Val called for Denise and spoke instead to Denise's daughter Hailey Price (Hailey) on the phone. Val again advised that PDD doesn't pay for family members to provide care and support.

July, 2006: Denise and Michael were married on the acreage.

August 31, 2006: Val phoned the number on the PDD intake application to follow up but the phone was not in service. Val made no further follow up attempts.

December 15, 2006: Denise contacted Driving Miss Daisy to inquire about transportation to day programs. Anne Marie (Anne Marie) Le Pen from Robin Hood met with Betty Anne and Denise to discuss supports. Robin Hood would not pay for Driving Miss Daisy. However, a Robin Hood application/intake package was given to Denise to complete.

2007

The stress of finances, work, family and Betty Anne began to overwhelm Denise. Behavioural issues were starting to arise. For example, Betty Anne was starting to plug the toilet with paper.

January 9, 2007: Denise, again, contacted PDD Edmonton to request supports for Betty Anne through the Robin Hood Association for day programs. Notes indicate that Betty Anne could be demanding. Michael was finding it difficult to deal with her while Denise was at work and **the family was very stressed**. Throughout, Denise was tearful and they indicated that they were **in great need of supports as soon as possible**. They had discussed having

Betty Anne move out. They needed transportation but Debra Ardessi (Debra), the PDD Community Support Coordinator (CSC), advised that PDD does not typically fund transportation.

January 16, 2007: Anne Marie from Robin Hood met with Denise and Betty Anne again and received the completed documentation. Denise completed and submitted an intake application for Individual Funding to PDD. Although Donald's number in Calgary was included on the Points of Contact Checklist, Denise was identified as the primary contact with her address and phone number in Sherwood Park (Ardrossan).

January 26, 2007: Debra met with Denise and Betty Anne at the acreage to gather information related to Betty Anne's support/respite requirements, her goals and desired activities. Notes indicate **Betty Anne was tearful throughout the visit stating she was lonely and bored.** Following the meeting, Denise left a message for Debra that Strathcona County Accessible Transit (SCAT) would not drive to and from day programs. **She reiterated again how stressed the family was and how desperate they were for respite care.**

January 30, 2007: Debra called Anne Marie at Robin Hood to discuss transportation. Robin Hood was to look into possible options such as car-pooling/sharing costs or staff members available to meet Betty Anne in the community so she could make use of SCAT.

February 5, 2007: Debra left a message for Denise regarding transportation cost estimates and her conversation with Anne Marie. Anne Marie left a message that there was no one in the area to share transportation costs.

February 9, 2007: Debra spoke to Leslie Jacobson at AISH who advised that a request for transportation must come through the family.

February 9, 2007: Debra left a message for Denise to call her regarding AISH and transportation.

February 15, 2007: Debra prepared a request for Funded Supports but left the cost estimate for transportation funding blank.

February 20, 2007: Debra left a message for Denise to call Debra again regarding AISH and transportation. She advised that the **request for funding had not been submitted** and that Debra was waiting to hear from Denise.

March 19, 2007: Debra spoke to Denise who indicated that she had not gotten back to her because she was having issues with her teenage daughter. She was still interested in supports for Betty Anne and noted that Driving Miss Daisy was \$22-25/one way to and from the Robin Hood day program. SCAT cost \$6.75 a trip but they were not able to give as much assistance as Driving Miss Daisy.

March 20, 2007: Debra left a message for Denise indicating that AISH may pay for transportation but that Denise needed to email AISH directly and that the **request could not come** from PDD.

March 23, 2007: Debra spoke to Denise who agreed to send a letter to AISH regarding transportation and that once she had a response, Debra would forward the requests for all supports.

The AISH file **does not disclose** that such a letter was received. There is no indication of any follow-up from Debra or otherwise, from PDD.

June 1, 2007: Donald sent a letter to Wendy Johns, the AISH worker, stating: “Betty Anne is getting settled in; just moved to the acreage last year and it requires a lot of work. Situation looks good and Betty Anne likes it there; personality has improved since she moved in with Denise”.

There was no further contact between PDD and Denise for almost two years until February 11, 2009.

2008

Issues continued between Denise and her daughter Hailey as well as with Betty Anne. In addition to plugging the toilet, Betty Anne was engaging in excessive masturbation and there were concerns about Betty Anne’s hygiene as she had feces on her hands. To compound matters, Denise was a registered nurse and she was experiencing disagreements regarding care of patients, particularly with respect to an individual doctor.

September 2008: Denise suffered a breakdown and was placed on disability from her work for depression, stress and anxiety. Michael did not work and Denise received 60% of her gross salary. Donald continued to receive Betty Anne’s AISH payments and only gave money for groceries and clothes from time to time.

September 11, 2008: RCMP were called to the house due to a fight between Michael and Denise. Denise left with Betty Anne to stay overnight at Michael’s mom’s, Mikaela Murray’s (Mikaela) place. Hailey remained as Michael was suicidal. Both Denise and Michael indicate that the RCMP were advised by Denise and Michael that he was suicidal but the RCMP did not provide any particular assistance.

September 15, 2008: Hailey was kicked out/moved out of the home.

September/October 2008: Both Michael and Denise made separate attempts to commit suicide. They were using cocaine and crack cocaine. The electricity on the acreage was disconnected and they were using a generator to power the furnace minimally and to wash clothes.

October/November 2008: Hailey and Mikaela contacted the RCMP, Children’s Services, Elder Abuse, AISH and the RCMP again, expressing their concerns that the couple were unable to care for Betty Anne but received no assistance. There is no record of these contacts.

October/November 2008: On the advice of the RCMP, Hailey and Mikaela visited the acreage, with the intention of taking Betty Anne with them, but they were denied access to Betty Anne and asked to leave the property.

October/November 2008: Hailey spoke by telephone to Donald and Denise’s two brothers, Paul and Barry about her concerns, but Donald did not want Betty Anne to leave the care of the family.

December 2008: Betty Anne stayed with Donald for Christmas. Donald’s wife was admitted to the hospital due to the stress of caring for Betty Anne.

2009

Denise’s mental health continued to decline. She was spending considerable time crawling into a

cupboard and crying. She had a miscarriage early in 2009.

January, 2009: Michael called Robin Hood, threatening to drop Betty Anne on their door step. **He told them he had had it and could take it no more.** Michael was advised that they were not set up as an emergency shelter; they did not have support approval from PDD to provide services and; that, if he did drop her off, the police would be called. He suggested that even if he could just leave her for two hours, it would help but they were not able to accommodate him. Michael remembers getting mad and turning around to drive home. Anne Marie from Robin Hood called him back. He tried to tell her how stressed he was feeling. She recommended that he either go to Emergency or call PDD for assistance. Anne Marie then called PDD to give them the heads up that they could expect a call. Anne Marie did not consider Michael's threat urgent, but just an indication of someone frustrated.

February 10, 2009: Denise called Wendy Johns (Wendy) with AISH wanting AISH to find a group home for Betty Anne as **she could not take care of her anymore.** Wendy told Denise that AISH does not find housing. Denise was going to see what she could find and was going to contact Robin Hood.

February 11, 2009: Denise left a voicemail with Sandy Thurston (Sandy), a PDD Community Support Coordinator, advising that she was no longer able to care for Betty Anne and needed Betty Anne to leave her home by March 31, 2009. She had been caring for Betty Anne for 3 ½ years without support and **could not do it any longer.**

February 12, 2009: Sandy spoke to Denise by telephone, setting a meeting for February 18, 2009. Denise advised that **she was very stressed and unable to continue to care for Betty Anne.** It was noted that on February 22, 2009, Betty Anne would be going to spend six weeks with her brother in Ontario. Denise asked that Sandy call Donald as he would like to be involved in the planning.

February 18, 2009: Sandy met with Denise, Donald and Betty Anne at Denise's home to update the file information and assess support needs. Denise indicated that she has been without paid supports since Betty Anne began living with her. Denise advised that she had applied for the Robin Hood day program a few years ago, but was told that PDD had no money.

Denise advised that she fell ill that past fall and that she was only able to start a slow return to work. Her niece and brother-in-law had moved out which decreased the family support available to assist with Betty Anne's care.

Denise stated she was **in a state of emergency** and **not able to care** for Betty Anne anymore. Denise wanted to see her move into a group home as soon as possible. Denise repeated that due to **her stress**, Betty Anne was going to her brother's in Ontario until March 31, 2009, which was the date that Denise had set for Betty Anne to move out.

Denise indicated that **she was desperate for supports** and firm on her deadline. She had already spoken to Robin Hood who had indicated that they would have more openings come fall.

Denise planned to check out Long Term Care facilities. Sandy explained that, without Betty Anne being in town, there would be **a lack of resources available** to PDD to proceed so quickly.

Sandy agreed to check into PDD funded agencies for availability and Denise was to call the following week.

February 20, 2009: Sandy spoke to Anne Marie from Robin Hood and learned that Michael had threatened to drop off Betty Anne at their door six weeks prior. Anne Marie had told him that they needed to connect with PDD and that they had absolutely no space available that would be appropriate for Betty Anne.

March 12, 2009: Sandy spoke to Denise and learned that Denise had spoken to a Public Health Nurse in Camrose and there was a possibility that Betty Anne could stay at one of their Long Term Care facilities. An assessment was required and Sandy recommended that Denise call Home Care. Denise hoped that Sandy would do this, but Sandy explained that, “no, she had to”. **At this point, Denise explained about her severe depression. She was crying saying she can’t handle this and cries all the time. She said she could not even make phone calls and insisted that Betty Anne could not return to her home.** Sandy agreed to call the Public Health Nurse.

March 12, 2009: Denise called Anne Marie at Robin Hood to inquire about residential spaces but was again told there were no vacancies.

March 13, 2009: Denise left a message for Sandy that she had received a call from Robin Hood that there was nothing until the end of the year and that arrangements for Long Term Care in Camrose needed to be made through PDD. Shortly after this, Denise attempted suicide but Michael successfully intervened.

March 16, 2009: Sandy attempted to call the Public Health Nurse who Denise had spoken to the previous week, but she wasn’t in, returning the next day.

March 16, 2009: Sandy left a message with Skills (an organization that provides short term, occasional supports to long term supports) seeking an emergency bed for April 1, 2009.

March 16, 2009: Sandy left a message for Denise giving her an update and asking that Denise refer anyone she speaks to, to her.

March 16, 2009: Sandy communicated with Allison Barker, the central PDD coordinator for the Camrose area learning there were no supports in Camrose and there was a waitlist.

March 18, 2009: Sandy contacted Independent Counseling Enterprises (ICE) seeking residential supports for Betty Anne who she described as being in **desperate need**.

March 19, 2009: Sandy prepared a Request for PDD funded supports which was approved in principle.

March 20, 2009: A potential placement in principle for a group home with ICE was identified for Betty Anne and another woman. Sandy left a voice message for Denise regarding the potential ICE placement and asked Denise to call her back. No attempt to contact Donald was made, despite his request to be included.

March 23, 2009: Denise left a voice message for Sandy, advising that Betty Anne was in Ontario.

March 24, 2009: Sandy left a voice message for Denise indicating that ICE will call her.

March 31, 2009: Denise had a panic attack, attending the University of Alberta Hospital emergency. She indicated she pleaded for help and support there but did not receive

assistance.

March 31, 2009: Betty Anne returned from Ontario, arriving in Calgary to stay with Donald for two weeks. His wife was admitted to hospital again.

April 6, 2009: Sandy left a voice message for Denise.

April 15, 2009: Sandy attempted to call Denise and Betty Anne. There was no answer and no voicemail was available.

May 4 and 5 2009: Brent Busch at Independent Counseling Enterprises (ICE) made attempts to contact Denise and Betty Anne by phone and letter. Brent continued to make attempts to contact Denise. Denise denies receiving any contact attempts.

July 7, 2009: Power to Denise's home was disconnected again.

July 16, 2009: A vacancy in a residence with the Robin Hood Association was identified as a possible placement for Betty Anne.

July 20, 2009: Sandy from PDD attempted to contact Denise regarding the vacancy at Robin Hood. There was no answer and she was unable to leave a message.

July 20, 2009: Sandy left a voice message with Donald at his home in Calgary.

July 27, 2009: A letter was sent to Denise advising that if the organization did not hear from her by August 27, 2009, Betty Anne's file would be closed.

Denise advised that she never received the letter nor were they aware of the possible placements. Donald regularly spent the summer in British Columbia (BC) and although this was noted in the Calgary PDD file, it was not noted in the Edmonton PDD file. Denise claimed he did not get the voice messages.

September 23, 2009: The PDD file was closed due to lack of contact.

October 2009: Donald returned from BC and found the voice message from PDD from July. Donald claims he advised Denise, but no steps were taken by either to contact PDD.

Late October/Early November, 2009: Denise visited her family doctor and discussed placement for Betty Anne at Alberta Hospital Edmonton. She says she was given 30 days to control Betty Anne's behaviour. The family was not supportive of such a placement over concerns that Betty Anne's behavior would be controlled by medications. The extreme and abusive measures to control Betty Anne's behavior escalated.

November 18, 2009: Michael Scriven rented a generator to provide power to the house and garage.

November 19, 2009: Donald and Denise decided that Betty Anne needed to be committed to Alberta Hospital Edmonton.

November 19, 2009: Betty Anne spent her last night in the school bus.

November 20, 2009: Betty Anne died.

Over the several years that Betty Anne was in the care of Denise and Michael, their requests for assistance were not consistent. Sometimes, Michael reached out for help; sometimes Denise reached out for help; and sometimes, neither reached out for help. They did not follow up in their requests for help nor were they persistent in seeking assistance. Donald did not seem to recognize the crisis as it was developing and in some ways, by holding onto most of the funding from AISH and taking the position that Betty Anne should remain with Denise and Michael, he added to the challenges.

Nevertheless, there were also many missed opportunities for authorities to intervene, which if fully and proactively acted upon may have prevented this very tragic and unnecessary death.

Recommendations for the prevention of similar deaths:

This report is intended to identify barriers and gaps to successful intervention by government supported agencies and to make recommendations to prevent future deaths.

As this fatality inquiry began, assisted by counsel who appeared at the hearing, the main issues were initially identified as:

What placement options were available to Betty Anne at the time of her death?

Placement options were limited at the time of her death. Given the extensive needs of Betty Anne in the months leading up to her death it was no longer feasible for her to remain with unsupported family members.

Given limited resources, in particular for rurally placed persons and waiting lists for supported living accommodations, once it was identified that supports and placement was needed, the application process was cumbersome, involving multiple agencies and the family needed to wait weeks and months to access supports and a placement. The wait times contributed to the inability of the family to follow up.

Once placement was determined, was this subject to oversight review, either initially or on an ongoing basis?

Once it was initially determined that Betty Anne was to live with family, a decision made solely by the family, it was not subject to oversight. For a person who was not subject to a guardianship or trustee order or in receipt of services, there was no oversight to this decision-making or review on an ongoing basis.

Once Persons with Developmental Disabilities were involved, what supports were available and what barriers were there to accessing such support?

PDD was involved prior to the decision to place Betty Anne with family. There was no follow up by PDD. When PDD was re-involved, the supports available were limited. Transportation to programs was an issue. Access to supported living accommodations outside the home was limited and unpredictable, with it being communicated to the family that waitlists could be up to a year. PDD did not offer emergency respite care, by way of in-home supports nor by immediately removing Betty Anne from the house, despite many red flags indicating that intervention was urgently needed, particularly in February/March 2009. The barriers will be discussed in more detail below but they include the volunteer nature of the program, a culture that normalizes stress and access to supports being dependent on one's advocacy skills.

Are there any changes to placement options or supports between the time of Betty Anne's death and the present time?

There have been some changes to the structure of the supports, but some barriers and gaps remain. This will be discussed more below.

As evidence was heard and explored, the issues developed and evolved:

(1) Government Funded Services Provided to Adult Persons with Developmental Disabilities

The following government funded services are available to adult persons with developmental disabilities:

- a) **Assured Income for the Severely Handicapped (AISH)** provides financial and health benefits to eligible Albertans with a disability.
- b) **Persons with Developmental Disabilities (PDD)** funds, monitors and evaluates the provision of services for individual Albertans with developmental disabilities. These services supplement the support of family, friends and community members, and assist individuals to live as independently as they can in the community. The PDD Program works with individuals, their representatives and families, community members and service providers to provide supports throughout Alberta.

Services are provided to support individuals in their home, work and social environments based on individual need. The PDD Program funds four types of services:

- Home Living Supports provide assistance to individuals in their home environment;
- Employment Supports train, educate, and support individuals to gain and maintain paid employment;
- Community Access Supports promote community access and participation;
- Specialized Community Supports are generally short-term services to assist caregivers and staff in determining and delivering appropriate services.

AISH and PDD are both voluntary programs.

- c) **The Office of the Public Guardian/Trustee (OPGT)** provides support and services to vulnerable persons by:
 - Protecting and advocating for individuals who are unable to make personal and financial decision for themselves;
 - Acting as guardian and trustee to represented adults when the OPGT is the most appropriate resource; and
 - Providing information, education and support to the public, private guardians and private trustees.

Barriers/Gaps:

During the fatality inquiry, the following barriers/gaps were identified that operated against successful intervention by government supported agencies:

- a. Shortage of day programs/group homes/long waiting lists.

Waiting lists for group homes were months, if not years, long. The demand outstripped the availability. New spots were available only if someone left a spot. Essentially, someone needed to leave, no longer required services or died to open up a spot. Most developmental disabilities

do not resolve themselves such that someone no longer requires services. **This was a critical and pivotal factor in the death of Betty Anne.** The anticipated delays in services lead to the sense of hopelessness in Denise and Michael and contributed to their inability to follow up to receive services.

- b. Lack of crisis respite beds or options.

There were limited crisis respite beds or options for families in need of respite. This was particularly acute for adults with complex needs. When Michael basically begged for just two hours, this was not available. **This was a critical and pivotal factor in the death of Betty Anne.** The lack of available respite beds or options, contributed to the sense of hopelessness for both Denise and Michael and contributed to their inability to follow up to receive services.

- c. Application process was cumbersome, involving multiple agencies and application/intake processes.

When Denise sought services for Betty Anne, she was required to complete separate intake applications/processes for AISH, PDD and the individual service providers such as Robin Hood, SCAT and Driving Miss Daisy. She was required to learn how to identify and navigate these services. There was no central intake or coordination of these services.

- d. A vulnerable adult who is not in care and not accessing services in the community or participating in activities in the community becomes invisible and opportunities for intervention are limited because no one is aware of the need for intervention.

When Betty Anne transitioned to the family, the “eyes on” her decreased from over 10 people per week to two people, in the end. Those two people were incapable of providing adequate care and had become not only neglectful, but abusive and torturous. This isolation made Betty Anne more vulnerable and led to a situation where nobody was making observations that would have led to an intervention. She was not someone who was not seeking care or seeking access to services. As early as 2007, Betty Anne was indicating that she was bored and lonely. She had previously actively participating in and enjoyed community activities. **The inability to access day programs or other community programs was a critical and pivotal factor in the death of Betty Anne.** Inclusiveness in the community is a major factor in safety for people such as Betty Anne.

- e. Links and communications between service funders and providers relied on Denise.

It was emphasized to Denise that it was her responsibility to seek out the services, get approval for funding, either from AISH or PDD and bring that back to the service providers. Denise would complete some of the process but it would be put on hold while she pursued the rest. This led to the whole process collapsing. For example, although Betty Anne would have been approved by PDD for funding and accepted into day programs with Robin Hood in 2007, those applications were put on hold waiting for approval for transportation funding. Despite three separate attempts to seek services, in June 2006, January 2007 and February 2009, the end result was that Betty Anne did not get any of the programming, services or supports that she needed and would have been approved for.

- f. Services funders, providers and public guardian's office relied on family members in absence of a formal guardianship order.

Even though it was likely that Betty Anne needed a formal guardianship order, the services funders and providers did not take any steps to involve the public guardian's office or to ensure that such an application was made. As a result, AISH and PDD took instructions from family members who were not formal guardians or trustees. Betty Anne was not able to avail herself to the oversight and protection under the PGTA.

- g. Reliance on/complacency in the voluntary nature of the program meant that there was limited proactive follow up.

At the time of Betty Anne's death, the legislation and framework upon which PDD was based emphasized the voluntary nature of involvement in the PDD program. The focus was on the self-determination of the adult and attempted to avoid a paternalistic approach to address the needs of adults with developmental disabilities.

As a result, time and time again, it was evident in the manner in which Betty Anne's needs were being addressed, that the PDD Community Support Coordinator (CSC) had and felt very little responsibility to be proactive in ensuring that Betty Anne's needs were being addressed. The witnesses from PDD emphasized repeatedly the voluntary nature of the program. At the time, PDD expected the adult and/or their family representative, in the absence of a legal guardian or trustee, to take the lead in identifying the supports and services they required and to bring those to PDD for funding. The role of the CSC was primarily that of reviewing and approving funding proposals for identified supports. When no follow-up was forthcoming by Denise, Donald or Betty Anne, it was presumed that the services were no longer being requested or had been acquired somewhere else, with no confirmation of such.

- h. No, little or inadequate training to identify depression or other mental disabilities interfering with the responsibilities or advocacy of family members.

Even though Denise was essentially broadcasting her own disability and inabilities to the PDD CSC, the CSC maintained the expectations of a person not encumbered by such a disability. By early 2009, Denise has indicated that she was being compromised by her own stress and depression and finding it difficult to care for Betty Anne. She indicated she was having difficulties even to make calls. However, PDD continued to leave messages for her to call them back but did not make a home visit or ask the police to do a check on welfare when these calls were not returned. There did not appear to be any recognition about how this disability could manifest itself and interfere with the care requested and provided for Betty Anne.

- i. Services provided dependent on strength of advocacy of requesting party.

At least one service provider indicated that services provided were in large part dependent on the strength of advocacy in seeking services. Given the cumbersome and voluntary nature of the process, knowledge and persistence were required. Service providers did not see themselves as advocates for the client. Given the limited resources and difficulty meeting demand, service providers were not as likely to create or advocate for more demand on their services.

- j. No linkages made during the change of jurisdiction.

There was no indication that any steps were taken by the service providers or PDD in Calgary to ensure that a file was transferred to the new jurisdiction when Betty Anne moved or to ensure that supports were in place. Steps to get the file in Calgary were only taken when Denise sought out services in the new jurisdiction. In the absence of a transition plan, Denise had unrealistic expectations about how she would go about receiving support services or what support services would be available.

- k. All or none thinking/lack of problem solving.

When Denise presented in early 2009 with the demand that Betty Anne needed to be placed in a group home no later than March 31, 2009 and the service providers indicated that there may be difficulty in getting such a placement, even suggesting that placement could take up to a year, there was no discussion about what supports could be provided in the meantime. The focus was directed solely at finding a placement in a limited field, with no contingency plan if a placement was not located. The focus was on removal and not on what could be done to stabilize and support the family. In some respects, that was a repeat of what happened in 2007. The application for day programs collapsed when Denise did not follow up on her requests for transportation funding.

- l. The culture within the government funded agencies tended to normalize crisis.

There were obvious red flags throughout the interactions with Denise and Michael to indicate that the situation was stressful, emergent and urgent; in other words, that this was a crisis:

- 2006: Denise seeking “respite” care.
- 2007: Michael was finding it difficult to deal with her while Denise was at work and **the family was very stressed**.
Betty Anne was tearful throughout the visit stating she was lonely and bored.
Throughout, Denise was tearful and they indicated that they were **in great need of supports as soon as possible**.
They had discussed having Betty Anne move out.
She reiterated again how stressed the family was and how desperate they were for respite care.
- 2009: Michael threatening to abandon Betty Anne on the doorstep of Robin Hood, saying, **that he had had it and could take it no more**.
Denise left a voicemail she was no longer able to care for Betty Anne and needed her to leave her home by March 31, 2009. She had been caring for Betty Anne for 3½ years without support and couldn’t do it any longer.
Denise advised that **she was very stressed and unable to continue to care for Betty Anne**.
Denise stated she was **in a state of emergency and not able to care** for Betty Anne anymore.
Denise **was desperate for supports** and firm on her deadline.
Denise explained about her severe depression.
She was crying saying she can’t handle this and cries all that time.
She said she could not even make phone calls and insisted that Betty Anne could not return to her home.

The CSC from PDD testified that “it wasn’t emergent, they were just stressed”. Other service providers admitted that families stay in crisis for a long time and that there are lots of families in crisis.

- m. Not client focused.

PDD referred and deferred to family members for decisions regarding services in the absence of legally appointed guardianship/trusteeship and when the family members did not follow up, they took that as an indication that the services were not required.

There was no follow up specifically with the actual client. Even when advised by Betty Anne’s caregiver and advocate Denise, that Denise was incapable of making telephone calls, PDD did not follow up with a home visit, or other method of contact, to contact Betty Anne directly.

- n. Funding framework often based on block service provider and funding did not follow the client.

Without going into the details of the funding frameworks, essentially this meant that a service provider was provided funding for a block of spots, unassigned to a particular individual. When an individual left that service provider and/or moved jurisdictions, the funding did not follow them. If the individual needed services somewhere else, an application for funding approval or services needed to be made again.

- o. Challenges for those living rurally – transportation, lack of available services.

Although resources are limited in many locations, it is much more acute in the rural areas. Transportation is limited and expensive. Funding for transportation is a separate application process. No or little programming is available within the rural areas themselves.

- p. No oversight of placement of persons with developmental disabilities in a family home.

In Betty Anne’s circumstances, she had been living in a supported roommate arrangement with regular oversight. It was identified that she required day support programs and that her care givers required respite care. Case plans and reviews were submitted regularly. She was provided considerable programming and supports. Her roommates were supported through the process. When Betty Anne moved, this support network completely vanished. The autonomy of the family/developmentally disabled adult and the voluntary nature of the programs did not call for oversight. There is and there should be no presumption that family or caregivers outside of government funded services are unable to provide adequate or even exceptional care; however, when Betty Anne was transitioning from fully supported services to no services, in the absence of a transition plan, Denise had unrealistic expectations about how she would go about receiving support services. Oversight may have connected the family with desired day support programs and respite care, well before the family became stressed and the matter turned into a crisis.

- q. No crisis line or crisis intervention team to contact when person, identified as a person with developmental disability, who may be abused or neglected is not in government funded care or is not represented under the *Adult Guardianship and Trusteeship Act*.

When the extended family members attempted to make authorities aware that they were concerned about Denise and Michael's ability to care for Betty Anne, they called several social services agencies, including the police without success. No one referred them to the PGTO, who might have been able to take steps to intervene if they had been able to determine that Betty Anne was in need of a guardian. No one referred them to the PDD caseworker. There was no central location to refer them to or specialized team to address those concerns.

- r. No legislation that provided a framework and authority for emergency interventions to investigation, assessment, warrants to enter to investigate and to remove/apprehend and place for safety, particularly for those who are not in publicly funded care or represented under the PGTA.

Police need to have reasonable and probable grounds to believe that someone's life is endangered to enter a premise to check on welfare. At the point that Hailey and Mikaela were expressing their concerns, it appears that these concerns did not lead the police to believe there were such reasonable and probable grounds as there was no action taken by the police, except to advise Hailey and Mikaela to go check in on Betty Anne themselves. And even if the police would have had the authority to check on welfare, there would have been no formal authorities, processes or framework for assessment, removal/apprehension and placement for safety. And without these processes and frameworks in place, the police would have been in the same position as Denise in seeking services. There were no or limited emergency respite beds or group homes to place Betty Anne into even if they had done a check on welfare and determined that Betty Anne was in need of protection.

Changes since the death of Betty Anne Gagnon:

1. The Role of the Community Support Co-ordinator

The role of the CSC has changed. The CSC meets with the adult to determine their needs. The CSC is then instrumental in identifying resources to meet those needs and in connecting the adult with supports. These changes should:

- lessen the stress on adults with developmental disabilities and their families in locating services;
- the CSC gains a better understanding of the needs and the circumstances of the adult with a developmental disability;
- the CSC is in a better position to recommend options including alternative and interim solutions when adult with a developmental disability is seeking supports, especially in the situation of crisis.

Comments: As a result of the expanded role of the CSC, when a PDD client moves between regions, the assigned CSC is in a position to assist the client in accessing supports in the new region. When Betty Anne left Calgary, it had been the Calgary Developmental Disabilities Resource Centre, the support agency that provided services for Betty Anne. As a result, PDD may not have been aware of the move and there was no formal transition planning role within PDD to facilitate the move to the Edmonton Region.

Under the current system, a Calgary CSC would have been meeting with Betty Anne and would have been directly involved in planning the services offered to her in Calgary. That CSC would have been in a position to assist Betty Anne in connecting with PDD in Edmonton so that there

was a file opened and consideration given to the transition of services and supports. This type of oversight as Betty Anne was transitioning from a supported living program to living with her family may have connected the family with the desired day support programs and respite care, well before the family became stressed and the matter turned into a crisis.

Clients transferring between regions, per policy now, maintain their eligibility for PDD and PDD regions contact one another as soon as they become aware that an individual is planning to relocate to discuss the individual's needs and related time lines and to work together to ensure continuity of service as much as possible, without the requirement to re-apply for supports.

Unfortunately, this does not address the shortage of group homes, the long waiting lists, or the lack of crisis respite beds or respite options. Service providers indicated that the system still responds to crisis as opposed to being proactive and strong advocacy is still required to receive the same.

2. Application Process for Supports

In 2014, the My Alberta Supports policy was implemented. Applicants can go to one website and apply for multiple government supports for which they may qualify. In conjunction with the launch of My Alberta Supports, the government department, Community and Social Services advises that they have implemented an integrated service delivery approach to facilitate increased communications. Under this policy, Betty Anne/Denise would not have been required to contact both PDD and AISH and to manoeuvre between the programs to obtain funding for transportation. These changes are designed to simplify the processes for the applicant. The CSC would have made the contacts on behalf of Betty Anne.

Comments: At least one service provider indicated that the process is still confusing: that the applicants get pre-approval from PDD and AISH for services, but the services still have to be approved by the actual service provider, based on whether adequate funding is being received and whether there is a “match” of client to service. As well, it was indicated that there are still inconsistencies across the regions.

3. The CSC works with the adult with a developmental disability directly

As noted, during the time leading up to Betty Anne's death, it was common for PDD to refer and defer to family members for decisions regarding services even though the family member may not have been the legally appointed guardian. Now, the process is as follows:

- PDD identifies at the outset whether an adult has a guardian or co-decision-maker and obtains relevant documents.
- If there is no guardian or co-decision-maker, the CSC must work directly with and obtain consents from the adult.
- If there is no guardian or co-decision-maker and one is required, the CSC will make the appropriate referrals to insure that one is appointed.

If a guardian is required, then the application is reviewed by the Office of the Public Guardian and Trustee (OPGT) and if no willing or suitable guardian exists, the OPGT will become involved and the Public Guardian may apply to become the guardian. There is a possibility of guardianship reviews as well as mechanisms for the OPGT to investigate any concerns regarding the conduct of the guardian or co-decision-maker and to intervene where appropriate. This will be discussed more in relation to the legislation governing the OPGT below.

Comments: In taking direction from the adult with a developmental disability directly, the CSC is in a better position to assess the needs of the adult and identify concerns. However, this does not change the voluntary nature of the program and in the circumstances of Betty Anne, if she, like her sister, did not follow through in seeking the services, there would still be no requirement that the CSC proactively seek out and follow up to ensure that Betty Anne no longer required services. This nature does not change whether it is family members seeking services or the adult with the developmental disability seeking services or a public guardian seeking services. A public guardian may be more knowledgeable and capable of following up to obtain services, relying on the established relationship between the OPGT and PDD, as well as other service providers.

4. Funding Model has changed

At the time prior to Betty Anne's death, PDD regions negotiated annual funding agreements with service providers based on the total number of individuals they supported, codes, units of services and rates. Agencies invoiced PDD for services provided and PDD released money based on those invoices. Some service providers were given funding on the basis of the number of spots they had available, no matter which client was filling those spots and without specific consideration of the individual needs of the client. This type of funding was referred to as block funding. Funding didn't necessarily get assigned to or follow the individual.

An overhaul to the funding model has been made and includes two funding routes: through a Service Provider agreement and/or a Family Managed Service (FMS) agreement. The FMS allows for a client, their family or a person close to the client to manage the delivery of services by hiring staff directly or by obtaining supports directly through a PDD approved service provider. The person who fulfills the management role is known as the FMS Administrator. Both funding routes focus on the individual needs of the client and do not require that a client reapply for funding if they change locations or service providers. The funding approval follows the client.

Comments: Specific and in depth information about funding was not pursued or provided at this fatality inquiry; however, there was testimony that there is pressure on service providers in terms of funding and that there remain lengthy waitlists for services. At least one service provider indicated that the funding is not sustainable and does not provide for planning and training.

In terms of the CSCs being proactive and pursuing follow up, funding impacts on this issue: when a system cannot meet demand, it is not as likely to follow up and be proactive when it will lead to more demand. Funding needs to be adequate and stable and allow the service provider to continue to provide services with anticipated fluctuations in the number of participants and the needs of the participants. At the same time, funding needs to be based on the individual's needs and must be able to follow/transition with the individual, if the individual moves locations or changes service providers. All efforts need to be made to reduce interruptions in services and to allow services to plan, train and be proactive, as opposed to reactive to crisis.

5. Abuse prevention

In 2016, the PDD developed and implemented an Abuse Prevention and Response Protocol that identifies proactive strategies for preventing abuse and procedures for service providers and PDD staff to follow when responding to allegations of staff to client abuse, including addressing the immediate safety and security needs of the individual. There is an obligation for PDD staff to report and take action and it is mandatory that PDD funded staff be made aware of the obligatory reporting of any incident of suspected abuse immediately to their Executive Director or designate,

the FMS Administrator or to PDD.

The Inquiry heard that PDD endeavours to hire staff who have the skills to recognize the needs of the population they serve and that they endeavour to train them to respond to concerns of abuse and neglect. As well, the PDD program is instituting mandatory Mental Health First Aid training for all CSC positions. The basic course is intended for adults interacting with adults (18 years and older). This course focuses on the four most common mental health disorders including substance related, mood related, anxiety and trauma related, and psychotic disorders.

Participants who take this course should be better prepared to interact about mental health with their family, friends, communities, and workplaces.

The PDD staff are trained to report concerns to the police.

Comments: The Protocol only applies to people who are in receipt of services and given that Betty Anne was not in receipt of services, it does not apply to people in her circumstances.

Although the RCMP gave evidence that their officers provide welfare checks on individuals and will respond whether or not the concerns are criminal in nature, in the hearing, despite the threats to abandon Betty Anne (a form of neglect) and the information that Denise gave to CSC that she was unable to care for Betty Anne anymore, the CSC did not even consider calling the police. The family members did call the police but the police did not conduct a welfare check and instead told the family members to go to the property themselves. As well, it is unclear as to what assistance the police could have given at the time the concerns were raised:

- At that point, it was not criminal in nature and it was unlikely there were reasonable and probable grounds to believe Betty Anne's life was endangered, they would not have had authority to enter the home to talk to/inquire with Betty Anne without consent.
- If they examined Betty Anne and determined that she was in need of care, their options were as limited as Denise's: no or limited immediate respite care available and waiting lists for a group homes. Presumably, they would not have been burdened by the ongoing stress of caring for Betty Anne or the addiction and mental illness suffered by Denise and Michael and therefore would have been able to perform the function of advocate more adequately.

And as noted above, the CSC who testified at this hearing repeatedly emphasized that their service was voluntary and that there was nothing in the presentation of Denise or Betty Anne to indicate that there was an emergent/urgent need for intervention. Although there is the saying that hindsight is 20/20, reflection has not changed her position. It is obvious on the record, including their own notes, that Denise was suffering from depression and was unable to cope or take steps as simple as making phone calls. Betty Anne was identified from the beginning of her involvement with PDD as requiring full-time supervision. It was obvious that Denise was no longer able to care for Betty Anne and therefore, Betty Anne was in need of emergent or urgent intervention. This was a crisis.

Any current training has either not been given or did not assist this worker in recognizing this as a crisis. It appears that the culture normalizes crisis and this does not yet appear to have been altered. Other witnesses supported the idea that crisis is the norm: "when families are in crisis, they stay in crisis for a long time"; "there are lots of families in crisis".

In general, people who are concerned about someone do not know who to contact. In the absence of a crisis line or crisis intervention team, similar to those available for seniors or those in care facilities, persons with developmental disabilities in the community, particularly those who have not accessed these voluntary services, who are being abused or neglected continue to be at risk.

The My Alberta Supports website does have some limited links to follow if someone is concerned

about someone who might be abused or neglected. It could use some improvement to make the links easier to locate, to ensure that complaints can be made anonymously and to ensure someone seeking to make a complaint is directed to the correct Service.

6. Legislation and Policy

The following relevant legislation existed at the time leading to the death of Betty Anne:

The Persons with Developmental Disabilities (PDD) Community Governance Act (1997)

This legislation established a voluntary program that funded, monitored and evaluated the provision of services of Individual Albertans with developmental disabilities. These services were intended to supplement the support of family, friends and community members, and assisted individuals to live as independently as they can in the community.

Six regional community boards were established and were responsible to identify community priorities in the provision of services, develop a plan for the delivery of these services and monitor and oversee the plan, all within the context of the directions and priorities established by a Provincial Board. The *Act* was updated in 2004 and continued to recognize the importance of the individual's self-determination and to be fully included in community life. Recognizing the need to support the community's ability to respond to the needs of the adults, the legislation identified the role of the Government was to provide funding but services were to be provided through the Boards and Regions.

In 2006, the legislation was updated to repeal the Michener Facility and the PDD Provincial Board and in 2008 the expiry date of the *Act* was changed to 2010.

Comments: Although the voluntary nature of the program has been identified as a barrier, the principle and policy basis that developmentally disabled adults, family and community supports have autonomy is valid. The challenge is when the voluntary nature of the program is used as a shield and leads to the desired services not being acted upon. This actually impedes autonomy. It must be remembered that Betty Anne and Denise were seeking services on three separate occasions and did not successfully receive them.

The Protection Against Family Violence Act (PAFVA) (1999)

This is an Alberta law that protects family members from family violence. Family members include seniors, women, men and children whether they reside together or apart. The legislation provides for a mechanism to seek an Emergency Protection Order (EPO) where family violence has occurred, the claimant has reason to believe that the respondent will continue or resume carrying out family violence, and that immediate protection of the claimant and other family members is required due to the seriousness and urgency of the matter.

Family Violence in this context means:

- any intentional or reckless act or omission that causes injury or property damage and that intimidates or harms a family member;
- any act or threatened act that intimidates a family member by creating a reasonable fear of property damage or injury to a family member;
- forced confinement;
- sexual abuse; and
- stalking

Those who can apply for a protection order are: claimants, designated persons with the claimant's consent, and any person on the claimant's behalf with "leave" of the court (typically in

extreme situations where the claimant cannot apply due to age or is incapacitated). Only certain people can apply for an Emergency Protection Order by phone. These “designated persons” are defined in section 3 of the Protection Against Family Violence Regulation. They are peace officers, or persons authorized by a police service to assist in applying for orders, a director designated under section 129 of the *Child, Youth and Family Enhancement Act*, or those authorized by the Minister of Human Services. There is no cost for an EPO.

The following conditions may be contained in an EPO:

- restraining the respondent from attending at or near a specified place that is attended regularly by the claimant or other family members;
- restraining the respondent from communicating with or contacting the claimant and other specified persons;
- directing the police to remove the respondent from the residence immediately or within a specified time;
- directing the police to accompany a specified person to the residence within a specified time to supervise the removal of personal belongings in order to ensure the protection of the claimant;
- directing the seizure and storage of weapons where the weapons have been used or threatened to be used to commit family violence;
- and any other provision that the provincial court judge or designated justice of the peace considers necessary to provide for the immediate protection of the claimant.

Comments: By the time the preconditions existed for the application of this *Act*, the family was isolated and those who could have made the application on behalf of Betty Anne, were not making the observations necessary to initiate or provide the basis for the application. At the time that Hailey and Mikaela were seeking assistance or even when Denise and Michael were seeking assistance, their concerns were not being expressed or identified as concerns of family violence, but instead were being expressed as concerns about Denise’s and Michael’s ability to care for Betty Anne. Even if this *Act* was resorted to, it begs the question of what would have happened to Betty Anne if Denise and Michael were the subject of an EPO, when there were waitlists for placements and no or limited emergency respite care.

The *Protection for Persons in Care Act (PPCA) (2000)*

This *Act* applied to persons receiving government-funded care or support services. It requires that every person or service provider who has reasonable and probable grounds to believe that a client was being abused to report the abuse. Abuse meant intentionally: causing bodily harm, causing emotional harm, administering or prescribing medication for an inappropriate purpose, misappropriating or improperly or illegally converting money or valuable possessions, failing to provide adequate nutrition, adequate medical attention or other necessity of life without valid consent or subjecting to non-consensual sexual contact, activity or behavior.

Comments: Because Betty Anne was not receiving care or support services, this *Act* did not apply to her circumstances.

The *Dependent Adults Act (DPA) (1978)*

This legislation addresses guardianship and trusteeship for dependent adults built around the notion of functional disability, rather than, ‘mental incompetency’. The *Act* included a list of matters over which the court could grant authority to the guardian, including living arrangements, social activities, nature and type of work, training and education, applications for licenses or permits, legal proceedings not involving the estate and day-to-day decisions including diet and

dress.

The *Act* established the Public Guardian and Trustee, which would apply to be guardian or trustee when no one else was willing or able to. Presumably the purpose of such a provision was to ensure that no one would fall through the cracks because they lacked family or friends willing or able to be appointed guardian.

Comments: At the time that Hailey and Mikaela were seeking assistance or even when Denise and Michael were seeking assistance, their concerns were not being expressed or identified as concerns in regard to whether the Public Guardian and Trustee should intervene.

The Adult Guardianship and Trusteeship Act (AGTA) (2009)

Shortly before Betty Anne's death, the *Dependent Adults Act* was repealed and replaced by this *Act* on October 30, 2009. The guiding principles of the *Act* are:

- presumption that an adult is capable unless the contrary is determined;
- the least intrusive form of decision-making assistance is utilized;
- the manner in which an adult communicates is not relevant to their capacity;
- substitute decisions are made in the adult's best interests and consider the wishes, values and beliefs the adult held while capable.

The AGTA provides for a continuum of personal decision-making options and trusteeship: supported decision making authorization; specific decision-making; co-decision-making order; guardianship order, trusteeship order and urgent guardianship or trusteeship order. This last order is referenced when an adult lacks capacity and is in immediate danger of death/serious harm or financial loss.

Reviews are scheduled to ensure that the needs of the represented adult are being met, that the Order Appointing Guardian is still necessary and appropriate, and that the guardian(s) is/are still willing and able to act. Review dates are unique to the represented adult and situation. In some cases, the review date may be a number of years in the future and in others, there may be no review date, for example, for those individuals with dementia. There is also the possibility of an early review. An early review may be completed if the situation changes for the represented adult or the guardian(s). For example, a review would be necessary if:

- the represented adult's ability to make decisions has changed (improved or declined),
- the guardian(s) is/are no longer able or willing to act as guardian.

There is authority under the *Act* for complaint officers and investigators to investigate complaints that a co-decision-maker, guardian or trustee is not fulfilling their duties or complying with the terms of an order and this failure is likely to cause harm or financial loss to the represented adult.

If the complaint is referred for investigation, an investigator will be assigned and have the authority to:

- Interview the adult and other parties about the investigation.
- Require production of relevant records from guardians, trustees, co-decision-makers, and service providers.
- Apply for court orders permitting entry to premises where the adult resides and access to relevant records if guardian refuses to allow access.
- Refer the complaint/investigation to the police for criminal matters or

other investigative bodies (e.g., Protection for Persons in Care, PDD Abuse Protocol).

- If the investigator determines that the complaint is founded, the investigator will notify the complainant and other parties of their decision.
- After this determination, the investigator may then attempt to resolve the complaint, through education or refer the complainant, the co-decision-maker, guardian or trustee to an alternative dispute resolution process.
- The investigator may also recommend that the Public Guardian or Public Trustee apply to the Court for a guardianship or trusteeship order, or any other appropriate order.

The Court may issue a temporary protection order upon the application by the Public Guardian and it may authorize a police officer to assist the Public Guardian or another person to remove a represented adult to a temporary place of safety and may appoint the Public Guardian as a temporary guardian.

Comments: There is no positive duty to report adult abuse or neglect under this *Act*. It only provides that an interested person can make a complaint to a complaints officer. By the time the *Act* came into force, the family was isolated and no one was making the observations that could have referred this to the Public Guardian for consideration of an application for a temporary protection order. As Betty Anne was not represented, there were no regular reviews as required by the *Act*. If no one contacts the PGO to express concerns, then it is impossible for the PGO to exercise their investigative powers.

Legislation and Policy that followed Betty Anne's Death:

The *Protection for Persons in Care Act (PPCA)* (2010)

This *Act* requires that every individual who has reasonable grounds to believe there is or has been abuse involving a person receiving government funded care or support services to report that abuse as soon as possible. The case services include: hospitals, seniors' lodges, nursing homes, mental health facilities, shelters, group homes, addictions treatment centres, many settings funded by the Persons with Developmental Disabilities program, and other supportive living settings.

This update removed the requirement that abuse required an element of intent and focuses the definition on serious harm. It placed more duties on persons who provide care or support services to protect clients from abuse. It established a complaints' officer and director and set out additional bodies which have the authority to investigate reports of abuse. All reports of abuse must be reviewed and whenever necessary, investigated.

An investigator has the power to enter the premises with the permission of the occupant or the legal representative of the occupant at any reasonable hour or by order of the Court and may:

- interview the client or any person with information;
- access all records including health information;
- examine and/or remove equipment for examination or testing;
- photograph or record anything in the premises.

More offences were created with higher penalties.

Every individual who believes that there is or has been abuse involving an adult who receives

care or support services from a publicly funded service provider shall report that abuse as soon as possible to:

- Protection for Persons in Care, call 1-888-357-9339.
- A police service, if the abuse is criminal in nature.
- A professional regulatory college or body, if the abuse involves a health professional or a member of a health discipline.
- The office of the Mental Health Patient Advocate, if the abuse involves a client who is or was detained under one or two admission certificates under the *Mental Health Act*, or is or was subject to a Community Treatment Order at the time the alleged abuse occurred.

***NOTE:** A client is an adult who receives care or support services from a publicly funded service provider.

There are several offences under the PPCA. These include:

- Failure to report abuse.
- Failure of a service provider to comply with their duties.
- Failure of a service provider or individual involved to comply with the director's decision.
- Service provider taking adverse action against a person who reports abuse or assists in an investigation or inquiry.

Comments: There is a positive duty to report abuse involving an adult who receives care or support services from a publicly funded service provider, but service provider does not include a family. Therefore, this *Act* and the protections it provides would not have operated to assist Betty Anne.

2012 PDD Safety Standards Regulation

This regulation required service providers to comply with eight standards with respect to building, grounds' safety, maintenance requirements, environmental requirements, medication assistance and water temperature. This was updated in 2015 to provide that service providers must ensure compliance with safety standards regulations including inspection under the *Public Health Act*, compliance with *Safety Codes Act*, compliance with zoning and fire inspection. Community Boards could not contract with service providers who did not comply. The regulation did not apply to families. The entire regulation was repealed in 2016; however service providers continue to have obligations under their contracts to ensure safety.

Comments: Given the living conditions, including the lack of electricity, the inspections under this regulation would have identified issues relating to Betty Anne; however, this regulation would not have applied in Betty Anne's situation given that she was not receiving services through a service provider.

2013 PDD Policy

As referenced above, the PDD policy and registration form was amended to address status under the AGTA. Documentation must be provided to the PDD program to verify the designation under the AGTA. PDD regional staff must ensure that all consents obtained from the client and/or their guardian or co-decision-maker are consistent with the parameters identified in the Order. Where there is no order or authorization, the individual must be the one to authorize the services.

Comments: This does address the aspect that PDD referred and deferred to family members in the absence of a formal guardian or trustee. In Betty Anne's circumstances, this may have

provided the linkage to the protections under the AGTA.

2014 PDD Services Act

This legislation repealed and replaced the *PDD Services Act*. The preamble stresses that adults have opportunities to exercise self-determination; that individual needs are most effectively met through the provision of services that are based on equitable opportunity funding and access to resources; that the Government of Alberta recognizes, values and supports communities responding to the needs of adults; and that the Government has ongoing responsibility to ensure the provision of programs, resources and services.

The legislation replaced the community board based service delivery framework with a department based service framework. The purpose was identified to provide a more consistent, one-organization approach to planning and delivering services, regardless of where the individual lives. Ideally, this framework facilitates and coordinates file transfer from one region to another better and allows for the continuity of services. The voluntary nature of the program still remains.

2014 My Alberta Supports Policy

My Alberta Supports provides access to information and assistance on Government of Alberta social-based services: via web, the contact centre and in-person sites. My Alberta Supports is designed to be an integrated services delivery model where they help clients find programs they need and assist in moving and connecting across programs.

Comments: As noted before, although this is an improvement, there is still confusion when initial application and approvals must be confirmed by the service provider.

2016 PDD Safety Standards Regulation

This regulation was repealed in its entirety but service providers continue to have obligations under their contracts with Alberta to address safety.

2016 Enhancements to the Abuse Prevention and Response Protocol Policy

This PDD policy framework identifies proactive strategies for preventing abuse and procedures for service providers and PDD staff to follow when responding to allegations of staff to client abuse, including addressing the immediate safety and security needs of the individual. This policy is complementary to the *Persons in Care Act* and makes it a requirement of PDD funding that staff be made aware that it is mandatory to report any incident of suspected abuse immediately to their Executive Director or designate, the Family Managed Services (FMS) Administrator or to PDD. It encourages erring on the side of safety by reporting matters when an individual is uncertain.

Comments: As noted in relation to the legislation, this policy would not have applied to Betty Anne's circumstances as she was not in care or receipt of publicly funded services. As well, as noted before, the PDD staff and the Robin Hood staff did not identify Michael's threats to abandon Betty Anne as neglect or abuse nor did they identify Denise's indications that she could not care for Betty Anne as a path for neglect or abuse.

2017 Advocate for Persons with Disabilities

The Advocate for Persons with Disabilities was recently passed and assented to on June 7, 2017. The Advocate is to represent the rights and interests and viewpoints of persons with

disabilities (s. 3). In carrying out the role, the Advocate may:

- a. Identify and study issues of concern to persons with disabilities and recommend action where appropriate.
- b. Review programs and policies affecting persons with disabilities.
- c. Participate in processes in which decisions are made about persons with disabilities through public education.
- d. Promote the rights, interests and well-being of persons with disabilities through public education.
- e. Provide information and advice to the Government with respect to any matter relating to the rights, interests and well-being of persons with disabilities.

Comments: It is premature to comment on whether this role will develop in a meaningful way. At this point, a search of the internet does not lead to direct contact information for the Advocate and it is unclear as to whether an Advocate has been appointed.

As well, there is a difference between advocacy needed to identify and address issues in the system versus the advocacy needed just to have basic needs met. Families and individuals with developmental disabilities need to be supported and involved in identifying issues within the system; however, the care and support from PDD that an individual with a developmental disability receives, should not be based on the strength of their advocacy or the advocacy of their families or guardians. Instead, it should be based on the individual's needs.

Legislation In Other Provinces

In Alberta, outside the limited scope of the *AGTA* and the *Protection of Persons in Care Act*, there is no specific legislation that provides authority for emergency interventions to investigate, access, to enter to investigate (warrants) and to remove/apprehend and place for safety, vulnerable adults such as persons with developmental disabilities who may be experiencing neglect or abuse.

Legislation in other provinces exists that provides specifically for these types of emergency interventions. [See Appendix 1: "Compulsory Care Legislation in Canadian Provinces and Territories" prepared by the representative of the OPGT]

Comments: This type of legislation could act as a safety net for those in need and provide authority to police and others to act when there are concerns.

CONCLUSION

This report is not intended to rebut the presumption that families and individuals are not able to independently provide for the needs of persons with developmental disabilities. However, for those who need services, PDD is not able to help those who do not reach out to PDD and PDD does not help those who do not respond to PDD. Nevertheless, once families and individuals reach out for assistance, a proactive and fully engaged role should be adopted by PDD to ensure that services and programs are provided to meet the needs of the person. There are risks when individuals are not well known to PDD and when families and other representatives do not respond to PDD's requests for contact. Individuals, their families and guardians, service providers and government all have a role to play to support safety for persons with developmental disabilities. This must focus on a foundation of inclusion that puts the person first. A balance needs to be struck:

- between autonomy and avoiding unnecessary intrusion into the lives of

- persons with developmental disabilities and;
- protection of these potentially vulnerable adults.

PDD program resources do not keep pace with the demand for services. Individual safety is compromised when they cannot get basic or timely access to programs.

RECOMMENDATIONS

1. Ensure there is stable and adequate funding for programs that support individuals with developmental disabilities, focusing on personalized and individualized support with the goal of inclusive lives in the community. This stable and adequate funding must reduce the wait times in a meaningful way.
2. PDD needs to discourage the culture within PDD that normalizes crisis and take steps to change address it.
3. Continue to simplify, integrate and standardize the processes to receive and secure funded services.
4. Once services are requested, a proactive and fully engaged approach by the CSC should be encouraged and supported by PDD to ensure that care, services and programs are provided on the basis of personalized and individual needs, not on the basis of the strength of the advocacy in requesting for the services. PDD may wish to look at the models present in Child Protection areas where there are meetings with families and all care providers to identify the needs.
5. When a person with developmental disabilities, their families, guardians or other caregivers requests services on an urgent, emergent or crisis situation, immediate steps need to be taken to stabilize and support the person pending longer term solutions. In other words, services should not be provided on an all or nothing basis.
6. Review and ensure that there are adequate programs, including transportation for persons with developmental disabilities who live in rural areas.
7. Create better, responsive and available respite care, including emergency respite care for all caregivers, specifically addressing the special needs families, guardians or other caregivers providing care.
8. Continue to encourage better and direct communication between support agencies.
9. Ensure contact information for the Advocate for Persons with Disabilities is present in multiple locations, on print and website media involving government services for persons with developmental disabilities.
10. Ensure information about where and how to report concerns that a person with developmental disabilities, whether they are in care or not, may be neglected or abused is present in multiple locations, on print and website media involving government services for persons with developmental disabilities. This includes improvement to the My Alberta Supports website to make the links easier to locate, to ensure that complaints can be made anonymously and to ensure someone seeking to make a complaint is directed to the correct Service.
11. Review and consider legislation that provides authority for emergency interventions to

investigation, for assessment, for warrants to enter to investigate and to remove/apprehend and place for safety, persons with developmental disabilities, whether they are in care or not, who are in need of protection. Authorities may wish to look at the Child, Youth and Family Enhancement Framework, where there are different levels of intervention including family enhancement agreements and child at risk response teams (CARRT) where Child Welfare Services Investigators and Police jointly investigate concerns regarding the welfare of children.

12. Develop and create education standards and plans to ensure that PDD staff are qualified to identify and to address the personalized and individual needs of the person with developmental disabilities. This must include identifying when the person might become susceptible to neglect or abuse. This education must include information regarding mental illness and other factors that may operate to interfere with the person with developmental disabilities, their families, guardians or other caregivers from identifying and seeking the supports they need or that may lead to a path of neglect and abuse.
13. Continue the review of PDD to explore how to improve services for Albertans with developmental disabilities as announced January 19, 2018.

DATED February 6, 2018,

at Edmonton, Alberta.

"M. M. Collinson"

M. M. Collinson
A Judge of the Provincial Court of Alberta