Witness Name: LEEANN BARNETT

Statement No.: WITN0683001

Exhibits: WITN0683002 – WITN0683010

Dated: 20 June 2022

ROYAL COMMISSION OF INQUIRY INTO ABUSE IN CARE

WITNESS STATEMENT OF LEEANN BARNETT

I, Leeann Barnett, will say as follows:

1. Introduction

1.1. My name is Leeann Barnett. I was born in 1974. I live in Dunedin. I am a staunch disability advocate.

1.2. I sustained a traumatic brain injury at the age of 9. As a result, I live with significant co-morbidities, including epilepsy and moderate fatigue levels.

1.3. My parents are GRO-B-1 and GRO-B-2. Growing up, my parents ran a social welfare home. They then opened Mount Cargill Trust (**the Trust**), which provides residential care and support to people with disabilities. My parents retired from the Trust about 10 years ago.

1.4. Because of the homes my parents ran, I grew up with lots of foster siblings. I am very close with some of these siblings, especially my brother Shannon. I was also very close with my brother Amos, who was for all intents and purposes adopted into our family when we were very young.

1.5. I would like to give evidence about Shannon's experience in a variety of care settings. I would also like to give evidence about my brother Amos, who died in 2001 while in the care of the Wakari Hospital.

2. Shannon GRO-A

Early Life

2.1. Shannon was born in 1984. He has autism, epilepsy and dyspraxia. He is non-verbal.

2.2. Shannon lived with his biological mother until he was about seven years old, at which point he went into foster care. He then remained in foster care until he entered the care of my parents at the age of 10.

My relationship with Shannon

2.3. Shannon and I have a very special relationship. When he first came into the Trust, I immediately became the key person in his care. For example, over the years I was responsible for developing most of his behavioural plans. I also led Shannon's social integration back into the community from the beginning.

2.4. I taught Shannon from third form through to School Certificate in History and English at Kaikorai Valley College. He passed with flying colours. While he was still at high school, I secured a vocational contract through MSD for Shannon (and others) to continue their studies after high school. Shannon went on to study creative writing at Massey University.

2.5. All the while, I continually had regular contact with Shannon. He would come into my home and stay with me. In Shannon's words, I became his teacher, his sister, his friend and his mother all rolled into one.

2.6. I am currently Shannon's welfare guardian, and I have been since 2014. This means I am totally responsible for all decisions that relate to Shannon's care and wellbeing.

Mount Cargill Trust

2.7. Shannon came to live with us when he was 10 years old. The reason he came to live with us is because the placement he had had broken down, his needs were not being met and there were concerns for his safety.

2.8. This was near the time when the Department of Social Welfare closed the home my parents were running, and as a result my parents started establishing the Trust.

2.9. At the beginning, the purpose of the Trust was to provide care for boys with extremely high needs and behavioural issues. The boys would come from Auckland to Bluff.

2.10. Over time, more and more young people with autism and other disabilities came into the care of the Trust. It gradually became a specialist care service for people with disabilities, with a particular focus on people with intellectual, learning disabilities and/or autism.

2.11. As the Trust grew, it opened up several homes across Dunedin. By about 1999, Shannon moved into one of these homes, GRO-C Road (later known as Cameron GRO-C). Shannon and Amos were both living there at the same time.

2.12. Over the few next years, Shannon moved between living at GRO-C Road and another home called GRO-C. Both of these homes were run by the Trust. In the late 2000s Shannon moved back to GRO-C Road.

2.13. My parents stopped running the Trust in 2013. However, Shannon remained in the care of the Trust.

2.14. As soon as my parents retired, the Trust became nasty and vindictive. They were not doing things right for Shannon.

2.15. For example, in the 20 years prior to my parents ceasing their involvement with the Trust, there had been no complaints to the Ministry of Health. However, a number of complaints were made after they left.

2.16. Around this time, I attempted to deal with Shannon's issues directly with the Trust. All of the management staff knew me personally, as I had worked with most of them over the years. They knew all about my impairments, and used them against me on multiple occasions. I was bullied, and attempts were made to deny Shannon and I from contacting each other.

2.17. Around 2014, I asked my mother to apply for welfare guardianship of Shannon. However, this was vehemently opposed by the Trust. I was then asked by my mother's lawyer to apply instead. Which I did, because I had serious concerns for Shannon's health and wellbeing.

2.18. Mount Cargill Trust went out of their way to oppose my application, including an intervention from Shannon's biological mother in court at the point where the judge was about to grant my orders. However, it was quickly found out by Shannon's lawyer that his biological mother was not suitable to undertake the role.

2.19. In the years since, I have rebuilt the relationship with her and have discovered that the reason she opposed my application was because she was approached by a member of management at the Trust, who told her some untruths about me. This has led to her having to pay back the legal fees over time, which she doesn't have the financial means to do so.

2.20. This intervention by Shannon's biological mother significantly delayed the process in me obtaining welfare guardianship. It wasn't until months later that it was finally granted. This extended process, as a result of inappropriate interference from the Trust, had significant impacts on Shannon, me and Shannon's biological mother.

2.21. There was misappropriation of Shannon's money that started around this time. The Trust was charging him for things that he either couldn't use, or things that weren't actually supplied. When I asked for receipts for proof of purchase, my requests were always denied.

2.22. For example, the Trust would require Shannon to spend his own money on taxis, when they should have been covered by the Trust. This was a gross breach of the Ministry of

Health service contract. This is an ongoing issue, as the money has never been returned. From my perspective, the Trust still owes Shannon this money, which totals nearly $2,500. I have been told my only recourse left is going to the small claims tribunal.

2.23. The Trust also used his money to pay for a swim card, even though Shannon wasn't able to swim during this time. Shannon had not been able to go in the water for many years.

2.24. I was eventually given access to the receipts for Shannon's expenditure, where I had to sit in an office and review the receipts while being glared at by two staff members from the Trust. They told me that it was their legal responsibility to decide who could and couldn't see Shannon's personal finances. This was in direct conflict with my rights and responsibilities as Shannon's welfare guardian.

2.25. The Trust would also do things like take Shannon to the doctors for a flu injection, which they couldn't legally do without my permission as his legal guardian. My lawyer said this was disingenuous misconduct, if not fraud.

2.26. One day Shannon turned up to visit me and his teeth were disgusting. He had gingivitis from not having his teeth brushed properly. However, the Trust completely denied any wrongdoing. The issue was so bad that I had to take Shannon to the doctor for treatment.

2.27. The amount of doctor's appointments Shannon was having at this time was outrageous. He was constantly sick with things like ear infections. It was clear that he wasn't being provided with a high standard of care in the Trust. When I tried to address this issue, the manager told me that staff had determined his infection had cleared up. But, because Shannon is non-verbal, and he had had all communication removed from him, the staff should have followed best practice and taken him back to the doctor.

2.28. During this time, I suspect that Shannon was being physically assaulted by staff. He would turn up to me on weekends with pock mark bruising on his arms. The Trust told me this was the actions of other residents, but I don't buy it. I have been told that some of the staff being very nasty to Shannon, so I have strong suspicions that there were physical altercations when I wasn't around.

2.29. I had serious concerns for Shannon's wellbeing and safety as a result of the negligence of the Trust. As a result, I had no choice but to take legal action. It cost $2,000 to instruct a lawyer, which I had to borrow. My lawyer then sent a letter to the board of trustees of the Trust, in an attempt to resolve my concerns. The response from the board of trustees was appalling, and I believe it was misleading and unlawful. These letters are annexed as WITN0683002 and WITN0683003.

2.30. I then laid a complaint with the Ministry of Health, which led to their ongoing involvement until I removed Shannon from the care of the Trust. This complaint is annexed as WITN0683004.

2.31. Shannon remained in the care of the Trust until I pulled him out on 1 October 2016. My first welfare guardianship order had a clause that prevented me from pulling him out of the Trust without mutual agreement between me and the Trust. However, due to the Ministry of Health's close involvement with the issues at the Trust, I was able to pull Shannon out regardless. Shannon then came to live with me for a while.

2.32. Just after Shannon left, I requested a copy of all his files from the Trust. All I got was a small stack of paper which had very little to do with Shannon's care. By this point, I had no energy to fight the Trust to get his complete files.

2.33. I also lodged a complaint to the Police about the financial irregularities regarding Shannon's finances. They came back to me and said that they received complaints like that all the time, and these organisations could just argue it was poor accounting. So the Police just put it in the too hard basket.

Living with me

2.34. When Shannon came to live with me after I pulled him out of the Trust, I was appalled at how badly he had been neglected. He ended up staying with me for over 3.5 years, even though he was initially only meant to be with me for two months. I didn't get any financial assistance or benefit to assist with caring for Shannon during this time.

2.35. Shannon had become very institutionalised after living in the care of the Trust. He was doped up on risperidone, which is a powerful anti-psychotic drug. Risperidone is used on people like Shannon for no other reason than chemical control. It is nasty, horrible and damning to say the least.

2.36. I was disgusted in the clothes that he had been wearing. Every single one of his shoes were two sizes too big, which meant he would get blisters from walking in them. He was also extremely overweight, which was the result of poor diet and inadequate access to exercise under the care of the Trust.

2.37. However, Shannon made big improvements even after living with me for just a short amount of time. WITN0683005 shows what Shannon looked like before and after living with me for just over a year. In those photos, Shannon went from a size 2XL to a medium. He lost 8kgs in the first three months of living with me.

2.38. After Shannon had lived with me for almost a year, I received 18 hours of support to assist me when Shannon was living with me. I had to fight tooth and nail to get this funding.

2.39. With this funding, Shannon's support people would take him to various activities throughout the week. They would walk tracks, do "guy things", do volunteer work, or do other things that Shannon liked. Shannon benefited from these relationships significantly, and he was able to reintegrate into the community. Shannon has received lots of positive recognition for his volunteer work.

2.40. As a result of this voluntary work and community integration, Shannon began to use verbal language for the first time in 20 years.

2.41. Unfortunately, these community activities have been reduced significantly in Shannon's current care arrangement. This is partially due the impacts of COVID-19.

Communication

2.42. Shannon communicates using a technique called facilitated communication. It involves a facilitator supporting Shannon's wrist, which he then guides towards a keyboard with a key guard to type out words. It is a controversial practice, but that's immaterial. It is the form of communication that Shannon has been using since he was 8 years old, which he is most comfortable with.

2.43. Shannon was using facilitated communication before he came to us, but only at school. When Shannon was 9, he participated in a year-long research paper through Otago University, in which he was the sole subject. This research concluded that facilitated communication is a legitimate and positive form of communication.

2.44. Shannon uses facilitated communication to type into a Lightwriter. A Lightwriter is a small machine with a keyboard on it, which has a key guard to prevent Shannon's fingers from sliding. It is worth $7,500. He types into it, presses a button and it speaks.

2.45. Prior to having a Lightwriter, Shannon sometimes used a laptop with a key guard for school work. Before that, he would use facilitated communication through a laminated sheet of paper with a qwerty keyboard, which was a laborious task.

2.46. When Shannon first got a Lightwriter, his personality changed overnight. The Lightwriter gave Shannon a voice, and he no longer needed to rely on other people to speak for him (using facilitated communication). He could even choose which voice the Lightwriter spoke in. All of a sudden, he was in control of communication with his own voice.

2.47. Shannon can read fine, but I tend to read to him because he is selective about when he wants to read things.

2.48. Poetry is one of Shannon's favourite things. He loves poetry. He is a very talented writer. Examples of Shannon's writing are annexed as WITN0683006 and WITN0683007. He has won prizes at open poetry competitions for the general public.

2.49. Around 2011, when Shannon was in the care of the Trust, one of the staff decided that facilitated communication was not a legitimate form of communication. So, it was taken off Shannon and he was no longer able to do facilitated communication. He was left with only two sheets of laminated paper that said "YES" and "NO", annexed as WITN0683008. This was despite him using this form of communication with many teachers / teacher aides and gaining high school qualifications.

2.50. I fought this decision, but I got nowhere. This meant that Shannon was completely stripped of his voice and could no longer communicate to his full potential. Shannon's life without facilitation is like having your hands tied behind your back and a piece of duct tape over your mouth.

Education

2.51. Shannon is very bright. In sixth form Maths, out of all the sixth formers at his high school, Shannon came sixth. He also got very good scores in his other School Certificate subjects

– especially English and History. I was one of the people who taught Shannon as a 1:1 teacher during this time.

2.52. In his earlier years of high school, Shannon was very popular with the seventh formers. He had a different kind of maturity, which meant he got on better with the older pupils and socialised with them.

2.53. Shannon went on to study creative writing at Massey University. He has enough credits to receive a Certificate in Arts. He started this while he was at high school, and continued this while he was in the care of the Trust with some vocational funding. There were many different people who could facilitate communication with Shannon at this time.

Life in care now

2.54. Shannon now lives in a care home by himself under the care of GRO-C Trust GRO-C, with 24/7 care. It took me over three years to secure the funding for Shannon to be able to live in his own place.

2.55. Shannon's day-to-day life is a bit dull and boring at the moment. He is not doing as many activities or outings as he used to. This is partly because of COVID-19, but there are some other factors at play too.

2.56. GRO-C has been reluctant to let Shannon use facilitated communication. I think there is some concern that he will use it to complain about staff, so that is a worry at the moment. It wasn't until I contacted the Ministry of Health to finally get a meeting set up with his speech and language therapist, who instructed GRO-C to stop denying Shannon his facilitation. Despite this, to this day GRO-C is still maintaining that Shannon cannot facilitate with his staff.

2.57. Currently, no one except me can provide the support for Shannon to use facilitated communication. But I am currently teaching Shannon's carer GRO-C how to facilitate.

2.58. Shannon is a keen volunteer for the Dunedin Fringe Festival. He volunteers for this festival every year – they rely on him. He is loved, accepted and brought into this community. It has opened up his world and it encourages him to try and verbally communicate.

Looking forward

2.59. I have a unique perspective because as a child from the outside looking in when I visited Amos in Cherry Farm. Then growing up, and as an adult, I was a part of the creation of care homes. I was always far ahead of everyone in terms of my thinking and ideals.

2.60. The way I look at it is we went from very bad institutionalisation with large institutions, to a different kind of institutionalisation with smaller group homes. We're still not out of institutionalisation.

2.61. The Government must accept that a complete and utter change needs to happen in disability care. The major issue is that disability care is run and funded by able-bodied people who, while they might be well meaning, have no real idea about disability.

2.62. I want the Government to acknowledge that nibbling around the edges is not going to solve the problem - it needs to be flipped upside down. The whole disability sector needs to be run by people with disabilities.

2.63. Disability organisations are too big. They lack the ability to offer individualised care from a true life perspective. Instead, their focus is on policy, procedures, funding and generalised care. Organisations (both government and private) lack the ability to truly perceive what honest integration within a community really looks like. In part this is because almost no organisation is run by a person with a disability.

2.64. There needs to be greater accountability of trusts and trustees. There is no regulation to vet the quality of people who end up on trust boards and no way for anyone to hold them accountable for the actions. Police checks for board members should be compulsory.

2.65. Care work has become about what you can pass in terms of a piece of paper, and not about who you are as a person or how well suited you are to the role. So, you ended up with people who shouldn't be doing the job at all.

2.66. Care workers don't stick around for long enough either. This is because it's not a valued profession. And it is people like Shannon who suffer as a result of this.

2.67. We are sick to death of able-bodied "do gooders" who come in and tell us how to live our lives. That's what happened with Shannon and his facilitated communication. That's what's still happening in these care homes.

2.68. Many of these issues are ongoing. I'm still fighting battles for Shannon.

3. Amos Cameron

3.1. Amos was another one of my foster brothers. I call him my non-biological twin. He was born in 1974. He had severe autism, obsessive compulsive disorder, Tourette's syndrome and paranoid schizophrenia.

3.2. Amos came into the care of my parents around the age of 11. Although my parents didn't adopt him, he was our boy. He was a core part of our family.

Wakari Hospital

3.3. When we were teenagers, Amos was placed in ward 9B at Cherry Farm, which was a secure psychiatric ward. I remember going in there to visit and it was terrifying.

3.4. The walls were stained dark brown, and there were keys jangling. It was like walking through a prison. I couldn't visit him in there because it was so horrible. We were just children at the time.

3.5. In 2001, Amos got very sick and his behaviour deteriorated, which led him to be placed in unit 10A at Wakari Hospital. This was not his first time being placed in Wakari Hospital.

3.6. He has previously been living at GRO-C Road (GRO-C House), but his mental health had deteriorated to such a degree that the Trust was no longer able to provide the support he needed. That is why he went into unit 10A at Wakari Hospital.

3.7. Wakari Hospital did a very poor job at caring for Amos. My parents raised concerns about him being moved to an unlocked ward, saying "it would be signing his death certificate". The staff ignored our concerns and continued on the path of care that they felt was appropriate for Amos.

3.8. My parents were the founders and heads of the Trust, and had run it for over a decade at this time. Despite my parents highlighting evidence of Amos' deteriorating behaviour, Wakari Hospital staff maintained that he was improving, and chose to ignore both our family understanding and professional understanding of Amos.

3.9. At this time, Amos' psychiatrist hadn't been seeing him – she had just been talking to management on the ward. She took him off most of his medication, and said he didn't have schizophrenia. According to the hospital he was getting better. But he clearly wasn't.

Amos' Death

3.10. On 26 June 2001, Amos went missing from Wakari Hospital. This sparked New Zealand's largest search and rescue operation in a decade, and to this day the biggest in the Dunedin region. Unfortunately, the mission was unsuccessful, as Amos was presumed drowned. He was 9 days shy of 27 at the time.

3.11. Amos was meant to have observations every ten minutes while on the unlocked part of Ward 10A. It was over half an hour before the staff realised Amos was missing. The staff didn't even search the grounds for Amos.

3.12. The unauthorised leave notification given to the police was so poorly written that the police didn't have any concerns. If the form had been filled in more accurately, a more prompt police response would have immediately occurred.

3.13. It wasn't until lunch time that my parents at the Trust were notified by Wakari Hospital, as the message was not escalated in accordance with the protocols that the Trust had in place for urgent notifications. Wakari Hospital was well aware of these protocols.

3.14. My parents were in Central Otago at the time, but some staff from the Trust immediately went to Wakari Hospital to find out what was going on. Once they discovered a search of the grounds hadn't been carried out, they decided to do this themselves.

3.15. At this time, there were some staff from the Trust who were in a training at Wakari Hospital. When the staff from the Trust went to help with the search, the person running the training said that the staff would fail the training if they left to help with the search. There was no care or recognition of the seriousness of the situation. Their response was adversarial.

3.16. Once my parents were informed, they immediately drove back to Dunedin. My parents immediately contacted the Dunedin police to notify them. At this time, my mother was informed that the unauthorised leave notification lacked detail and did not reflect the seriousness of the situation. My mother then told the sergeant that “if they didn’t find Amos by dark, they’d be looking for a body”.

3.17. At this point, the police immediately recalled LANDSAR from their training at Berrick to focus on the search for Amos. Due to the delay in time, the police and LANDSAR faced a number of challenges. Once of these was the issue of getting information out into the public arena e.g. on the radio. This meant we had no idea which direction Amos had gone in, which we didn’t find out until 7pm that night.

3.18. For three days my family endured a freezing, windswept coastal point where LANDSAR had set up a base to search for Amos. For three days, we watched helicopters fly in and out. We saw dozens of vehicles come and go, where sometimes one or two people would exit, occasionally with a dog. We watched a yellow square van grow branches from its roof. We listened to boats off the coast being directed to look out for Amos. We waited for searchers as far as Kaitangata to report back. We heard the crazy stories of the psychics who had rung up.

3.19. On one occasion, there was a report that had come in that there were possible footprints found at Livingstone Park, which was not far from the search base. My father, brother and one of the staff from the Trust jumped in the car, and despite the dimming light, raced around the corner to search for Amos. We didn’t know the area that well, and almost got lost ourselves trying to find our way off the beach back to the car.

3.20. On the third day, our family, and some of the staff from the Trust, sat on an old park bench on the domain where the base was set up. We knew instinctively that the search was coming to an end. The image of the police and LANDSAR walking towards us with drawn faces is one of those that will never be erased from my memory. It was obvious that they were coming to tell us that they could do no more at that point.

3.21. Fifteen months and three days later, Amos’ jaw bone was found by a member of the public walking along the beach, at Kuri Bush (3 kilometres north of Taieri Mouth). This was the only remains that were ever found.

3.22. I cannot speak highly enough of both the Dunedin police and LANDSAR for the effort and work they did in searching for my brother.

3.23. A year to the day after Amos’ disappearance, my father was compiling a death notice for the newspaper at work. Suddenly, he had a serious heart attack, where he was dead for twenty minutes. When he woke up, he had to be told once again that his Amos had gone missing. As a result, he now lives with a significant brain injury. I believe this was connected to the stress and devastation of losing Amos.

Investigations

3.24. The coroner’s decision is annexed as WITN0683009.

3.25. The coroner acknowledged that a real difference could have been for Amos if he was better monitored while he was in Unit 10A.

3.26. The coroner also found that when a patient goes missing and there are fears for their safety, media broadcasts should be instituted as soon as possible

3.27. The coroner's inquest into Amos' death was a whitewash. The psychiatrist that did the review, Dr Bathgate, excused the behaviour of all the staff at Wakari. In my opinion, it was all a cover up.

3.28. I have deep concerns that Dr Bathgate had conflicts of interest and potential bias due to his connections in Dunedin's mental health services.

3.29. I believe that the report that my family submitted to the coroner's court clearly outlines our concerns with the investigation. This report is annexed as WITN0683010.

3.30. Because of these concerns, Mum rang and wrote to Richard Thompson, the chairperson of the DHB at the time, who had not been informed of anything in regards to Amos' disappearance.

3.31. Richard Thompson and his Board subsequently tried to withdraw the Dr Bathgate report because it was not impartial, given Dr Bathgate's proximity to other people involved in the investigation. However, the coroner refused to withdraw it because it had already been submitted to the coroner's court. There was never acknowledgement from the coroner that the Southern DHB had attempted to withdraw Dr Bathgate's report, let alone why.

3.32. We were unable to put a complaint to the Health and Disability Commission because of the heart attack my father had experienced and the significant long term recovery as a result of it. This significantly impacted the whole family. We went into survival mode, and we were unable to make a HDC complaint.

3.33. As a result, we were not able to challenge the issues that the coroner did not address regarding the major issues leading up to Amos' disappearance.

3.34. In this instance I strongly believe that an advocate should automatically be offered to assist with any complaint to HDC (as suggested by the coroner) to avoid families becoming overwhelmed and not carrying through with a complaint. Thus allowing wrongdoings to go without adequate independent scrutiny.

Statement of Truth

This statement is true to the best of my knowledge and belief and was made by me knowing that it may be used as evidence by the Royal Commission of Inquiry into Abuse in Care.

Signed GRO-C

Dated: 20 June 2022