

**ABUSE IN CARE ROYAL COMMISSION OF INQUIRY
DISABILITY, DEAF AND MENTAL HEALTH INSTITUTION HEARING**

Under The Inquiries Act 2013

In the matter of The Royal Commission of Inquiry into Historical Abuse in State Care and in the Care of Faith-based Institutions

Royal Commission: Judge Coral Shaw (Chair)
Paul Gibson
Julia Steenson

Counsel: Mr Simon Mount QC, Ms Kerryn Beaton QC, Ms Ruth Thomas, Ms Lucy Leadbetter, Mr Michael Thomas and Ms Kathy Basire for the Royal Commission
Mr Gregor Allan, Ms Sandra Moore and Mr Vaughan Dodd for the Crown

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Abuse in Care Royal Commission of Inquiry
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TRANSCRIPT OF PROCEEDINGS

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Hearing opens with waiata Ka Pioioi and karakia by Ngāti Whātua Ōrākei

[10.13 am]

CHAIR: Tēnā koutou katoa kua huihui mai nei ki runga i te kaupapa o te rā nei te kaupapa Ūhia te Māramatanga. Greetings to everybody who's come today for this very, very important day of the hearing. I want to particularly welcome the survivors who are attending, particularly those from the disability communities, from the Deaf communities and those who suffer mental distress. This hearing is all about you and yours, and it has been a privilege for us to sit and listen to that through these last few days. So welcome very much to you, whether you are here in person or whether you are watching on the livestream.

I'm now going to ask Ms Thomas to introduce our next witness. Thank you, Ms Thomas.

MS THOMAS: Thank you, Madam Chair. This morning we are here to welcome our next witness, Lusi Faiva. She is supported here today with Kelly and Umi from the Donald Beasley Institute and her boss and friend John, and Lusi is able to and ready to take the affirmation and then we'll go to her evidence.

CHAIR: Talofa Lusi, welcome, welcome, welcome to the hearing, we're happy that you've been able to come. And we also appreciate that you've got Kelly and Umi and John there in full support of you, so you're well surrounded. Lusi here's the affirmation.

LUSI FAIVA (Affirmed)

QUESTIONING BY MS THOMAS: Good morning, Lusi. Prior to this morning, have you prepared your full statement with support with Kelly and Umi and have you already recorded all of your statement and you'd like to share into your communication device?

A. **[Nods.]**

Q. Would you like to share that with the Commissioners and with the public now?

A. **[Nods.]**

Q. Thank you.

A. "I will open my statement with key words that will recur in themes of my statement : freedom, expression, choice, routine, fear of being forgotten/left, worry, restricted, respect, affection. I am a proud Sāmoan woman. I am an artist, dancer and passionate freedom seeker. I was two years old when I was diagnosed with Cerebral Palsy. There was little support for disabled children and their families when I was little. The doctor instructed my mum for me to go to an institution, he said, it would be better this way. Soon after I was moved to Kimberley Centre (a specialist hospital for the care of people with intellectual disabilities).

1 I only remember small amount from my years at Kimberley. I was sharing a room
2 with other children there. During the day we sat in the recreational room but there were no
3 activities going on. We hardly interacted with each other. In the shared space there were
4 people of all ages with different disabilities. The institute felt dark and cold.

5 I did not know how to express myself. There were no tools or strategies offered to
6 me to communicate with people around me so I could express what I wanted to and needed.
7 It was assumed that I did not have the mental capacity to communicate, and it was assumed
8 that I had an intellectual disability. No-one thought to ask me what was going on for me. I
9 was under five at this point but old enough to remember how trapped I felt in myself.

10 No-one ever talked to me about my Sāmoan heritage either. I felt like people didn't
11 know or care about my Sāmoan culture. Even if they did, there was no recognition, interest
12 or inclusion. There was no respect or effort to recognise me for who I am.

13 The nurses didn't look after me properly. The only times that the nurses came on to
14 the ward was to give us children our medicine and then they left. Once, I fell and broke my
15 ankle because no-one was watching me. If I had received better care then , my physical
16 health would be better today. I never received any specialised support until I left the
17 institute even though my mum was told that being there would be better for me.

18 I think that the concept of institutions are not set-up to care and look after the
19 disabled people because it is built on a system that dehumanises disabled people and I think
20 that hasn't changed much for how the current state care works. Care was about medication,
21 change, showering and other very clinical procedures that does not take into account of the
22 very individual needs such as human connection and affection.

23 I can remember doing schooling at Kimberley. I believe there was kind of school
24 scheme. I think I was just five years old when I started. There were two staff members
25 who were a couple. They visited Kimberley every day and they were the only ones who
26 taught us kids. They recognised that I was switched on and started teaching me how to read
27 and write and to express myself, finally, after I was five. It was strange to see words in the
28 beginning. But as the time went on, I could understand what they were teaching me. I was
29 a fast learner. I had a blackboard with chalk that I was able to hold. They taught me how
30 to spell things. They were kind and gave their time to come and play with us. It was the
31 only time we could do other activities like games and drawing. I learned ways to express
32 myself. I remember them dearly.

33 While I was in the Kimberley Centre, my mum never visited me. The first time she
34 came was when she came to take me home. I didn't know who she was and I felt nervous.

1 The two staff members who taught me how to express myself kept in touch with Mum and
2 convinced her to take me home. I felt upset to leave Kimberley because I didn't want to
3 leave them. I did not see them for a long time after I left Kimberley, yet they still remain
4 significant people in my life. Their regular interactions with me taught me that I was
5 someone, I was Lusi and I deserved to be loved. I left Kimberley Centre when I was seven
6 years old.

7 Returning to live with Mum was challenging. She was in an abusive relationship.
8 Living with his family was so confronting and scary. Mum had only been in New Zealand
9 for eight years at this point and she was left alone without moral support for her. It was a
10 tough time for her.

11 I liked going to school because it gave me a sense of normality. I could switch off
12 from what was going on at home. I was interacting with other children and learning. But
13 this came to a halt when we had to escape from mum's boyfriend eventually. We went to
14 Women's Refuge first. Then while mum was looking for a place to live for us, I was in a
15 hospital.

16 As I was coming to the terms with my CP, the doctors decided to make me walk
17 through surgeries. I had a surgery to straighten out my legs and ankles, followed by
18 rehabilitation. The doctors didn't explain what they were doing with me. I felt like my
19 body was being manipulated. They were working with my cerebral palsy as if it was
20 disconnected from me and my feelings did not exist.

21 My mum came to pick me up at the end of the rehabilitation and we took a train to
22 Auckland to stay with my auntie and her family. She had a four-bedroom house with 15
23 people in it and everyone spoke Sāmoan. I went from not really understanding my Samoan
24 identity, nor hearing my language, to being thrown into this rich but overwhelming space.
25 This transition required a lot of adjustment from me. I was receiving the cultural
26 knowledge I had longed for but my Sāmoan family didn't know about cerebral palsy and
27 therefore didn't know how to care for me.

28 We only stayed with them for a short while, and we eventually moved to our own
29 place in another suburb. While I was living with my aunty I went to a school for children
30 with cerebral palsy and I stayed in the same school after we moved. They didn't really
31 teach us, though, because the school was focused on recreation and rehabilitation. Also,
32 none of the schools or education I received had good understanding of my culture.

33 When things were really hard at home with my family I sometimes wished that
34 I hadn't gone home. However, looking back now, I think that if I had stayed in Kimberley

1 for any longer, my life would have been worse. I wouldn't have had the freedom that I later
2 experienced to explore my own life. I wouldn't be the Lusi I am today.

3 When I was 15, I joined an acting group. It was my first step towards exploring
4 myself and what I wanted to do. Soon after I started to rebel by partying with my friends.
5 After a while of doing that, I decided that I wanted to explore how far I could push my
6 personal boundaries, break free and be reckless by leaving home. It was risky and at times
7 an unsafe way to live but I needed to feel this, explore this, in order to gain some autonomy
8 on who I am and what I wanted to do with my life. This was life-changing. Meeting
9 similar people often broken by their own history and, like me, seeking their own truths.
10 These people became my family during this time, they got me.

11 Eventually, I had to return home for obvious reasons. I went flatting in a house run
12 by a disability support service. They provided support workers so that I could do things
13 I needed but I didn't really like it there. I felt restricted and I wanted my freedom back.
14 I moved out after a year to a state house where I've lived ever since. I have support workers
15 who come in mornings and nights now. Sometimes I feel scared living on my own because
16 sometimes support workers don't turn up and I get stuck. There was a lady who passed
17 away alone who lived near my area, and sometimes I get scared it might happen to me.
18 I feel like don't have control over this situation. This sense of fear and restriction brings me
19 back to the memory of being in Kimberley.

20 I joined a dance group for disabled people by disabled people when I was 28. I had
21 no training, but I knew that this was my passion. I feel free when I dance. To be honest,
22 I still struggle with putting myself on the stage because I feel judged. But I put a facade on
23 to be on the stage and I pour my heart into my performance. I express my identity through
24 my dance. I need it to be real, and it can be challenging to get my moves right. Through
25 dance, I have reconnected more strongly with my Sāmoan culture.

26 If I met myself in Kimberley, I believe that this little Lusi would be happy seeing
27 someone like her wanting to play alongside her. That little Lusi at Kimberley wanted to
28 know she was important, loved and deserved of affection, that she was from a rich and
29 vibrant Sāmoan heritage and she had so many strengths.

30 As an adult, I fell in love with the performance world. The creative space allows
31 me to explore myself through dance. It brings me beautiful moments, movement,
32 interactions, tears, love and laughter.

33 Being in care was like a slap in my face. There was no freedom of choice in
34 entering care. I was lost in care. There was no acceptance, brief or trust from others that

1 I needed freedom. Freedom is acceptance of who I am as an individual. There was no
2 voice of freedom in the institution.

3 Living independently now is a source of freedom, but it has moments of good and
4 bad. Although I am living independently, the support services are not resourced enough to
5 be reliable when I need them urgently, even today. It frustrates me a lot. Care still
6 fundamentally operates under a similar system where I am left without care and support for
7 a long period of time. This reality is a reflection that the system lacks the respect for
8 freedom and even basic human needs."

9 **Q.** Thank you, Lusi. Are you okay to carry on?

10 **A.** [Nods.]

11 **Q.** In preparation for your evidence today, the Commissioners have given you four questions
12 which I understand you have already typed in to your communication device. If I read
13 those questions one by one, would you like to respond to those now?

14 **A.** Yes.

15 **Q.** The first question is what would be the ideal living situation with the right support, what
16 would this look like for you right now, Lusi?

17 **A.** Answer 1. It is hard to say. The support I have now is good in terms of the support
18 workers I have, but there is always uncertainty whether they will turn up or not, and not
19 having that security is very hard. Right support for me looks like having consistent support
20 where I don't have to feel worried about how I am going to get out of bed, or I can come
21 home at night when I want to and still be able to get ready to sleep with support.

22 **Q.** Thank you. Question 2, would your relationship with your family be different if you did
23 not go to Kimberley?

24 **A.** Answer 2. Maybe if I didn't go to Kimberley, I would have known more about my mother's
25 earlier life, which would have given me more idea about who she is. The time I went to
26 Kimberley, my mother was still a new migrant from Sāmoa and she had struggles in
27 settling in this country. At this time, she was in a poignant time in her life and when I was
28 placed in Kimberley, I was at a poignant development phase of my life. When I came
29 home, it felt like we were strangers and it has been really hard to make-up the years we
30 missed out on being with each other.

31 **Q.** Thank you. Question 3. Does the government provide you funding for communication
32 supports?

- 1 A. Answer 3. Yes, they supported me via the Ministry of Health and this has been good. But
2 funding isn't easy to get because New Zealand is often not aware of new technology. So to
3 get funding for the latest technology that works better for communication is not easy.
- 4 Q. Thank you. And question 4, what more can we do to ensure people's needs to communicate
5 are not neglected, what do people providing care and all other members of the public need
6 to know about communicating with people who use communication devices or augmented
7 communication systems?
- 8 A. Answer 4. People need to know and understand that people can communicate and through
9 taking time to know the person, people can come to understand how to communicate with
10 the person. There are so many ways to communicate. Through different communication
11 abilities, such as my technology, my eye and my hands, and people need to understand that.
12 Sometimes people need to have a training and patience to understand that everyone
13 has the ability to communicate. The system of caring inside an institution or in the
14 community is dictated by the routine of the day and it does not necessarily allow
15 uniqueness of individuality to be respected, which means that some people providing care
16 and some other members of the public do not have patience to communicate well.
- 17 Q. Thank you, Lusi. Thank you for all of your evidence today and for your answers to those
18 questions. I'm just going to leave you now with the Commissioners who would like to
19 speak with you.
- 20 A. [Nods.]
- 21 **CHAIR:** Thank you so much, Lusi. Commissioner Steenson is going to thank you formally.
- 22 **COMMISSIONER STEENSON:** Talofa lava Lusi. You're so brave, your statement was so
23 inspiring. So insightful for the Royal Commission to hear and everybody here. Thank you.
24 You've given us such a huge amount of information and what really stuck out to me was
25 how you talked about institutions dehumanising people, and how the clinical procedure is
26 not human care. And I want to acknowledge your resilience, incredible resilience, you're
27 very inspiring. And it's beautiful to know how you connected with your Sāmoan culture
28 through dance, just beautiful. So, on behalf of the Royal Commission, manuia, ngā mihi
29 nui, tēnā koe, thank you.
- 30 **CHAIR:** We will take a break now.
- 31 **MS THOMAS:** Yes, if we take the morning adjournment now until 10.45.
- 32 **CHAIR:** Thank you Lusi.
- 33 **Adjournment from 10.31 am to 10.57 am**
- 34 **CHAIR:** Ms Thomas.

1 **MS THOMAS:** Thank you Madam Chair. The next witness this morning is Matthew Whiting
2 and he is ready to take the affirmation before we begin.

3 **CHAIR:** Good morning Matthew. Thank you so much for coming, taking an interest in the
4 Commission and being prepared to give your evidence, we really appreciate it. I'll read you
5 the affirmation.

6 **MATTHEW FRANK WHITING (Affirmed)**

7 **MS THOMAS:** Good morning, Matthew. Would you like to start with your mihi?

8 **MATTHEW:** Yes. Ko Makora te maunga, ko Rotokakahi rāua ko Whangape ngā awa, ko Te
9 Rarawa te Iwi, ko Te Uri o Tai te Hapū, ko Taiao te marae, no Ōtautahi ahau, ko Matthew
10 Whiting ahau.

11 **CHAIR:** Tēnei te mihi ki a koe mō tō pepeha, tēnā koe, tēnā koe.

12 **MS THOMAS:** Thank you, Matthew. Would you like for Yonel, who is seated next to you, to
13 now read through your statement to the Commissioners?

14 **MATTHEW:** Yes.

15 **MS THOMAS:** Then once Yonel has finished reading your statement, we'll take a short break and
16 then I'll ask you some questions and then the Commissioners can ask some questions.

17 **MATTHEW:** Okay.

18 **MS THOMAS:** Thank you.

19 **YONEL:** "My name is Matthew Frank Whiting. I was born 1965. I grew up in Christchurch
20 New Zealand. I work as the Regional Disability Leadership Coordinator for the Southern
21 Region (South Island) and as a Service Manager – Adult Services in Christchurch at CCS
22 Disability Action. I have been working there for almost 21 years. First and foremost, I am
23 a disability activist.

24 My birth mother was Māori and my adoptive family were Pākehā. I was diagnosed
25 with Cerebral Palsy when I was nine months old. I have spastic quadriplegia with a speech
26 impairment. At the early stages of my diagnoses, the specialist believed I had a learning
27 impairment as well. At four-and-a-half years old, a child psychologist tested my
28 intelligence and found that I was above average.

29 My birth mother lived in Auckland but I was born in Christchurch. Before I was
30 born, my birth mother had a child who had been whangai'd out. Her father said you can
31 only have one mistake. They were a Catholic family and both pregnancies were out of
32 wedlock. He forced her to adopt me out.

33 When I was two weeks old, my adoptive parents, Bill and Mary, were phoned by a
34 parish priest and asked if they wanted another baby. I don't suppose they were looking for

1 another as they had already adopted two children, my brother Anthony and my sister Mary -
2 Ann. My understanding is that the adoption was official but it was obviously an unusual
3 approach, especially compared to the system we have now.

4 When I refer to my mum and dad, I am talking about Bill and Mary. I contacted my
5 birth mother in the late 1980s through an agency I recall being called the Social Welfare
6 Adoption Information Service. They passed a letter from me to her. She said no to
7 meeting me as she was scared of her father finding out. But I persisted and I still wrote to
8 her and rang her on occasions.

9 I contacted her to let her know that I was going to be in Auckland for a conference.
10 I told her the name of the hotel I was staying in and said, "Now it's up to you." She came
11 and met me. She had caught three buses to get there, which told me that she did really want
12 to come. This was extremely emotional for both of us. My extended family mostly have
13 blonde hair and blue eyes. When I met my birth mother, it was the first time I saw
14 someone who resembled me.

15 We met around seven years before she passed away. When she died, my
16 half-brother found a letter I had sent her in her belongings and contacted me. We remain
17 connected to this day. I have limited knowledge of my whakapapa.

18 When I was nine months old, Mum took me to the doctor as it had become clear that
19 I was missing developmental milestones. The doctor told Mum not to make a fuss and that
20 she was overreacting. She wasn't taken seriously at all. Mum asked for a second opinion
21 and I was diagnosed with Cerebral Palsy with a cognitive impairment. She was told that I
22 would live only until I was five years old. This had a huge effect on my mum's mental
23 health. Therefore, she decided that she would not take any photos of me from then
24 onwards.

25 Another consequence of this, some of my family members and my parents' friends
26 told Mum and Dad to hand me back. You need to remember this was all within the context
27 of the time and the understanding of disability in our society, with its influential history of
28 eugenics. Mum and Dad were told to return me and to get a perfect baby instead.

29 At four, I had my first taste of institutional life. I have a very hazy memory of being
30 in Templeton. Some professionals said I should go there --

31 **MS THOMAS:** Yonel, can I just ask you to speak slightly more slowly? Thank you.

32 **YONEL:** Sorry.

33 "Some professionals said I should go there, so I went there. This ended up being for
34 a few months only, as a psychologist at Templeton said that I had some brains. The

1 psychologist had me go to a special school, the School for Cerebral Palsy in Worcester
2 Street, for further assessment for two weeks to see if I could learn. Obviously that was not
3 an issue.

4 So at four-and-a-half years old, my diagnosis of learning impairment was found to
5 be wrong. Thank God somebody understood and got it right, because if they didn't, I would
6 have stayed in Templeton. I know many people who were probably as intelligent as I am
7 and who never had the same opportunity to receive a proper diagnosis. They were
8 institutionalised for a long time.

9 It wasn't that my parents pushed the issue of a more considered diagnosis. I was
10 just fortunate. In those days, doctors had this remarkable power. My parents never said
11 anything against them. Dad was a very perfect man in that regard. He was very complia nt.
12 Mum was very smart but she could not read. She never had the opportunity to get an
13 education as she had Rheumatic Fever. Her memory was very good. No-one ever knew
14 that she could not read.

15 After leaving Templeton, I lived at home. When I was five years old, I had a big
16 operation on my legs to try and make me walk. It didn't work. The operation was a
17 response of the time and illustrates the medical model of disability that persisted.

18 I stayed in hospital to recuperate for six weeks. One day my bed was moved from
19 the main ward to a side room. I thought my parents would never be able to find me. I had
20 no idea what was happening, no-one explained anything to me. I very clearly remember
21 feeling distressed. Those feelings are very close to the surface for me, even now. That
22 experience was probably the first time I felt traumatised.

23 Home life was difficult. Mum had mental health issues that were undiagnosed at
24 this stage. She was very angry and screamed a lot. When I was 20 years old, she was
25 diagnosed with schizophrenia and chronic depression. Dad was an alcoholic. His drinking
26 was relatively severe and he was often out of control. I believe he had Post Traumatic
27 Stress Disorder (PTSD) from his time in Korea.

28 The combination of the two of them meant that we had a difficult upbringing. I
29 would describe it as significantly dysfunctional. There was a lot of verbal violence
30 between Mum and Dad. At least once every day someone would go off. There was also
31 violence between my siblings and my parents, and between my siblings.

32 I don't think my parents were equipped to raise me - to- raise children. My sister
33 Mary--Ann was forced to take care of me and took me everywhere with her. She resented

1 this as a teenager and a young woman. It has caused difficulty in our relationship with each
2 other, in the past.

3 Mum had her first breakdown when I was seven. She was placed in the Ferguson
4 Clinic at Sunnyside Hospital. I was taken there to see her once. She was in a small, square,
5 fully padded room and knocked out on drugs. I remember it so well. I didn't understand
6 what was happening. Seeing my mother in there was the next time I remember being
7 traumatised. I was diagnosed with PTSD in 2018. It was those two incidents that were the
8 beginning of my trauma and led to the PTSD.

9 When Mum was at Sunnyside, it was decided by the doctors and professionals
10 working with our family that I would go into an IHC family home.

11 At only seven years old, I was removed from home. I don't have a learning
12 impairment but the IHC family home was the only place for me to go. I believe I was
13 considered too much hard work for Dad to manage. Also, at that time it was expected that
14 children with sufficient impairments would not live at home.

15 I lived there with five or six other children. I was taken care of and Mrs was nice to
16 me but I hated it because it wasn't home. On the weekends, I got to go back home and see
17 Dad and my siblings. I really wanted to stay there.

18 When I talk about being taken away from my home at only seven years old, I feel
19 very upset. It really affected me and it still does today. I was just a kid wanting to be at
20 home. Nobody had any idea about how I felt. There was no discussion about it or what
21 I wanted. I just had to stuff down those feelings.

22 I lived at the IHC family home for at least six months, probably longer, until Mum
23 came home again. I then lived at home with my family until I was 10 years old, and
24 I attended the School for the Physically Disabled, formerly known as the School for
25 Cerebral Palsy."

26 **CHAIR:** Yonel, if you just pause for a moment.

27 Are you okay to carry on, Matthew?

28 **MATTHEW:** Yes.

29 **CHAIR:** You're very brave. I'm sorry this is so hurtful for you in bringing back some bad
30 memories, isn't it, yeah. We're happy to take a short break if you would like us to?

31 **MATTHEW:** No.

32 **CHAIR:** Okay.

33 **MATTHEW:** Yeah.

34 **CHAIR:** All right, thank you very much. Thanks, Yonel.

1 **YONEL:** "When I wasn't at my school because of holidays, I went to an IHC school. It was very
2 boring. At seven years old, I was in the top class. I was in class with teenagers and young
3 adults who had a learning disability.

4 In 1976, I moved into a CCS family home. At 10 years old I was told I couldn't live
5 at home. Not many people would go against what doctors said at that time. You trusted
6 them and went with their recommendations. A medical model of disability dominated. My
7 parents were the same. I was only ten, but it was not hard to pick up on the idea that it was
8 my impairments that were to blame for our family's difficulties. I was the only one who
9 had to leave at that stage. My brother and sister stayed at home for that moment. I'm not
10 stupid, what else can you take from that? The theory was that if we take Matt away
11 everything will be hunky-dory for the family.

12 The files I have received from CCS do not include anything about my placements at
13 CCS family homes. This is because these files are missing. I physically burnt the bastards
14 sometime in the 1990s to assist with my anger.

15 From my recollection, I lived with a Dutch couple with two children of their own at
16 a house owned by CCS. They took in children with disabilities who needed somewhere to
17 live. There were four children, including myself, who lived there. The couple were quite
18 strict, and very particular.

19 I got pneumonia while I was living there and became very unwell. The couple
20 thought I just had a cold and that I was getting better. They didn't recognise the seriousness
21 of the illness and I got worse. When they finally took me to a doctor, he said if I hadn't
22 gone in that day, I potentially could have died. I was off school and recuperating in bed for
23 eight weeks.

24 I kept attending the School for the Physically Disabled while I lived at the CCS
25 family home. I wasn't being taught to my abilities, the teacher used to try and keep the
26 whole class together despite there being a wide range of impairment. As an example, when
27 I was 12 I was doing a level of work that was for eight-year-olds.

28 The Dutch couple decided not to carry on with having the family home. They
29 indicated they needed to exit, and so I had to exit. I was not told about the plan to close the
30 family home. At 11 years old, I was told I was going on "holiday" to Pukeora in Central
31 Hawke's Bay.

32 Whoever was making these decisions, the doctors and professionals, advised Mum
33 and Dad not to tell me what the plan was and to let me think it was a holiday. Nobody
34 asked me what I wanted. In reality, it was a seven-week trial visit to see if I could cope

1 with living there permanently. It was my first ever time leaving Christchurch. I was alone.
2 I didn't know one person. I was disempowered.

3 Hawke's Bay District Health Board have said they hold no files from my time at
4 Pukeora. I can say that I am disappointed to not have any records but I am not surprised.

5 It was an institution and you did what staff told you to do. It was impersonal.
6 That's how you run institutions; power and control. The staff had huge issues with this,
7 some people when they have that power, they abuse it. Pukeora was power and control
8 every day. There were over 100 people there and it was mainly adults. I believe that I was
9 the youngest. I was very far from home and very naive.

10 The whole time I was in Pukeora, I was terrified. I felt like I was being controlled
11 all the time. I needed to conform. The medical system and structure that Pukeora was
12 operating within is a hierarchical system. Other residents would come up to me and try and
13 intimidate me. The staff wouldn't notice. When you're institutionalised, this is what
14 happens. The power and control issues start emerging in the people who live there. It was
15 like sending someone to prison at 11 years old.

16 One day I went to go to my bed. We didn't have our own rooms, we were in
17 dormitories. I went in and came across two guys performing oral sex on each other. They
18 were probably in their early 20s. I didn't understand what was going on. I didn't have any
19 experience to reference that to. What put me over the edge, it created pure fear in me, was
20 what happened afterwards.

21 I was in the bathroom when they cornered me."

22 **MS THOMAS:** Sorry, Yonel, if we can just take a wee pause. Perhaps even if the

23 Commissioners would take a few moments.

24 **CHAIR:** Yes, we will. Let us know when you're ready to come back.

25 **MS THOMAS:** Thank you.

26 **Adjournment from 11.16 am to 11.20 am**

27 **CHAIR:** Thank you, Ms Thomas.

28 **MS THOMAS:** Thank you, Matthew.

29 Yonel, if you could keep reading Matthew's statement.

30 **YONEL:** "One day I went to go to my bed, we didn't have our own rooms, we were in
31 dormitories. I went in and came across two guys performing oral sex on each other. They
32 were probably in their early 20s. I didn't understand what was going on. I didn't have any
33 experience to reference that to. What put me over the edge and created pure fear in me was
34 what happened afterwards.

1 I was in the bathroom when they cornered me. I was bailed up by these two men
2 and threatened. They said if I ever told anybody about what I saw, they would smash my
3 fucking head in. I was very frightened. I couldn't physically defend myself. I did not have
4 a power chair at the time and I was physically cornered. I could push myself in the chair I
5 had at the time in a limited way. I was stuck there unable to go anywhere. I was 11 and I
6 had no fucking idea what had happened.

7 To cope, I just withdrew from everyone and went within myself. I was so scared,
8 the last thing I wanted to do was speak to anybody about it. I absolutely believe that what
9 they threatened was true. I have no idea if the staff noticed my behaviour. I had nobody to
10 talk to.

11 These two men threatened me on multiple occasions. I felt completely vulnerable
12 and powerless. I remember wondering if this was something I had to submit to. I told my
13 mum about it several years later. It became too much to keep inside. I remember that she
14 gave me a hug. Mum believed me.

15 It was the absolute powerlessness I experienced in the toilets that really traumatised
16 me, more so than the sexual stuff. I had no support. For those two men, their behaviour
17 was reflective of the culture of the environment we were in.

18 I was placed in a room by a staff member and the door was shut and I couldn't get
19 out. I couldn't move about within the room as I found it hard to freely move my wheelchair
20 on my own. I have a very vague memory of this and I can't remember for how long I was
21 in there or if it happened more than once. But I very strongly remember how I felt when I
22 was in there. I saw this happen to other people who were living at Pukeora too. It was
23 always for punishment.

24 After my seven-week trial at Pukeora, I returned to Christchurch and lived at the
25 CCS house. The professionals were trying to find a permanent place for me to live. The
26 next year, that CCS family home closed for Christmas, so I had to be put somewhere. 20
27 December 1978, I got institutionalised. I was sent to Burwood as an emergency admission.
28 I was 13 years old.

29 Burwood Hospital was operated by Canterbury District Health Board and is in the
30 north-eastern suburbs of Christchurch. I was put in ward nine, which was meant to be for
31 younger people and people with muscular issues. There were also people with brain
32 injuries there. Obviously sometimes people with brain injuries can have resultant
33 behavioural issues, but when you're 13, you don't understand that, it's just scary.

1 When I was sent to Burwood, I never got told what their plan was. What happened
2 was that a social worker came out from CCS to Burwood just before Christmas and took
3 me for a drive. She told me that I was going to go back to Pukeora to live in two weeks'
4 time. The initial plan had been to just hold me in Burwood before they sent me up to
5 Pukeora permanently. I wasn't asked what I wanted or where I wanted to live. There was
6 no choice. There were no discussions about me staying at home.

7 There was no way that I wanted to go back to Pukeora. I said, "There is no fucking
8 way I am going there, I'd rather kill myself." I cried for several days. I guess people
9 wondered why I was so upset but the staff didn't stop and ask me what was going on.
10 I didn't have anyone in my life that I could talk to about Pukeora or why I didn't want to go
11 back.

12 Dad negotiated with the charge nurse about giving me more time at Burwood. The
13 thinking was that I would come around to the idea if given a bit more time and be calm
14 enough to get on the flight. In the end, the charge nurse agreed that I could stay for one
15 month more. Then it was extended by another two weeks. They thought I would get over
16 it.

17 I was so upset at the idea of going that my parents discussed selling up in
18 Christchurch and moving up to Napier to be closer to me. I kept swearing my head off.
19 I said it so many times, "I'm not fucking going." My parents said that I had to go because
20 that was what the professionals thought would be best for me.

21 This cycle continued on and about ten weeks passed. The charge nurse asked if
22 I wanted to stay at Burwood. "If you could stay here, would you be happy?" I said yes, if
23 only because it was near my family. Even though my family is in chaos, it was my family
24 that loved.

25 This started my imprisonment for eight years at Burwood Hospital. I didn't use that
26 word lightly. Burwood had the same hierarchical system as prison, but in the health
27 system, it is just that there were no bars. If I wasn't so fucking pig-headed, I would have
28 been sent back to Pukeora. Looking back, I think I did quite well in standing up for myself.

29 There were only one or two other people my age at Burwood. I had no choice in the
30 time I went to bed or the food I ate or when I was washed. I was living day after day in a
31 system of power and control. In the dormitories on the wards, there were six beds on each
32 side, so 12 people in total. They were mainly adults. I had my own things but no place of
33 my own to put things. There was no privacy. I could hear grown men jacking off at night.

1 I would go home on the weekends. Home was an upset environment with Mum and
2 Dad always arguing. But it was still better than Burwood. I was dropped back on Sunday
3 night. I hated that drive, knowing I was going back to Burwood. Even now, when I'm
4 driving around my home and go on that same route, it is a reminder of being that little boy
5 and those feelings. Dad knew I was upset, but if I talked to him he'd say, "What are you
6 moaning about? You've got food and shelter, what's wrong?" He really believed Burwood
7 was the best place for me.

8 When I was older, I was lucky to have a single room. This is because I was doing
9 fifth and sixth form at the time. When someone in the dormitory was unwell or dying
10 I used to get moved out from the room, then I would get moved back in after the person got
11 well or had died.

12 It's a really hard thing to explain to people how you survive when you live in a
13 hierarchical system. I used to play *The Bitch is Back* by Elton John on my ghetto blaster
14 when a certain nurse came on duty. I did it on purpose. Everyone knew but her.

15 Another thing I used to do was go into the lifts and when they were halfway
16 between floors, I would open the door and force the lift to stop. I'd hide in there so no-one
17 could get me. This was important to me, it was somewhere to go when I needed personal
18 space. From the lift, I could hear my name being called out over the loud speaker,
19 "Matthew Whiting, please return to ward nine." This really fucked that particular nurse off
20 and the more she got wound up, the more I did it. It was a way to take my power back.

21 I remember being pushed around in my manual wheelchair to places I didn't want to
22 go. When you can't move yourself, you don't have a choice. The way that staff members
23 wanted things done, that was the way it was done. There is a massive power imbalance in
24 the systemic way we organise places like prisons, hospitals and residential care, and that
25 was the case in Burwood too. There was very unequal power and no watchdog. There is
26 always going to be people who love to have power over people and then some really weird
27 shit that happens.

28 When I was 15, a nurse at Burwood Hospital befriended me. She felt sorry for me
29 and she led me on letting me think that we could be a thing. She did some sexual kissing
30 and touching with me. I didn't have a choice in what was happening. This went on for
31 about a year. I felt really conflicted. It felt nice at the time but she also wasn't my
32 girlfriend, she was a staff member. It was very secretive. It took me being an adult and
33 looking back to realise that she was taking advantage of me and that it was abusive. I've

1 spoken with my counsellor about this and it took a long time for me to understand it as
2 abuse.

3 When I was 20, a different nurse came on to me. I responded by putting my hand
4 up her skirt and touching her. She went to the charge nurse and said that I had tried it on
5 her. Fortunately, the charge nurse knew me enough to come to me and ask me what
6 happened. It was lucky that she was on shift that day and she understood. But I was still
7 the one who got told off. The charge nurse did have a conversation with that particular
8 nurse and she didn't try it on with me again.

9 These are just two examples of many power abuses around sexuality that
10 I experienced at Burwood. My realisations as an adult of these experiences as abuse has
11 been really upsetting.

12 We didn't have choice in the food we ate. One meal time I didn't want to eat what
13 we were given -- what they were giving me, so I refused it. A nurse got behind me, she
14 held my nose and shoved the food down my throat. I was using a power chair at the time.
15 I backed it up to the wall so she was caught between the wall and my chair to try and stop
16 her force-feeding me. She put my chair into manual, which meant I couldn't move it
17 myself. It was easy for her to do things like that because she was in charge of the ward I
18 was on.

19 A staff member put me into a room in Burwood and locked me in there. I couldn't
20 leave. I have no idea of the length of time I spent in there but my guess is that I was in
21 there because I hadn't been compliant beforehand. This happened more than once. I saw
22 this same punishment happen to other people.

23 My education changed when Glenda Laurence started teaching at the School for
24 Physically Disabled. I was around 13 years old. I was given an opportunity again, just like
25 when someone took the time to properly assess my academic ability. I know so many other
26 people who had had the same experience within education but were never given the same
27 opportunity I was.

28 Glenda became a key person in my life and still is today. She had never taught
29 disabled people before and so she never had the limited thoughts and perceptions about
30 teaching disabled people. She didn't lump in everybody's abilities, instead she had
31 expectations of what ordinary children would do. I had met a person who could believe in
32 me. I became excited to learn, by learning. I wanted more and more and more. I loved
33 mathematics. In about four months of being taught by her, I went up five year-levels.

1 It was like she placed all these dots – she introduced me to the civil rights
2 movement and exposed me to ideas such as social justice, discrimination and being a strong
3 advocate. Then as an adult I connected those dots. I had a very conservative father and a
4 Catholic family, but Glenda was not a traditionalist or conservative at all.

5 Glenda then asked me a question when I was about 14 years old. She said, "What
6 do you really want?" And I said that I wanted to go to a normal school.

7 It took so much advocacy to get there. It was not easy. Glenda and a psychologist
8 attached to the School for the Physically Disabled were on board. Glenda made it her own
9 school project, even writing to the Ministry of Education. But 14-year-old me, I really
10 advocated for myself. It came from within me. Finally, I went to Hagley High School in
11 central Christchurch. I attended Hagley for three days a week and the School for the
12 Physically Disabled for two days a week.

13 It was unusual for me to even be at Hagley High. At first, I was placed in a low
14 stream, but this didn't last long and I was moved up. Within a couple of months, I was in
15 the highest stream. I was pleased to be there and to get challenging work. I got involved
16 with the classes. I got respect because of my academic ability and I finished school with
17 Sixth Form Certificate and University Entrance.

18 There was not much time for socialising or making friends. I used to get picked up
19 from Burwood by a van operated by the Hospital Board and taken to school, and then taken
20 straight away at the end of the day. I thought this was shit, but that was the deal. This was
21 all before teacher aides. If I could have had had a teacher aide at Hagley High, it might
22 have made a difference. I needed more support in the classroom. I don't think this has
23 changed much as my school experience is the same as what happens today for a lot of
24 disabled children. The student needs support and so do other students and the teachers.
25 They also needed guidance when it comes to supporting this. It has to be a wrap-around
26 support.

27 When I decided to leave Burwood, it wasn't people coming to me and assisting and
28 doing the organising. It was me saying I'm going to leave.

29 I met a young social worker from CCS Disability Action at Burwood when I was 19
30 years old. She was pretty naïve and new to working with disabled people. She asked me
31 what I wanted in the future. I said to leave Burwood. I kept on moaning about Burwood
32 and how unfair it was. It was all I could talk about.

33 I had a really sucky year with my family and I was in a place where I wanted to hurt
34 myself. I decided to kill myself. I had planned it all out. I had followed through with the

1 plan. Nobody knew. I didn't tell anybody about it for years and years. This was an
2 important moment, even though I was not okay, it was an important part of me taking my
3 path back.

4 About a year later, the social worker challenged me. Instead of responding to my
5 complaining by going , "Oh poor Matt, never mind." She said things like, "If you're so angry
6 about being here, why don't you do something? Stop complaining. I don't want to hear it
7 anymore, I just want to see some action."

8 This surprised me as no-one had ever spoken to me like this before. I took this as a
9 challenge. I was and still am very grateful with her approach. I regard this as setting me
10 free. Thank you, Allison.

11 It took me about two years to get organised, but I did it. I moved out of Burwood at
12 21 years old.

13 I didn't have much support from my parents or the staff at Burwood about moving
14 out. When I raised it with Dad he said, "Don't be stupid, just stay there, what's wrong with
15 it?" It became quite a contentious issue, so I cut off all communications with my parents
16 about moving out. I continued regardless.

17 I'll always remember the phone call I then made to my parents to say I was moving
18 out within the month and telling them my new address. Dad stopped talking to me for
19 around two months. I think Dad was really scared. He had been told that I would need to
20 live in Burwood until I died. I was also Catholic and moving in with my girlfriend.

21 My girlfriend was a nurse from Burwood. She moved into the state house with me.
22 We had begun a relationship nine months earlier. Now I can see that this was a really
23 unhealthy relationship. Some staff thought I was being stupid. They said to me, "How can
24 you move out when you can't dress yourself, when you can't talk yourself, when yo u can't
25 do anything?"

26 I moved out of Burwood with no care and only my girlfriend, a bed and a stereo. It
27 came down to me being bloody pig-headed.

28 The placement in Pukeora and the abuse I experienced there, and then being told I
29 was going to be placed there permanently, had a huge impact on family relationships,
30 particularly with my mum and dad. It caused distrust. For me, it completely broke down
31 our relationship. As an 11-year-old kid, from a child's perspective I thought it was my
32 mum and dad sending me away. This has had a huge impact on the rest of my life. This
33 sense of distrust has been with me for a long time.

1 I did a presentation once about supported living and one of the cool things about it
2 was that Dad came along. I used my own story in the presentation. I had applied for my
3 files and used them in there as well. Dad got up and said he was wrong; publicly. I didn't
4 lose it at the presentation but it was a huge moment for me. I was in my thirties before
5 I forgave my parents and came to see that what had happened was a system issue, not a
6 rejection by my parents.

7 Over time, our relationship repaired and Dad came along to my wedding in
8 November 2013. He was pleased to be there and see me get married. I was glad he got to
9 see that before he died in November 2015.

10 When you're disabled and with a speech impairment everybody thinks you're dumb.
11 After I got university entrance, I really wanted to have a job. I was repeatedly told that
12 I could not work as I was too disabled. I was 36 before I got my first permanent role.
13 Before that I set up my own business and did short-term contracts as I didn't want to be
14 unemployed. I ran a care agency business with another disabled person.

15 I had applied for a job at CCS Disability Action 18 times over 15 years. For one
16 application in 1999, I had an interview and I was asked different questions from the other
17 applicants. I was interviewed by a different interview panel. They asked me questions like,
18 "With your speech, how can you communicate?" I didn't take shit from them. I ended up
19 taking them to the Human Rights Commission. They asked discriminatory questions
20 within a discriminatory process. CCS didn't contest it at all. Two years later, I finally got a
21 job with them and I am still there.

22 It is hard work to constantly be fighting back. Every day it's hard work. I get
23 fucked over by systems, by individuals. I'm treated like a second-class citizen every day.
24 On the bus, at the shops, at work, I'm treated like I can't do it, like I can't talk. I am put
25 down.

26 Every single day, my sense of self is affected. Every day this is underlined. It has a
27 cumulative effect and it sends me straight back to being bailed up in that toilet at Pukeora.
28 Every day, I have to draw on strength. Every day, I have to hold on to my sense of self.
29 Every single day. But when you underestimate me, there's trouble. It gives me an
30 advantage.

31 When I get stressed now, I revert to being institutionalised, even though it has been
32 a long time. I had said to myself: no-one will ever control me again. That resolution has
33 turned out to be good and bad. It has been really destructive for me as well as positive. I

1 have been determined to not let anybody shut me up anymore, which has created some
2 issues at work.

3 I get into a place where I can't back down, which isn't helpful. In situations where
4 I feel powerless, I respond with immense distress. It is completely overwhelming. This is
5 the reality of living with PTSD as a disabled person.

6 An example is fairly recently where a more senior person at work decided to target
7 me. It was workplace bullying. This person thought I was doing unsafe practices at work
8 when in fact I know I wasn't. I believe I was targeted because this person thought I was
9 vulnerable, an easy target, and they had a bias towards disabled people. I was also
10 outspoken and needed to have a lesson taught. They had an opportunity presented to them
11 to accuse me of failing in my duty of care for someone I was supporting. That was
12 personal because of my strong sense of my duty of care. All the other crap I could deal
13 with, but I couldn't deal with that accusation. For me, I was triggered.

14 I was stood down for nearly six months. I had to obtain legal representation as
15 I wasn't in the union at the time. I was prepared to go to the Human Rights Commission
16 again. There were so many holes in this person's story. I stood up for myself, was
17 supported, got my role back.

18 This person left. Were they pushed or go on their own accord? Who knows? But it
19 took me back to the same place as institutionalisation, feeling disempowered. It pushed a
20 lot of buttons and distressed me severely. It was not good for me at all.

21 I have had a supported assessment in 2019, and an ACC impairment assessment in
22 2020 as part of my sensitive claim with ACC. I had two assessments done as ACC decided
23 to challenge the first. My impression is that this ACC process was more about how much
24 damage you could display. It looks at you based on a deficit model.

25 I am quite privileged in that I have never had some of the impacts that abuse has on
26 people, such as alcohol or drug abuse. I can function at a high level by compartmentalising
27 situations and I can continue to work. But it was as though I had to prove the impact on my
28 life of the sexual abuse before I could get compensation. This is a narrow definition of my
29 abuse and the impact it had and continues to have on my life. It needs to change.

30 Within this process, responsibility for the abuse does not get attributed.
31 Responsibility lies with the Burwood Hospital Board. This ACC process was also only for
32 the sexual offending against me. There is a gap for the rest of the abuse. When you have
33 been institutionalised, it is impossible to separate out different forms of abuse. It's like

1 trying to separate your grey hair and your natural hair, you can't. I don't think the ACC
2 process can understand institutional abuse.

3 As a result of these assessments, I receive \$4000 every five years to compensate for
4 the apparent 10 per cent impairment I have from PTSD due to sexual abuse in care. I also
5 receive counselling.

6 The Health and Disability Commission is medically orientated --

7 **Q.** Sorry, Yonel, I think you've missed para 4.5.

8 **YONEL:** Sorry.

9 "If you just look at eight years of imprisonment and living under power, what would
10 somebody get for eight years for false imprisonment? It was even before then. Every day
11 I got up, I wasn't at home, I was forced from home at 10 years old. How many kids leave
12 home at 10 years old?

13 CCS used to stand for Crippled Children's Society, which in the context of the time
14 it was named, this was a proper name to give. It is now known as CCS Disability Action.
15 It is the same company I work for now. I chose to work in this field to make a difference
16 for other people. I would like to have "CCS" removed from the official name. The
17 problem is that when it comes to bequests and donations, people won't know who to give
18 the money to.

19 I don't want this Commission to be a talk fest. There is so much money being spent
20 on it, political stuff and the election cycle always have an impact on any advocacy too. My
21 concern is that there will be no systemic action and all of this will be for another report that
22 will sit on a shelf.

23 You can see how much this takes out of people in what we are doing in speaking to
24 the Commission. The Commission's expectation of an outcome needs to be systemic and
25 sustainable change.

26 We must change the way we think about support and the way we provide support as
27 a country or nothing will change. Systemic change must address the imbalance of power.
28 The system sets it up, it needs this and lets it happen. It does not safeguard against it.

29 We operate on an hierarchical system which leads to an abuse of power. Within the
30 system, there are two levels of power. It is in its hierarchical format and also an
31 individual's power over another person. Both of these aspects of power are abused. By its
32 very nature, there is built-in power differential, this is how institutions work.

1 Some people, when they have power, they don't understand this. They don't
2 recognise they have it. Some people do recognise this and they abuse it. Often the biggest
3 oppressors are those who are oppressed themselves.

4 There must be a way of providing support without taking power away from people.
5 We must get the power closer to the individual and teach people about recognising power
6 and control.

7 As a disability service coordinator, I had power over people, but I understood that I
8 had that.

9 A watchdog would even the power differential. It would also orientate the care of
10 disabled people to a more customer-service model. We need to stop creating systems and
11 start focusing on services.

12 It is essential that we learn from history. The current abuse and neglect endured by
13 disabled people is a result of systemic issues. We need to learn how to stop damage before
14 it happens. If reforming the system, it is not about ticking boxes, it must be genuine. The
15 current system is tick box. We still have narrow systemic thinking. If you can't fit here,
16 then you go there.

17 There are not many safeguards in place. The only ones we have are contractual.
18 There is a severe lack of resources in the disability sector and it is significantly
19 under-funded. The Disability Commissioner doesn't have enough power.

20 The Health and Disability Commission is medically orientated. The Ombudsman
21 has huge financial pressure and a lack of resources. Residential homes are mini-
22 institutions. There are not big institutions any longer, just smaller ones. While audits
23 occur, they are scheduled and are only every two to three years. This is not regular enough.
24 The auditors only see the good days.

25 Everyone should have control over their own belongings and the support they need
26 to live independently. Some people might need a lot more support than others.

27 Maybe what we need is a Truth Commission, like what happened in South Africa
28 with apartheid. It would hold organisations and the government to account and ensure that
29 fault is found. It would make a finding that someone or an organisation is liable. It would
30 seek out and go speak to people.

31 This Commission isn't that type of Commission. My account is being heard only
32 because I rang the 0800 number and put myself forward. This Commission has been called
33 for by the disabled community for years and years. And for years and years, the
34 government said no. Not only National, it was right across the board, it was no.

- 1 **MS THOMAS:** So, the only person you trusted was yourself.
- 2 **MATTHEW:** Even that was marginal at times.
- 3 **MS THOMAS:** Even that was marginal.
- 4 Matt, we also talked about the promise that you made to yourself as a result of your
5 experiences in state care. You promised yourself that no-one would ever control you again,
6 and you've said that this has caused you "some shit", I think in your words, and it's also
7 been a good thing. Would you like to talk to the Commissioners about that promise you
8 made to yourself?
- 9 **MATTHEW:** At times it really destroys my relationships because I felt I'm a fighter and I didn't
10 take any prisoners.
- 11 **MS THOMAS:** So, at times you said you were a fighter and you don't take any prisoners.
- 12 **MATTHEW:** Yes.
- 13 **MS THOMAS:** So, sometimes that's been awkward?
- 14 **MATTHEW:** Yes, and sometimes it's unnecessary.
- 15 **MS THOMAS:** Sometimes it's unnecessary.
- 16 **MATTHEW:** Yeah, but for me it's hard to pull back.
- 17 **MS THOMAS:** It's hard to pull back.
- 18 **MATTHEW:** Other times, for example, the incident at work I really needed to fight and that was
19 a really good thing.
- 20 **MS THOMAS:** So, the incident that happened at work that you talked about in your statement,
21 you really needed to fight for your rights there and that was a really good thing.
- 22 **MATTHEW:** Yeah. But it's hard to balance it. And it takes a toll on me.
- 23 **MS THOMAS:** Sorry, I missed that bit -- it takes a toll?
- 24 **MATTHEW:** Yeah. Because when you're in fight or flight mode it is emotionally,
25 psychologically, it takes a toll on me.
- 26 **MS THOMAS:** Yeah, when you're in fight or flight mode it emotionally takes a big toll.
- 27 **MATTHEW:** Yeah.
- 28 **MS THOMAS:** Matt, are you okay if we put up a photo on the screen?
- 29 **MATTHEW:** Hell yeah.
- 30 **MS THOMAS:** Okay. Let's put that up now and then we'll talk about this. Can you tell us, what
31 does this photograph show?
- 32 **MATTHEW:** For me, it shows eight years of institutionalised living from 13 until I was 21.
- 33 **MS THOMAS:** Right.

1 **MATTHEW:** And in that photo you can see the hospital ward. I actually lived on the other side
2 of the fence, but it was the same design. They pulled the ward down and I knew they were
3 pulling the ward down, so I snuck in and took a photo before they pulled the ward down b
4 because for me, it was really important to have the memory. Even though it was a shit hole,
5 but it's an important memory from my past, so that's why I got someone to drive in and we
6 took the photo and never got caught.

7 **MS THOMAS:** Right, so this is a photograph of Burwood and you snuck in to take this before
8 they pulled it down.

9 **MATTHEW:** Yeah.

10 **MS THOMAS:** Even though it was a shit hole, I think you said, you wanted this photograph as
11 part of your memory of this. And I think you said that where you spent your eight years in
12 this place, which you described as a prison, was just over the fence that we can see in that
13 photo.

14 **MATTHEW:** Yeah, yes.

15 **MS THOMAS:** You've said in your statement that Burwood was like a prison.

16 **MATTHEW:** Hell yeah.

17 **MS THOMAS:** Is there anything more you'd like to add on that?

18 **MATTHEW:** I'm going to take a few seconds.

19 **MS THOMAS:** Sure.

20 **MATTHEW:** When the institution is run a very hierarchical system, it means the power goes up
21 and then and-- when you've got disempowered people, it often attracts people who have
22 low self-esteem and they use their power over people, -although I-- don't say the word, but
23 I'm going to have a go - nar- -- can someone help me?

24 **MS THOMAS:** Can we help you with?

25 **MATTHEW:** Narciss --

26 **MS THOMAS:** Oh, narcissistic.

27 **MATTHEW:** And it really attracts people to work there, I was here yesterday in the public
28 gallery and it came back there was some narcissism around people's evidence.

29 **MS THOMAS:** So, when you were watching in the public gallery this reminded you of some of
30 the power and control and some narcissism came through some of the themes in the
31 evidence.

32 **MATTHEW:** Yes.

33 **MS THOMAS:** Right. You've also talked to me about Burwood as being a place where there was
34 a loss of personhood for you when you were in there for eight years.

- 1 **MATTHEW:** Completely, my personhood, it was dehumanising. For example, I had
2 suppositories three times a week to control my bowels.
- 3 **MS THOMAS:** So, you had suppositories three times a week --
- 4 **MATTHEW:** Yeah.
- 5 **MS THOMAS:** -- to control your bowels.
- 6 **MATTHEW:** Yeah, and even though it is hidden behind medical reasons, my belief is that it is
7 control and power issue around people's bowel movements. When I first moved out of
8 hospital, the first thing I did was not have suppositories and, it's too much information, it
9 took me 10 days to have a bowel motion, but for me it was me taking back control of my
10 own body and even this morning when Lusi talked about the same sort of issues.
- 11 **MS THOMAS:** You took control back of your own body.
- 12 **MATTHEW:** Yeah.
- 13 **MS THOMAS:** And even this morning when Lusi talked about those exact same issues.
- 14 **MATTHEW:** Yeah.
- 15 **MS THOMAS:** If we could take that photograph down now. There's another topic that I'd like to
16 talk to you about, Matt, and it's in your statement. You've said that every day it's hard work,
17 you've said every day you are fighting against the systems and the attitudes. Could you talk
18 to us about some examples of that that you experience every day.
- 19 **MATTHEW:** If I go to the supermarket -- before- I do, I was having breakfast at the hotel
20 yesterday and the waiter was talking to the people I was with instead of asking me what
21 I wanted. And even though it's an everyday experience with disabled people, it's a societal
22 issue that we need to address.
- 23 **MS THOMAS:** So, it's a societal issue that we need to address.
- 24 **MATTHEW:** Yeah.
- 25 **MS THOMAS:** Because, for example, you said just yesterday at the hotel the waiter spoke to the
26 people that you were with and didn't actually --
- 27 **MATTHEW:** Yeah.
- 28 **MS THOMAS:** -- speak to you about what you would like to eat.
- 29 **MATTHEW:** Yeah.
- 30 **MS THOMAS:** And is there an example you spoke to us about last night, just a common
31 occurrence getting on the bus to get to your job, for example.
- 32 **MATTHEW:** I got asked what day service I was going to.
- 33 **MS THOMAS:** So, you were asked what daily service you were going to?
- 34 **MATTHEW:** No.

1 **MS THOMAS:** Day service, sorry.

2 **MATTHEW:** Yeah.

3 **MS THOMAS:** How did you respond to that?

4 **MATTHEW:** For once, I never swore.

5 **MS THOMAS:** You didn't swear.

6 **MATTHEW:** No. For once I just moved on.

7 **MS THOMAS:** Right.

8 **MATTHEW:** And we're talking about ableism here.

9 **MS THOMAS:** We're talking about what, sorry?

10 **MATTHEW:** Ableism.

11 **MS THOMAS:** Ableism.

12 **MATTHEW:** Yeah, and I believe part of the issue with abuse in care, there is a lot of ableism.

13 For example, if you understand the history of disabled people, it started in the mid -1800s

14 when we had the industrial revolution, before that disabled people were quite included.

15 **MS THOMAS:** So, you're saying before Europeans came to New Zealand, oh and --the industrial

16 revolution, before that disabled people were included.

17 **MATTHEW:** Mostly.

18 **MS THOMAS:** And then things have changed.

19 **MATTHEW:** And then we had -- there were --

20 **MS THOMAS:** Eugenics?

21 **MATTHEW:** Yeah. We've still got eugenics working and it works in the disability sector today.

22 **MS THOMAS:** Eugenics is still present today.

23 **MATTHEW:** For example, women get a scan to prevent an abnormal baby's birth, even though

24 it's not a simple argument because there's all sorts of arguments around people's rights

25 around their own body. What I'm talking about, is if you take a disability perspective.

26 **MS THOMAS:** So, it's not a simple argument, but what you're talking about is making sure

27 people have a disability perspective as part of that information.

28 **MATTHEW:** Yeah.

29 **MS THOMAS:** My final topic that I think you would like to -- that we discussed that you would

30 like to talk a bit more about with the Commissioners was power and control. So, that's a

31 theme that's throughout all of your statement.

32 **MATTHEW:** I've been here, I've been here all day yesterday, and power and control, everyone

33 talked about power and control and I don't think it's a simple issue to fix -- because why

34 would we spend millions of dollars talking about it in this room? I think it's a complex

1 issue. I don't think -- unfortunately, we've got the same situations we had from 1950 to
2 199-- today and unfortunately, we haven't talked about the elephant in the room. And my
3 hope one day we will be brave enough to talk about the elephant in the room, because --
4 sorry, Coral, it's my turn, -- because I think some people think it's in the past. I work in the
5 sector and we have the same levers working.

6 And for me, I think we often try and fool ourselves about that's in the past and we're
7 talking -- in this Commission we're talking about 1950 to 1999 and it's all over, and from
8 my perspective it's not all over. I think we understand it more, but I don't think we stop it.
9 Although -- I think we try and gloss over it because it's a lot easier to do that than really
10 talk about the shit.

11 **MS THOMAS:** You've said sometimes we try and gloss over the situations which, we're not
12 talking about the elephant in the room, which is the power and control, that we've heard
13 about from 1950 to 1999 and continues today.

14 **MATTHEW:** Yes.

15 **MS THOMAS:** And it's still happening in the situations.

16 **MATTHEW:** Absolutely.

17 **MS THOMAS:** Thank you, Matthew. I'm going to see if the Commissioners have any questions
18 for you as well.

19 **COMMISSIONER STEENSON:** Tēnā koe, Matthew, thank you for your statement. You're a
20 very strong soul and it's a very powerful statement. You talk about the control and power
21 and powerlessness in unsafe situations, and you've given us a lot around those -- a lot of
22 examples from when you were a child put into those unsafe, powerless situations. So, I'm
23 interested to know how you think that dynamic of power and control might be brought into
24 balance, particularly for children and safety.

25 **MATTHEW:** It is a very complex situation. I don't think we have any idea of how completely --
26 obviously people need support to live their lives and obviously, on the whole, even though
27 it's changing a wee bit, we still have a hierarchical system that we work with, even though
28 we're trying to change it through EGL, system transformation and better training for staff.
29 But it is very complex and I don't think we will resolve it today.

30 **COMMISSIONER STEENSON:** Do you think part of the solution, I absolutely agree with you,
31 it's extremely complex, but do you think part of the solution is around being able to make
32 decisions, allowing them to have their say in what happens to them and making sure they
33 understand the options fully?

1 **MATTHEW:** Yeah, although I think that I'm --although I think when you've got a physical
2 impairment I don't think people realise how abusive the system is because they have to rely
3 on that support.

4 **COMMISSIONER STEENSON:** Yeah, have to rely on that support, yeah.

5 **MATTHEW:** And for myself, it took me a long time to realise what happened to me was not
6 okay.

7 **COMMISSIONER STEENSON:** Just reflecting on your evidence about as a child, how the
8 doctors were in a lot of control of what happened to you and it was, even though you were
9 really clear you didn't want to do something, so just thinking about how that put you also in
10 a powerless state.

11 **MATTHEW:** Yeah. And if we really want to talk about the real issues, I think we need to talk
12 about disempowerment of disabled people in the support system. For example, how many
13 disabled people are here today? And even though I know not all impairments are visible,
14 nothing about me without me, and we have lots of lawyers in the room -- sorry Ruth and
15 Elise, but you know what I mean.

16 **COMMISSIONER STEENSON:** That's great, thank you for answering, tēnā koe.

17 **CHAIR:** I hardly know where to start, Matthew. So, I'm not going to go on for too long. Can
18 I just pick up on that theme of the doctors. I know you've been sitting watching the
19 evidence and I've seen you in the audience. So, you will have heard some of the evidence
20 that we have about over-medicalisation.

21 **MATTHEW:** Yes.

22 **CHAIR:** And that applies to people with disabilities, it applies to Deaf people and it applies to
23 people with mental illness as well.

24 **MATTHEW:** And women as well.

25 **CHAIR:** Yeah, that's right. So, this fits in, I think, with your very strong message about power
26 and control and the hierarchy, because as you said, your parents believed in doctors.

27 **MATTHEW:** Absolutely.

28 **CHAIR:** Absolutely, they trusted them and, I mean, my parents did too, we're of an age when
29 doctors placed themselves, or we placed the doctors on a pedestal and we did what was
30 told. So, part of this medicalisation, which you are shining a light on for me, is that it
31 seems from your evidence at least, and Lusi, that the first point of contact is from the
32 doctors who try to cure you, fix you, treat you with medicine and operations and things like
33 that. Do you agree with that?

34 **MATTHEW:** I would take it one more step.

- 1 **CHAIR:** Yeah.
- 2 **MATTHEW:** My belief is that the medical profession don't know about the social model of
3 disability and my belief is that they only get a very minimal --
- 4 **CHAIR:** Yes, training.
- 5 **MATTHEW:** -- training, and then my belief is that we need to employ people in neonatal units as
6 people who have got specialised knowledge around impairments, know about everything --
7 of social model of disability, as well as the UNCRPD.
- 8 **CHAIR:** Yes, I think last week, I'm not sure if you followed our evidence last week, but we heard
9 about the call for better training of all the medical professions, you know, neonatals,
10 everybody, to -- in issues about disability. But I want to put a proposition to you as an
11 expert and I'd just like your views.
- 12 **MATTHEW:** I'm not an expert.
- 13 **CHAIR:** Yes, you are, I'm going to argue with you about that, Matthew. The proposition is that
14 instead of starting with the physical, medical stuff, would we not be better in having a
15 system that started with the rights and the needs of disabled people?
- 16 **MATTHEW:** Absolutely. And also having the right, my -- tongue is twisted.
- 17 **CHAIR:** Do you want a drink?
- 18 **MATTHEW:** No, I'm fine. We need to change their power.
- 19 **CHAIR:** Because if you start with the rights, the human rights and the needs that psychological,
20 educational, spiritual, etc, needs of disability, then that's got to be led by survivors, doesn't
21 it?
- 22 **MATTHEW:** Yes, although I believe what Paul Milner talked about last week about
23 dehumanisation -- because when you dehumanise people, it's really easy to take the next
24 step.
- 25 **CHAIR:** Thank you for that. So, that's something we're taking very seriously, that whole notion
26 of changing the model so that disabled people's needs are met. The only other -- then I
27 want to know -- a question. You were in Buroopwood for eight years, a terrible long time.
28 Were there any other people there for as long as you? Was that a common thing that you
29 were there for as long as you?
- 30 **MATTHEW:** Not at Burwood, but it was a common thing in the 80s.
- 31 **CHAIR:** Right.
- 32 **MATTHEW:** And the only reason why I got to Burwood was my protest of being sent up to
33 Pukeora.
- 34 **CHAIR:** But that just would have been another institution, wouldn't it?

- 1 **MATTHEW:** Yes.
- 2 **CHAIR:** That's right. I just wondered if you were typical at that time, whether it was usual to be
3 in one institution for that long period of time.
- 4 **MATTHEW:** Yes.
- 5 **CHAIR:** I think your answer is yes, it was.
- 6 **MATTHEW:** Yeah.
- 7 **CHAIR:** I want to ask you about the elephant in the room.
- 8 **MATTHEW:** We haven't got all day.
- 9 **CHAIR:** Well, exactly, we don't have all day, but I'm going to make a suggestion. It's not an
10 elephant, okay, we know it's here, okay, we know it's here, we know it has to be add ressed.
11 We don't have all day, but I'm going to suggest that if you wanted to, whether you'd be
12 prepared to give us some of your ideas about the current situation later in writing.
- 13 **MATTHEW:** Yes.
- 14 **CHAIR:** Would you be interested in doing that for us?
- 15 **MATTHEW:** Absolutely.
- 16 **CHAIR:** And we would be extremely grateful for your input and your insights into the elephant in
17 the room. Because we need to know to what extent, if any, improvements have been made
18 so that we can recognise that when we make our recommendations.
- 19 **MATTHEW:** And it's not only me, I'm not the only one --
- 20 **CHAIR:** Of course.
- 21 **MATTHEW:** -- who has this point of view, there's many people and lots of disabled people --
- 22 **CHAIR:** Yes.
- 23 **MATTHEW:** -- as well. And you've got one --
- 24 **CHAIR:** Right there, yes. We're very aware of that. But he's not an elephant.
25 Can I just then come to my last point. This is something that you raised quite a
26 proper concern that you have about the Royal Co mmission, and its role and its function.
27 And whilst the Royal Commission has a lot of powers to call people and get evidence and
28 the like, you are right to the extent that our powers are limited in what we can do. And
29 that's just the way we've been set up. But we do have the very powerful tool of making
30 reports and recommendations.
- 31 I share your concern, I think everybody shares your concern, that we will do our
32 best, we will make what we hope are the best recommendations, but the question then is,
33 what next? And I think that's your concern, isn't it?
- 34 **MATTHEW:** Yes. And I don't get paid enough --

1 **CHAIR:** No.

2 **MATTHEW:** -- to do that.

3 **CHAIR:** Well, I know you don't get paid enough, nobody gets paid enough to do that. But what
4 I want to share with you is something that -- this is not new, I've shared with other
5 witnesses and many people I speak to. And that is that the Royal Commission will vanish
6 at the end of our time, by this time next year, we won't exist. But what we will leave
7 behind are our reports and our recommendations. What we also, I hope, will leave behind
8 are people like you and many others who will become champions for those
9 recommendations, who will not let them sit on a dusty shelf, who will be loud and powerful
10 voices, as I know you can be.

11 **MATTHEW:** Sorry about that.

12 **CHAIR:** To ensure those recommendations get the airing and the time and the support of the
13 whole disability community, and all of the people of New Zealand. So, I know you don't
14 get paid enough, but I'm going to invite you to be one of our champions, as well, once we
15 have vanished into thin air.

16 **MATTHEW:** I will be here.

17 **CHAIR:** That's wonderful. Thank you very much. I'm now going to leave you to the not -the-
18 elephant-in-the-room sitting next to me.

19 **MATTHEW:** Yes.

20 **COMMISSIONER GIBSON:** Thanks, Matt, I've got some comments and questions, then it's
21 going to be my privilege to thank you. But first a comment. You're a disabled person,
22 you've spent a lot of time in care and support services, you're a survivor of abuse in care
23 and support services. You work in the provider area, you've done that for a number of
24 years. You're an activist, a disabled person's activist and you've been involved in DPOs,
25 disabled people's organisations. The idea that you're not an expert, I think you need to trust
26 yourself on this one, not just marginally, that you are an expert and with all of that range of
27 experience.

28 I suppose, first, I'd ask some questions from different perspectives, some as an
29 activist, but also first within the provider world, and as a disabled person, you've
30 seen -- and this is knowing that you might provide some more evidence, but you've seen the
31 inside of special schools, people with physical impairments, people with learning
32 disabilities, and residential --

33 **MATTHEW:** Yes.

- 1 **COMMISSIONER GIBSON:** -- institutions. Today, what should we be doing with those baby
2 elephants?
- 3 **MATTHEW:** In my opinion, we need to close them down, even though I know some of the
4 disabled community will say the opposite. And I understand their argument, but if we
5 really believe in including, if we close it down, we need to support people really well. This
6 is not about main dumping, this is about proper support, at home, at school, anywhere.
- 7 **COMMISSIONER GIBSON:** Not about main dumping?
- 8 **MATTHEW:** Yeah.
- 9 **COMMISSIONER GIBSON:** I think that's a phrase that not many people would have
10 understood, but people need to be included not just dumped outside of wherever they were
11 previously excluded.
- 12 **MATTHEW:** And I knew you would understand that, Paul.
- 13 **COMMISSIONER GIBSON:** Yes. We worked in the same organisation a few years ago and
14 you had a great reputation of connecting with people and of getting people out of more
15 institution-like facilities one at a time from -- the building of a lot of trust, but you seemed
16 to be able to do that as a disabled person in that role better than others. Would you say that
17 was fair?
- 18 **MATTHEW:** Yes, and I'm still doing that today -- not today, you know what I mean.
- 19 **COMMISSIONER GIBSON:** And are we utilising the -- we heard yesterday about the number
20 of unemployed disabled people, are we utilising disabled people enough in these roles?
- 21 **MATTHEW:** Unfortunately, no, because I'm unusual, because I work in a provider, and I'm not
22 just -- I'm a manager of a provider and I'm so unusual. And I'm privileged as well, because
23 I believe in privilege and I never forget how privileged I am because I'm working.
- 24 **COMMISSIONER GIBSON:** It took a lot of battles to get the role, and I think providers need to
25 be conscious of the barriers that they put in place that stop people who can really
26 contribute.
- 27 **MATTHEW:** Yes. And we have to somehow recognise disabled people's experience as a
28 qualification.
- 29 **COMMISSIONER GIBSON:** You've described yourself as a disability activist. Most of
30 New Zealand wouldn't associate those two words with each other. Do you want to talk
31 about, have you been an activist in any other areas, gone on any marches, walks, what's
32 been your journey and also, I think the role of activism in creating change, ending abuse in
33 care?

1 **MATTHEW:** At 15 years old, I went on my first protest against the Springboks tour, and
2 although -- obviously I'm not right wing, I'm a very left-wing ideology and I had many
3 protest marches, not only for disability issues but for social justice.

4 **COMMISSIONER GIBSON:** Do you think people recognise ableism, discrimination,
5 oppression, do people, in general, in the public, in the same way they do racism,
6 discrimination and oppression in that context?

7 **MATTHEW:** No. No, because I think in our society we think we need to be nice and polite to
8 disabled people, and that's why it's not recognised as racism or sexism. I'm sure, Judge
9 Coral, you faced exactly the same issue when you became a lawyer. I'm not sure how long
10 you've been doing this, but you're older than me, sorry to say that.

11 **CHAIR:** Hundreds of years.

12 **COMMISSIONER GIBSON:** Hopefully there's a few young disabled people listening out early
13 on a journey of understanding. What would you like to say to them? What might be the
14 role of advocism, of working --

15 **MATTHEW:** Don't be passive because when we have a passive stance, disempowerment comes
16 along. And the systemic issue we have in Aotearoa because we like to be nice to each other
17 and want to be not offensive to each other, but we need to support young disabled people to
18 take up their rights. And I think, often, young disabled people think they have the rights
19 now. Activists of old, when I was young we had to fight for everything. But today, I don't
20 have to ring up a restaurant to make sure if it is accessible. I don't -- I'm not restricted. If I
21 want to go to the movies, I don't have to ring up to get the seats removed. And I can go on
22 all day with examples. I think we really need to put energy in to young disabled people.

23 **COMMISSIONER GIBSON:** Thanks, Matt, I could go on all day too. It's a privilege to have
24 been on the same side in many battles as you have. I think it's better to be on the same side
25 as a fighter, thank you so much. There's been a few.

26 **MATTHEW:** And there will be more.

27 **COMMISSIONER GIBSON:** There will be more, but hopefully result of this Inquiry and as a
28 result of your evidence there won't be as many, I hope -- you have -- you've really given a
29 challenge about this not being a talk fest. As I was saying, you've had a reputation in the
30 services of getting shit done and that's a challenge for us. Sometimes it might take 10 days
31 or even longer but we'll get there.

32 **MATTHEW:** Good luck.

33 **COMMISSIONER GIBSON:** Can I thank you for your spirit, your relentless determination,
34 your, at times, insistence on what needs to happen on doing the right thing. You really are

1 an expert. You drew a lot of different experiences together and the individual , personal
2 experience of abuse and neglect in institutionalisation and really joining the dots up to the
3 systemic change that needs to happen. How services, power and control, we need to be
4 reframing those, we need to be hearing endlessly and learning from the voices of people
5 with lived experience, those who have got that collective wisdom which you bring to the
6 table today for the solutions for the future.

7 We'll insist amongst ourselves that this won't be a talk fest, we'll make sure this
8 does result in something.

9 Thanks so much for sharing, it's a cliché saying it's courageous to do this, but it
10 really is. Having known you for so many years, to hear some of this is, again, quite
11 impactful, so thank you, kia kaha.

12 **MATTHEW:** Thank you, Paul.

13 **COMMISSIONER GIBSON:** Thank you. Ms Thomas.

14 **CHAIR:** We're allowed lunch now, so we will -- please go and enjoy yourself. Can I just say
15 finally before we finish, we have seen the pain that you have been through in telling your
16 story, and I want you to make sure you take whatever well-being we can offer you to
17 support you, so that pain doesn't remain with you, we don't want to do you any further
18 harm. You've gifted us your evidence, and the best we can do is make sure your well-being
19 is cared for. So, please make sure you rely on as much of that as you need.

20 **MATTHEW:** Thank you.

21 **CHAIR:** Not at all. Please enjoy your lunch as well.

22 **MATTHEW:** I will. Can't you see my slim physique?

23 **CHAIR:** Yes, I can, I know you will enjoy your lunch, as we will.

24 **COMMISSIONER GIBSON:** No, I can't see, there are no elephants in the room.

25 **MS THOMAS:** If we come back for a 2.15 start.

26 **CHAIR:** 2.15, thank you.

27 **Lunch adjournment from 12.54pm to 2.28pm**

28 **CHAIR:** Yes, Ms Basire.

29 **MS BASIRE:** Thank you, Commissioner. This afternoon our next witness is Leeann Barnett and
30 her brother, Shannon. Shannon has chosen to watch the bulk of the evidence from the AVL
31 room and he will come in and take questions at the end.

32 **CHAIR:** Can Shannon see us now? I hope he can.

33 **MS BASIRE:** Hopefully. JJ? Yeah, he can see you now, so I'll hand over to you for the
34 affirmation process.

1 **CHAIR:** Good afternoon, Leeann, thank you so much for coming, tēnei te mihi ki a koe. I'll just
2 read you the affirmation.

3 **LEEANN BARNETT (Affirmed)**

4 **CHAIR:** And I'm just going to send a greeting through to Shannon and say thank you for listening
5 and we'll see you later.

6 **QUESTIONING BY MS BASIRE:** Please tell us your full name.

7 A. Leeann Kerry Barnett.

8 **Q.** Thank you. Now Leeann, you're here today to give evidence about two of your foster
9 brothers -- Shannon, who we've just introduced, and he's here; but also, another brother,
10 Amos.

11 A. Correct.

12 **Q.** You also have disability, can you briefly explain that for those who are listening?

13 A. I have a childhood traumatic brain injury, so when I was nine I was hit by a car and as a
14 result, I live with multiple lifelong impairments.

15 **Q.** Thank you. Growing up, your parents ran a social welfare home and then set up the Mount
16 Cargill Trust which provided residential care and support to people with disabilities; is that
17 correct?

18 A. Yes.

19 **Q.** Your parents retired from the trust in approximately 2012, but because of the homes that
20 your parents ran and the later trust, you grew up with lots of foster siblings, didn't you?

21 A. About 100.

22 **Q.** And these were young children through to adults who came into your parents' care?

23 A. Yes.

24 **Q.** Today you want to talk about Amos Cameron and Shannon?

25 A. Yeah.

26 **Q.** And so, we're going to focus on Amos to start with. Tragically, Amos died in 2001?

27 A. June 26th.

28 **Q.** What age was Amos when he came into your parents' care?

29 A. Ace, we call him -- are about the same age, I can't quite remember, maybe 12, somewhere
30 around there.

31 **Q.** So, you were born in 1974 and so was Ace?

32 A. Yes, yeah, yeah.

33 **Q.** And so he joined your family at about the age of 12 and you were 12 also?

34 A. Yeah.

- 1 **Q.** What disabilities did Amos have?
- 2 **A.** There were multiple --different diagnoses over the years, but the most accurate is primary
3 diagnosis of Autism, he was a savant, so those who have seen the movie Rain Man, he was
4 a Dustin Hoffman-type level of Autism. He also had Obsessive Compulsive Disorder,
5 Tourette Syndrome and paranoid schizophrenia.
- 6 **Q.** Thank you. When you and Ace were teenagers, you recall Ace becoming very unwell and
7 he was placed in Ward 9B at Cherry Farm?
- 8 **A.** Yeah, I have this one memory of him being down there and going in to visit him and being
9 terrified. I'm not entirely sure of the year, but it was a frightening experience.
- 10 **Q.** Why was it frightening?
- 11 **A.** It was like being in a movie of the past, everything was dark stained-wood, the layout was
12 jail-like almost, it was corridors, there was staff with keys jangling on them, there was a
13 hall and down the side of the hall there was these cubicles where they slept, it --wasn't a
14 welcoming environment, and the people in there were adults with him.
- 15 **Q.** And so Amos was a lot younger than the people he was in Ward 9B with?
- 16 **A.** Yes, Amos was tiny, he was 5 foot 1.
- 17 **Q.** So he always looked younger than his chronological age?
- 18 **A.** Yes.
- 19 **Q.** Now, because you were only a teenager yourself, you don't have the exact timeline, but
20 when he came out of Cherry Farm, whose care did he come back into?
- 21 **A.** Ours.
- 22 **Q.** And so at times when he was mentally unwell, he would go into psychiatric institutions but
23 he would always come back to your parents?
- 24 **A.** Mmm, a little bit, -he then went into Wakari after that, Wakari - opened, because it shut
25 down in '91, Cherry Farm. So then --he would go to Wakari, but throughout our later teens
26 and his, up until probably just before he went missing, he didn't spend any time i n there that
27 I recall at all. He was fine, his psych illnesses were under control.
- 28 **Q.** So from your memory from the time he had that admission into Cherry Farm, until he was
29 in his 20s --
- 30 **A.** There was a couple of times after that that he did go into Wakari, so Cherry Farm closed
31 down, and it moved into town, into Dunedin, and became Wakari Ho spital.
- 32 **Q.** Yep.
- 33 **A.** But there was a couple of times, but not much.
- 34 **Q.** Right. So if we take you to when Amos was 26 years old, so were you?

- 1 A. No, I was 27.
- 2 Q. Oh, because you're a couple of months older?
- 3 A. Yes.
- 4 Q. Got to get that right. Now, you're talking about Wakari Hospital in Dunedin?
- 5 A. Yes.
- 6 Q. And that's what took over the psychiatric care of people in the Dunedin region after Cherry
7 Farm closed?
- 8 A. Yeah.
- 9 Q. And there's a ward there 10A?
- 10 A. Mmm-hmm, dual diagnosis.
- 11 Q. He was initially in a locked ward?
- 12 A. 10A has two halves to it, part of it is a secure ward and another part is unsecured. For most
13 of the time he was in the secure ward. Two weeks prior to his disappearance they moved
14 him out of there.
- 15 Q. Because your parents and other caregivers were very concerned about Amos's mental
16 health, he was displaying bizarre behaviour and those who knew him best were really
17 concerned about his mental stability?
- 18 A. Just prior to them moving him from the secure half of the ward, my parents said to the
19 ward: If you remove him from the secure unit and put him in the unsecured unit, you will
20 be signing his death certificate. Profound --in hindsight.
- 21 Q. The psychiatrist involved in his care at the time disagreed and reduced his medication?
- 22 A. The psychiatrist at the time would quite often not even bother going in and seeing him, he'd
23 just ring the manager.
- 24 Q. But psychiatrist was the one who was controlling his plan?
- 25 A. Yes.
- 26 Q. Medications were reduced?
- 27 A. Yes.
- 28 Q. And he was moved into the open ward?
- 29 A. And his behaviour continued to escalate.
- 30 Q. Family members discussed this with the hospital?
- 31 A. Yes.
- 32 Q. But the decision was made by the professionals?
- 33 A. Yes.

- 1 **Q.** Amos went missing on 26 June 2001. You've noted in your statement that he was nine
2 days shy of 27 years old?
- 3 **A.** Mmm-hmm.
- 4 **Q.** A later coroner's hearing concluded that he'd accidentally drowned that day at Taieri
5 Mouth?
- 6 **A.** That's the conclusion of the coroner.
- 7 **Q.** They concluded that it was accidental because there was no evidence he was suicidal?
- 8 **A.** No.
- 9 **Q.** Was Amos's body ever found? I'm sorry, Leeann, you don't have to say if --
- 10 **A.** No, no, it's fine, he's the one person that gets me. His jawbone was found 15 months and
11 three days later at Kuri Bush which is 3K north of Taieri Mouth. So no, his body was not
12 found but a part of him was.
- 13 **Q.** Your family felt that Amos's death was preventable?
- 14 **A.** Completely, totally. And it wasn't an accident. As far as we're concerned, his death was as
15 a result of neglect and incompetence.
- 16 **Q.** The coroner found that some errors had been made by hospital staff on the day, but
17 declined to consider the wider issue about whether Amos was receiving appropriate care
18 overall. That's correct, isn't it?
- 19 **A.** Yes.
- 20 **Q.** The coroner at the time said to the family they should take the concerns about the overall
21 care to the Health and Disability Commissioner, as the coroner felt she was not qualified to
22 consider that issue?
- 23 **A.** Correct. We were unable to do so.
- 24 **Q.** Because after the coroner's finding, your father --
- 25 **A.** Just before.
- 26 **Q.** Yeah.
- 27 **A.** So Amos's --the coronial inquiry was pushed forward after the discovery of Amos's
28 jawbone and the identification from the odontologist in Dunedin. However, on Tuesday the
29 25th of June 2002, a year to the day after Amos had gone missing, my father --at work, had
30 a heart attack and was dead for 20 minutes. He was recovering and it took many years for
31 him to get to the level he is now from that incident. And he too now lives with a brain
32 injury as well.
- 33 **Q.** At 26 this was a big thing for you to take on to go to the Health and Disability
34 Commissioner?

- 1 A. I wasn't, --it took me six years to move past Ace's death, I couldn't have done it.
- 2 Q. I just want to summarise, just because we really don't have time, but I'm sorry that we're
3 going through so quickly, because --
- 4 **CHAIR:** But we do have your full statement here, which we've read.
- 5 A. Yes, thank you.
- 6 Q. So don't feel you're being overlooked, will you?
- 7 A. No, I get the time.
- 8 Q. You get the time, okay.
- 9 **QUESTIONING BY MS BASIRE CONTINUED:** I just want to acknowledge for Amos that
10 this is not something that we want to brush over.
- 11 A. Yeah.
- 12 Q. And it's an important part both the psychiatric, the story you have today about Amos and
13 about Shannon straddles both areas of our inquiry, the psychiatric and disabled, and Amos's
14 story is really important.
- 15 A. Well, he's a combination of them both.
- 16 Q. Yup. So, the errors that your family considered the most, and I'm just going to read them
17 out, the issue that the medication had been changed despite his disturbed behaviour?
- 18 A. Mmm-hmm.
- 19 Q. That he should not have been on the open ward?
- 20 A. Correct.
- 21 Q. That on the open ward he was on, he was supposed to be monitored every 10 minutes and
22 he wasn't?
- 23 A. Correct.
- 24 Q. The mistakes that were made on the day, firstly it was 30 minutes before he was noted to be
25 missing?
- 26 A. Correct.
- 27 Q. He had last been seen at 10.45 that morning, and the staff noted he'd gone at 11.15. But it
28 took another hour and 10 minutes before his absence was escalated to the Police?
- 29 A. And that was by my mother.
- 30 Q. Yeah.
- 31 A. My mother did that, not the hospital.
- 32 Q. When the report that the hospital have to fill out to send to the Police in these
33 circumstances was filled in, it was not filled-in in full and it did not follow policy?
- 34 A. No.

- 1 **Q.** It gave a description of his clothes and mental state but did not point out that he looked a lot
2 younger than his chronological age?
- 3 **A.** Yes, correct.
- 4 **Q.** The report did not give the Police any indication of what area he was likely to go to?
- 5 **A.** Correct.
- 6 **Q.** Radio broadcasts about him going missing were only aired at 3.50pm that afternoon?
- 7 **A.** And that was as a result of the Police not being aware of the significance of his
8 disappearance.
- 9 **Q.** And that was related back to the incomplete filling out of the form from the hospital?
- 10 **A.** Mmm-hmm.
- 11 **Q.** At 5pm, a member of the public had phoned to say he'd seen a young man wearing only
12 underpants near the Taieri Mouth?
- 13 **A.** Yes.
- 14 **Q.** But it was only after 8pm that area was searched?
- 15 **A.** Began being searched, yes.
- 16 **Q.** Began, yeah. Some of Amos's clothing was later found there?
- 17 **A.** I still have them at home.
- 18 **Q.** One of the issues that the staff at the Trust and your family members had was that day,
19 when they went up to the hospital as soon as they'd found out, the general feeling they got
20 was the staff thought they were overreacting?
- 21 **A.** Yes.
- 22 **Q.** And staff weren't that worried?
- 23 **A.** Correct.
- 24 **Q.** Your family members were reacting because Amos was not somebody who ran, was he?
- 25 **A.** No. Amos was vulnerable, Amos was completely vulnerable, he was, it's-- like putting a
26 toddler out in the wild.
- 27 **Q.** Now, I know there's something that you want to say about the report and the chairman.
28 Can you explain that?
- 29 **A.** When the coroner's --coronial inquiry was instigated, the hospital undertook a review of the
30 circumstances surrounding Amos's disappearance. Once my mother had received that, we
31 discovered that the psychiatrist who had undertaken that review was someone who worked
32 within the Dunedin system and that particular psychiatrist was not independent, he had
33 close contacts with everybody concerned. She therefore contacted the then Chair who had
34 not been around at the time of Amos's disappearance.

1 **CHAIR:** Your mother contacted the Chair?

2 A. Yes, yes, of the board of DHB. He, both in writing and verbally, expressed that he, or he
3 apologised and admitted responsibility, that the hospital was responsible for Amos's
4 disappearance eventually, but he also said that they had no idea of the inquiry, they had not
5 been made aware of the circumstances surrounding Amos's disappearance, nor were they
6 aware that the doctor concerned -- sorry, they also knew that the doctor concerned should
7 not have been done, once they heard who it was, the review. They then went to the coroner
8 and attempted to --Kathy, what was the word I used?

9 **QUESTIONING BY MS BASIRE CONTINUED:** Withdraw the --

10 A. Thank you.

11 **Q.** So the board went to the coroner?

12 A. Yeah, the board went to the coroner and tried to withdraw the review that they had
13 submitted, the coroner refused.

14 **CHAIR:** Just to be clear, the review that was done by the hospital, by the psychiatrist, was
15 submitted to the coroner; was that right?

16 A. Correct, and he should never have done it.

17 **Q.** And the board tried to have it rescinded, brought back?

18 A. Mmm.

19 **Q.** And the coroner said no?

20 A. Correct.

21 **Q.** Thank you.

22 **QUESTIONING BY MS BASIRE CONTINUED:** Then the coroner relied on that report?

23 A. Correct. We were told within the report to go to HDC and as I've said before, with Dad,
24 there's nowhere, nowhere for us to go to get the support. We couldn't do it, we had the
25 skills, we didn't,-- so and I got a copy sorry--, I know I'm going on. - I got a copy of an
26 incident that had occurred a number of months earlier-- on that year in Invercargill, of a
27 young man who had committed a crime from --the Invercargill psychiatric hospital, an
28 HDC report. The issues within that report were identical to the ones that Amos had. Had
29 we have gone to HDC, who knows.

30 **Q.** You might have felt some more closure?

31 A. Well, maybe there's been one or two other people from somewhere around the country that
32 might not have had to have gone through what we've gone thro ugh, because there's been
33 plenty since.

- 1 **Q.** So just finishing on Amos, you've told us in your statement that you believe that advocates
2 should be automatically offered to assist with any complaint about HDC?
- 3 **A.** Independent.
- 4 **Q.** Yeah, independent, to avoid families becoming overwhelmed and not carrying through with
5 a complaint?
- 6 **A.** Yes.
- 7 **Q.** Thank you. I just want to turn to talk about Shannon. Shannon's 10 years younger than
8 you?
- 9 **A.** Yes.
- 10 **Q.** He was born in 1994 , no --1984?
- 11 **A.** '84.
- 12 **Q.** Yeah, get it right.
- 13 **A.** He won't be impressed with you, Kathy.
- 14 **Q.** No, he'll be listening, laughing, I think, knowing Shannon. So you were aged 20 because
15 you are 10 years older than him?
- 16 **A.** Yes.
- 17 **Q.** You weren't living at home, but you worked at the farm because your parents operated the
18 Trust out of a farm?
- 19 **A.** So the Trust was in the process of being set-up, it hadn't quite received certification at that
20 point. He came in as our foster child.
- 21 **Q.** So you worked in your parents' business effectively as a support worker?
- 22 **A.** It wasn't a business, but yeah.
- 23 **Q.** And so you had a lot of contact with Shannon from the time that he came into your parents'
24 care until now?
- 25 **A.** I have been it. I am, for all intents and purposes, it in his life and have been from day dot.
- 26 **Q.** I believe in his pre-record he calls you friend, advocate, mother extraordinaire, something
27 like that, everything rolled into one?
- 28 **A.** Mother, sister, teacher.
- 29 **Q.** Yeah.
- 30 **A.** And it used to be friend on the end, but he's taken that out.
- 31 **Q.** Now, your understanding is that Shannon lived with his biological mother and then was
32 moved into foster care?
- 33 **A.** He lived with his biological mother until he was seven, then he went into CYFS foster care
34 and, for a period of time, just prior to coming to live with us, we were taking him in on

1 respite, and it was decided as that placement broke down that he would come and live with
2 us full time.

3 **Q.** At that time, there were concerns for Shannon's safety?

4 **A.** Correct.

5 **Q.** Although nobody's really sure what went on in those CYFS homes?

6 **A.** Yeah.

7 **Q.** Can you tell us about Shannon's disabilities?

8 **A.** Shanny has severe Autism, he's non-verbal, he has epilepsy and he has another health
9 condition that affects his intestines. He's incredibly intelligent, he's a very, very bright,
10 very, very capable young man with a wicked sense of humour. And a gusto for life and a
11 wanting for life.

12 **Q.** Yes. When he came into your parents' care, he had begun to use facilitation to
13 communicate at the age of eight at his school?

14 **A.** Correct.

15 **Q.** Can you explain for us what is facilitation?

16 **A.** Facilitation came around in about the 70s, mid-70s, somewhere - in Melbourne. It's a form
17 of supported communication where the hand or the arm is gripped and there is pressure
18 backwards while the person pushes forward to type out what they're saying. In -Shannon's
19 case, - the- way I teach people, if you think of a pair of bunny ears on a TV, the TV --for
20 those who are old enough, that is, the TV's all fuzzy. You put your hands on the bunny ears
21 and you earth it and it brings it back to life. For all intents and purposes that's what you're
22 doing because, the messages are dropping out, he has dyspraxia, sorry, as well, so
23 dyspraxia causes the messages to drop out from the brain to where it's going to in his body,
24 which is part of -- a large part of what's affecting his vocal cords.

25 **Q.** Thank you. So when you said you hold his arm and you pull it back, and then he pulls
26 forward?

27 **A.** Pushes hard.

28 **Q.** Pushes hard, yeah, when he first began this process, it was clearly with teachers at his
29 school?

30 **A.** Yes.

31 **Q.** And all he would have had is the alphabet laid out in a QWERTY keyboard way?

32 **A.** I didn't -- he wasn't living with us then, so I can only guess yes. There were in those days
33 a, I think it was called Canon? It's a weird machine, like we're talking ancient materials
34 from what we have now, so yeah, I'm not entirely sure, but I think so.

- 1 **Q.** But certainly when you got to know him, it was simply --
- 2 **A.** It was a white A4 page with QWERTY keyboard on it, laminated.
- 3 **Q.** And QWERTY keyboard, you mean the layout as you have on a computer or laptop?
- 4 **A.** Correct, yeah. Can we also point out here too that in 1993 a paper was done by --
- 5 **Q.** Yeah, I was about to ask you that.
- 6 **A.** Sorry, yeah.
- 7 **Q.** No, you're doing well, Leeann.
- 8 **A.** -- by Dr Trevor McDonald, where Shannon was the subject, it was a 400-level education
9 paper, Trevor McDonald later went on to become Dr Trevor McDonald and worked in the
10 field of communication and disability for a number of years in America, as well as here in
11 New Zealand, and Shannon is the subject of that year-long paper.
- 12 **Q.** And the conclusion of that university paper, research paper, was that facilitation was a
13 positive?
- 14 **A.** Yes.
- 15 **Q.** And it was a legitimate form of communication?
- 16 **A.** Pretty much.
- 17 **Q.** However, this was when Shannon was nine?
- 18 **A.** 1993.
- 19 **Q.** Yeah, 1993, which is some 28 years ago now?
- 20 **A.** Yes.
- 21 **Q.** When Shannon went to high school, he had a number of teachers that would use this
22 facilitation process with him?
- 23 **A.** Including me.
- 24 **Q.** And including you?
- 25 **A.** Mmm-hmm.
- 26 **Q.** But you were by far not the only person who facilitated with him?
- 27 **A.** No, no.
- 28 **Q.** Can you tell us what school subjects that Shannon passed in high school using this process
29 of facilitation?
- 30 **A.** I taught him English and history, which he passed with flying colours. He had another
31 teacher for maths. In Sixth Form, --so I was --one of his main --one-on-one teachers. He
32 was fully mainstreamed, but he had one-on-one teachers with him in those classes. In the
33 Sixth-, so - Third Form to Fifth Form - -Sixth Form on, I wasn't there. He - did maths and

- 1 English in the Sixth Form -and oh-- no, stats and calculus, I think, or one of the two, and
2 English in the Seventh Form. In the Sixth Form -- oh, shall we leave him to tell that story?
- 3 **Q.** Yeah.
- 4 **A.** Okay.
- 5 **Q.** I think the point that you want to make about this, and Shannon wants to make about this, is
6 that many different people facilitated with him?
- 7 **A.** And by the way, I might have taught him, but I never took him for those exams.
- 8 **Q.** Right. So, if you were teaching him, you didn't take him for the exams, somebody else
9 would do the process of facilitation?
- 10 **A.** Correct.
- 11 **Q.** And he passed School Cert, University Entrance, you weren't involved when he was in the
12 Sixth Form but he still got sixth in class in maths?
- 13 **A.** Sixth in his year in his school, for Sixth Form maths.
- 14 **Q.** Yes. So as Shannon later tells us, he's a clever cookie?
- 15 **A.** That's the polite way of putting it, yes.
- 16 **Q.** He went on to do a Massey University creative writing course. This started at high school
17 and after he left school?
- 18 **A.** It's not a course as much. He has a certificate in art, so for all intents and purposes he has
19 half a degree.
- 20 **Q.** Yeah.
- 21 **A.** Most of it was creative writing but he did a number of other subjects, religious studies,
22 anthropology, I can't remember what else.
- 23 **Q.** Thank you. Sorry, you saw me talking to Nick, just queuing up an exhibit, and this is
24 Exhibit 1, which shows some of Shannon's writing when he is --
- 25 **A.** Third Form.
- 26 **Q.** Third Form?
- 27 **A.** **[Nods.]**
- 28 **Q.** Now, it's a bit hard to see on your screens. That's because it's currently glued into a scrap
29 book with all his work?
- 30 **A.** Yes.
- 31 **Q.** And that's my iPhone taking a picture of it?
- 32 **A.** Would you like me to read it?
- 33 **Q.** Yes, but can you read that out for us?

- 1 A. "Life in my own world. I was scared to go on the bus to Outram. You see, I live in a silent
2 type of world. I was born with Autism. It makes me feel like screaming sometimes.
3 Anyway, I did go in the minivan this day. I have to do things that scare me all the time. If
4 I didn't, I wouldn't be living my life. Like it scares me to walk up and downstairs, but I do
5 it every day. People sometimes call me dumb, or they say I am a moron. What they don't
6 realise is that I am a clever cookie. A clever cookie in a silent world. Silent because I can't
7 talk or communicate well. Silent because I am on my own in it. But silence isn't bad, just
8 scary sometimes."
- 9 Q. Thank you, Leeann. That's one of numerous pieces that Shannon has written over the
10 years?
- 11 A. Yeah, I didn't facilitate that one with him, so yes.
- 12 Q. What I want to do with the time that we've got available is talk about Shannon's care more
13 recently.
- 14 A. Mmm-hmm.
- 15 Q. Your parents eventually retired from the Mount Cargill Trust and others took over the
16 running of it?
- 17 A. Mmm-hmm.
- 18 Q. This was around 2011, 2012, transitional period?
- 19 A. 2012.
- 20 Q. 2012.
- 21 A. I think, yeah.
- 22 Q. Shannon had been in a number of homes from the time he left --
- 23 A. The farm.
- 24 Q. -- the farm and left school, living under the umbrella of the Mount Cargill Trust?
- 25 A. Mmm-hmm.
- 26 Q. Some worked for him better than others?
- 27 A. Yeah.
- 28 Q. But generally your view was he was doing okay?
- 29 A. Yes. The last few years, --yeah.
- 30 Q. It wasn't perfect?
- 31 A. It wasn't perfect, nothing's perfect.
- 32 Q. But it's particularly from 2012 to 2016 that you want to talk about?
- 33 A. Mmm-hmm.

- 1 **Q.** You became concerned about what was happening for Shannon and his care situation.
2 When he facilitated, at some stage in his life he'd gained a machine called a Lightwriter?
- 3 **A.** In the Fourth Form.
- 4 **Q.** Can you explain for us what a Lightwriter is?
- 5 **A.** A Lightwriter, the one you will see on his video, is the original model that he got in 1999.
6 It is an augmentative computer equipment, piece of computer equipment he types into. It
7 has two, what do you call them, where the words come up, screens where the words come
8 up.
- 9 **Q.** There's a screen at the front and a screen at the back?
- 10 **A.** And a screen at the back, yeah. And it speaks. That particular one speaks in a
11 horrendously monotone, -- it's horrible. Nevertheless, it was a remarkable piece of
12 equipment, it gives Shannon a voice and an independence he'd never had and literally
13 overnight his personality changed when he got it. I can't highlight enough how much his
14 personality changed --in the Fourth Form, --a speech and language therapist from that time
15 at school gave it to him.
- 16 **Q.** Because prior to that, although he could point to letters that made up words, somebody else
17 had to voice it for him?
- 18 **A.** Yes.
- 19 **Q.** And so he was the one who could choose which voice came out of the Lightwriter?
- 20 **A.** Mmm-hmm.
- 21 **Q.** It was originally Betty, I understand?
- 22 **A.** Yeah.
- 23 **Q.** Yeah. But fast-forward to 2012 and Shannon's Lightwriter had been lost --
- 24 **A.** Yes.
- 25 **Q.** -- by a caregiver, misplaced?
- 26 **A.** It was actually one of his um, so - for the Trust, I had gained the Ministry of Social
27 Development contract for the high needs wards' funding and put in place so he could -- he
28 and some others could continue on with his studying at Massey University and it was one
29 of his tutors that lost it.
- 30 **Q.** Right, okay, thank you for clarifying that. And around the time that he'd lost it, there were
31 less people facilitating with him at that time?
- 32 **A.** Yes.
- 33 **Q.** Yeah.
- 34 **A.** But there was still a few.

- 1 **Q.** Yeah. Because it's a learned process, helping somebody via the process of facilitation, isn't
2 it?
- 3 **A.** Yes, otherwise you get people pushing his finger towards places and it's not his voice.
- 4 **Q.** It's fair to say by 2012 the process of facilitation had fallen out of favour, for want of a
5 better word?
- 6 **A.** Yes.
- 7 **Q.** In fact, today it's quite controversial?
- 8 **A.** It has been for a long time.
- 9 **Q.** And it's because of what you said that studies have shown there is a danger that it can be
10 manipulated?
- 11 **A.** It doesn't fit the able-bodied specialist's ideal of empirical data.
- 12 **Q.** Yeah.
- 13 **A.** And that's a quote.
- 14 **Q.** Yeah. So cut to the chase, a psychologist would say that it's not appropriate to use this
15 machine anymore?
- 16 **A.** Correct.
- 17 **Q.** Thank you. So Shannon's Lightwriter got lost by a tutor, and on the advice of a
18 psychologist, the Mount Cargill Trust didn't replace it, did they?
- 19 **A.** That's the first I've heard that the psychologist, but you told me that --I was not told that.
- 20 **Q.** Right, so the Trust's view, which has been communicated to us, was that it was on the
21 advice of a psychologist?
- 22 **A.** That's what they told you.
- 23 **Q.** Yeah. And, but you would agree that they declined to replace the Lightwriter?
- 24 **A.** The Lightwriter had been lost sometime before that.
- 25 **Q.** Yeah, but they didn't support --
- 26 **A.** No.
- 27 **Q.** -- your efforts to get him another Lightwriter?
- 28 **A.** No.
- 29 **Q.** And facilitation to be used as a communication?
- 30 **A.** They -- at that point, they literally took all -- and he wasn't the only person in the Trust,
31 they literally took all facilitation away.
- 32 **Q.** I just want to draw up another exhibit which unfortunately is also labelled 1, but it's the
33 laminated card.
- 34 **A.** That's what he came to me with, that's all the communication he had.

- 1 Q. So they didn't believe that the process of facilitation was authentic anymore?
- 2 A. But he could do that.
- 3 Q. What he got was a "yes/no" card?
- 4 A. Mmm-hmm.
- 5 Q. And that was it?
- 6 A. Mmm-hmm.
- 7 Q. Did anyone facilitate him pointing to "yes" or "no"?
- 8 A. I have no idea, I doubt it.
- 9 Q. Explain to us why you believe that the process of facilitation is authentic communication
- 10 for Shannon?
- 11 A. You mean why do I think FC is fine?
- 12 Q. You know it works with Shannon?
- 13 A. Because I can feel him doing it.
- 14 Q. So, when --for example, if I ask Shannon a question and he wants to answer, what does he
- 15 do with his arm?
- 16 A. **[Indicates].**
- 17 Q. He puts his arm up?
- 18 A. Well, it could be anything from stuffing --or putting his finger in your face to just a slight
- 19 flick of, you can't see it, just this [indicates] or he could literally go [points].
- 20 Q. So he will indicate to you when he wants to answer or talk?
- 21 A. Yes, yeah. Sometimes he will literally stand up and walk over to the Lightwriter.
- 22 Q. To talk?
- 23 A. Yeah.
- 24 Q. Other times he'll reach out for it or reach his arm towards you?
- 25 A. **[Nods.]**
- 26 Q. If he doesn't want to talk?
- 27 A. He doesn't do anything, he just doesn't move.
- 28 Q. Yes. And as you say, you can feel because you're pulling his arm back and he's pushing it
- 29 forward?
- 30 A. Mmm-hmm.
- 31 Q. So one of the issues you had in very recent times was this removal of communication?
- 32 A. **[Nods.]**
- 33 Q. Another issue, which is a subject that's come up a lot in this hearing, was your concerns
- 34 about an antipsychotic drug being prescribed to Shannon?

- 1 A. Yes.
- 2 Q. Now the Trust's view is that that was prescribed by a GP?
- 3 A. GP is guided by what the staff tell them. A GP is guided by what I believe to be a
4 manipulation of circumstances. The medication Shannon took didn't actually mitigate
5 behaviours at all, any of the behaviours that they were supposedly concerned about.
- 6 Q. Right. Because he only had a "yes/no" communication system at that time, when he went
7 to a GP he's dependent on who he's at the GP with?
- 8 A. Unless he was with someone like me, he had absolutely no say with the GP. It was all staff.
- 9 Q. So in that period of time, you became aware that he had been prescribed the drug
10 Risperidone?
- 11 A. Yes.
- 12 Q. And that's an antipsychotic?
- 13 A. He'd been on it for quite some time. It may have even been before 2012. And I had
14 consistently raised concerns, but was repetitively ignored and told -- this is a very harsh and
15 very controversial and potentially dangerous claim, but it is a drug that's used throughout
16 the disability world as a behaviour control.
- 17 Q. Because it's a drug that was developed for use in schizophrenia and bipolar disorder?
- 18 A. That's right.
- 19 Q. But it is at times used to treat Autistic people for what others might consider challenging
20 behaviours?
- 21 A. And it didn't stop them.
- 22 Q. The side effect of that drug is it causes sedation and weight gain?
- 23 A. Mmm-hmm, and essentially turns them into a dummy.
- 24 Q. To be fair, you've said that he may have been on that medication before the change in
25 management?
- 26 A. Yes.
- 27 Q. But you became aware and were really concerned and had advocated for a long time for
28 him to be taken off that drug?
- 29 A. Right from day dot.
- 30 Q. There were a number of other concerns that you had about his general well-being, some of
31 those things are in your statement?
- 32 A. Mmm.
- 33 Q. The Trust's view is that they were operating at all times on medical advice, but you knew
34 Shannon well?

- 1 A. Here's the Trust's view - I forget to tell you this. I went to the doctor about his weight and
2 suggested to his GP, as he had previously been on a dairy- and gluten-free diet that we try it
3 again. The GP agreed with me and suggested we start with dairy. He wrote a letter to
4 Mount Cargill Trust saying that that should be and that-- we should go ahead with that. By
5 this stage, I was his legal guardian. Mount Cargill Trust then went to the nutritionalist, got
6 her in, and we'd had her before and she's not the best person to deal with these issues. She
7 decided that Shannon didn't need to go on it, despite what the GP had said, which overruled
8 both myself and the GP.
- 9 Q. And it's fair to say that the relationship between you and the Mount Cargill Trust broke
10 down, which eventually led to both parties agreeing that Shannon should go into your care?
- 11 A. I dispute that.
- 12 Q. Right.
- 13 A. I dispute that they did anything. I had had the Ministry of Health involved, was trying to
14 deal with the issues with them for nearly a year. It was because Mount Cargill Trust made
15 me put into my court orders, my PPP&R, that Shannon could not be removed without both
16 of us agreeing that he be removed. It was because I had the Ministry of Health involved,
17 and they were getting in trouble from the Ministry of Health for not doing things they were
18 supposed to do, it was because I had the Ministry of Health involved that I was able to take
19 him out without having to go back to court.
- 20 Q. We'll briefly just cover that issue. To become his welfare guardian you had to pay your
21 own money for a lawyer to go to court to have that process?
- 22 A. Yes.
- 23 Q. And basically because of the amount of time we've got today, I just want to move on to
24 when you actually did manage to get Shannon out of the Trust's care and into your care?
- 25 A. Mmm.
- 26 Q. You cared for him for three-and-a-half years without any support?
- 27 A. No, no financial, none.
- 28 Q. No financial support?
- 29 A. None.
- 30 Q. And briefly describe for us the changes in his behaviour when you stopped giving him that
31 drug and you changed his diet?
- 32 A. I immediately changed the diet. Within four months he lost eight kgs. Do you want to put
33 the photo up of him?
- 34 Q. Yeah, so we've got some before and after photos. Describe the photo on the left.

1 A. This is Shannon when he came to me, just before he came to me, in the orange top. This is
2 Shannon, he came to me on 1 October 2016, this is Shannon at Christmas in 2017 at my
3 parents' house. So, you can see the dramatic change in the man. That man in the orange top
4 was for all intents and purposes behaving in a largely institutionalised manner, his health
5 was appalling, he was doped up to the eyeballs on Risperidone. I actually waited for nearly
6 a year before I began taking him off the Risperidone because there was so much else going
7 on, I didn't want to do everything all at once. But you can see. I don't think words can add
8 too much to what's on the screen.

9 Q. Those of us who have seen the photos up close can see not only the weight reduction but
10 the alertness in both his face and body language?

11 A. Yeah.

12 Q. So you had him at home for three-and-a-half years without any support?

13 A. I had a little bit of individualised funding but that was to have someone come in and take
14 him out during the day, but not much.

15 Q. And now he's under the care of a different trust?

16 A. Yes.

17 Q. Things are a lot better for him but of course not --

18 A. Still some major issues.

19 Q. Still some major issues?

20 A. Around communication.

21 Q. Around communication. Just briefly on that, when you and Shannon contacted the Royal
22 Commission, myself and Nick Baker went to visit you and Shannon in Dunedin. We met
23 Shannon on a couple of occasions, and then went back to Dunedin to film the pre-record
24 that we're going to see.

25 A. Mmm-hmm.

26 Q. That pre-record was delayed because the machine wouldn't work?

27 A. That's right, so he had an old-school one that --like he got in 1999, and it is so old, it is now
28 obsolete, it's no longer made. However, it was breaking down all over the show. On the
29 day that we first started recording, I was able to contact his speech and language therapist
30 who is responsible for getting the equipment, who's really great, and she realised the
31 dilemma we were in. Thankfully, a month later, he now has a brand spanking new one and
32 his new voice, you'll hear, is wonderful.

33 Q. So this is one of the challenges, so he had an old Lightwriter that wouldn't work very well?

34 A. And isn't made anymore.

- 1 Q. And isn't made anymore. You were hitting your head against a brick wall trying to --
- 2 A. It wouldn't charge, remember?
- 3 Q. Yeah, it didn't even charge. I think we used it with you holding the connection together?
- 4 A. Yes.
- 5 Q. But the issue still remains that speech and language therapy, first of all there's no funding
6 for adult speech and language therapy?
- 7 A. He currently pays for his own and he can't afford it, but he can't not have it. So far he's
8 probably paid out close to, I think it's close to two grand. I've just a quote in for six months
9 of speech and language therapy that is desperately required. He has a Dunedin -- two
10 speech and language therapists, he has one in Dunedin, and it is \$3,404 for six months, and
11 he doesn't have that money.
- 12 Q. Right?
- 13 A. But that's to support him and his team in his house, his support staff, so they can all learn to
14 communicate together, because his support staff don't know what they're doing.
- 15 Q. Right. So because by the time he was with you, you are the only one who knew how to
16 facilitate with him?
- 17 A. Left, yeah.
- 18 Q. Yeah, and although speech and language therapists support him using the machine, their,
19 for want of a better word, code doesn't allow them to learn to facilitate with him?
- 20 A. Speech and language therapy as a body refuses to engage with it, which is completely
21 wrong, it's an able-bodied group of people saying, "We don't believe in it anymore, so you
22 can do it but we're not going to actually agree with you."
- 23 Q. So you're kind of on your own with teaching caregivers to use the machine?
- 24 A. Yes. Not "kind of", totally.
- 25 Q. Totally. So on that note, what we have done is we've done a pre-record, it was filmed over
26 two days in Dunedin. We're going to show the first 21 minutes of that. For the viewers it
27 has been sped up because the process of typing into the machine is laborious and
28 time-consuming, and so sometimes we're sort of just jumping to the answers, questions and
29 then the answers.

30 And then, Madam Chair, we'll take an afternoon tea break, come back and watch the
31 second half and then Shannon's going to come in. Thank you, Leeann.

32 **SHANNON AND LEEANN BARNETT**

33 **[Video played]**

1 "(Narrator) Shannon and Leeann Barnett. Shannon is of Pākehā descent and has
2 Autism. Shannon was in State foster care and residential homes from the age of seven.
3 Leeann is Shannon's foster sister.

4 Shannon is sitting on the left, Leeann is sitting on the right. They sit in a room with
5 Shannon's text-to-speech device on a table. Shannon wears purple and Leeann wears a
6 green-coloured jumper. Two interviewers are off-screen. Shannon uses a Lightwriter
7 machine to communicate. He does this by a process of facilitated communication, where
8 an assistant holds his arm and he directs what is typed. The typing process is
9 time-consuming, so for reasons of time, this video has been edited and does not show the
10 full time it took for Shannon to type his answers. Shannon is also communicating through
11 his head and vocal voice throughout the video."

12 **MS BASIRE:** Shannon, like we talked about before, we're now filming you for the Royal
13 Commission, and I wondered if you could tell me your full name.

14 **SHANNON:** Shannon [GRO-A].

15 **LEEANN:** You haven't spelled your first name right.

16 **SHANNON:** Tough.

17 **MS BASIRE:** And Shannon, I know that you were born in 1984, so that makes you 38, am
18 I right?

19 **SHANNON:** Yes.

20 **MS BASIRE:** And you started using the machine in front of you called a Lightwriter when you
21 were about eight to 10, is that right?

22 **SHANNON:** No, I started facilitating at one.

23 **MS BASIRE:** So you started --

24 **LEEANN:** So, Shannon, what's happening is, they're not doing the numbers, you're going to have
25 to spell the numbers out.

26 **MS BASIRE:** The machine's not working with the numbers?

27 **LEEANN:** No, it's the way it's configured.

28 **SHANNON:** Eight.

29 **MS BASIRE:** So you started facilitating at eight?

30 **SHANNON:** I was in the Fourth Form when I got SALW.

31 **MS BASIRE:** So you know how you said you were facilitating at eight?

32 **SHANNON:** Lee and my teacher got it.

33 **MS BASIRE:** Got the Lightwriter for you? That's what you mean, isn't it?

34 **SHANNON:** Yes.

- 1 **MS BASIRE:** Before you had the Lightwriter, did you used to have to use like at laptop with a
2 special keyboard? Or was it like a typewriter with a special keyboard?
- 3 **SHANNON:** I had a white A4 laminated page with a keyboard on it.
- 4 **MS BASIRE:** So you had a white laminated page with, like, a QWERTY keyboard? Did that
5 work very well for you?
- 6 **SHANNON:** Yes, and no, because I still didn't have a real voice.
- 7 **MS BASIRE:** And that's because somebody else had to write down what you were pointing to
8 and speak?
- 9 **SHANNON:** Yeah.
- 10 **MS BASIRE:** So when you got the Lightwriter, when you were in the Fourth Form, that was the
11 first time you could speak.
- 12 **SHANNON:** Free.
- 13 **MS BASIRE:** And so you're telling us that that made you feel free; is that right?
- 14 **SHANNON:** Free to be me.
- 15 **MS BASIRE:** That must have been a great feeling.
- 16 **SHANNON:** Exhilarating.
- 17 **MS BASIRE:** It was exhilarating to be able to have a voice, is that right?
- 18 **SHANNON:** Yeah, yeah.
- 19 **MS BASIRE:** Now, what I understand that facilitation is that Leeann's doing with you, is she's
20 holding your arm so you can type into the keyboard, is that right?
- 21 **SHANNON:** Anchoring my thoughts so I can get to words.
- 22 **LEEANN:** I think they need a bit more explanation. What do you mean by "anchoring" your
23 thoughts?
- 24 **SHANNON:** My mind loses them when I try to get them to my hand.
- 25 **MS BASIRE:** So you're saying that the facilitation helps you get your words from your mind to
26 your hand?
- 27 **SHANNON:** Earths my physical body.
- 28 **MS BASIRE:** Okay, I understand. So we know that when you were at high school there were a
29 lot of people who facilitated with you, wasn't there?
- 30 **SHANNON:** Yeah.
- 31 **MS BASIRE:** You said "yes" then, didn't you? And not just Leeann who's your sister, there were
32 a whole lot of teacher aides, weren't there?
- 33 **SHANNON:** Teachers, my teachers.

- 1 **MS BASIRE:** So the people who helped you facilitate at school were your teachers, not teacher
2 aides?
- 3 **SHANNON:** Yes.
- 4 **MS BASIRE:** Great. And what we know from looking at your school records and what Leeann's
5 told us is that you did very well at high school, didn't you? You got sixth in maths in your
6 class in the Sixth Form.
- 7 **SHANNON:** I am good.
- 8 **MS BASIRE:** Yeah, you're really good. And you like writing, don't you, and you went and did a
9 creative writing course at Massey University?
- 10 **SHANNON:** I'm bloody good.
- 11 **MS BASIRE:** You've just said, "I'm bloody good". I wanted to read out to you a piece of writing
12 you did in 1998 which would have been when you were...
- 13 **LEEANN:** Third Form.
- 14 **MS BASIRE:** Third Form? At age 14. Now this is something that you wrote, you may not
15 remember it, it's called *Life in my Own World*. "I was scared to go on the bus to Outram.
16 You see, I live in a silent type of world. I was born with Autism, it makes me feel like
17 screaming sometimes. Anyway, I did go in the minivan this day. I have to do things that
18 scare me all of the time."
- 19 **SHANNON:** That was at the farm.
- 20 **MS BASIRE:** Was that at Mount Cargill farm?
- 21 **LEEANN:** [Nods.]
- 22 **MS BASIRE:** Yeah, I saw you say "yeah".
- 23 **SHANNON:** My home.
- 24 **MS BASIRE:** Because at that time you were living at Mount Cargill farm in the Mount Cargill
25 Trust with mum and dad and lots of people. In your story, you said: "If I didn't, I wouldn't
26 be living my life, like it scares me to walk up and downstairs, but I do it every day. People
27 sometimes call me dumb or they say I'm a moron. What they don't realise is that I'm a
28 clever cookie. A clever cookie living in a silent world. Silent because I can't talk or
29 communicate well. Silent because I'm on my own in it. But silence isn't bad, just scary
30 sometimes."
- 31 **SHANNON:** So I like that work.
- 32 **MS BASIRE:** You like the story that you wrote?
- 33 **SHANNON:** It's about where I was at at that time, and how far I've come.

1 **MS BASIRE:** So you say that that story was about how you were feeling at that time and how far
2 you'd come. Because at the end of that story, you say, "Silent because I can't talk or
3 communicate well. Silent because I'm on my own in it. But silence isn't bad, just scary
4 sometimes."

5 **SHANNON:** Yes.

6 **MS BASIRE:** One of the reasons why we're talking to you, Shannon, is for you to be able to tell
7 the Commissioners and the public of New Zealand about what we need to understand about
8 somebody who doesn't speak words. What do you want to tell us about somebody like you
9 who's non-verbal? What do we need to know?

10 **SHANNON:** (Typing.)

11 **LEEANN:** Want to start that again?

12 **MS BASIRE:** Well, Shannon, to make it easier, what I could see on the screen is that you said
13 that "people need to stop treating us like idiots and respect that" -- and then I wasn't sure
14 what was going to come next.

15 **SHANNON:** Different ways of being are equal to able-bodied ways.

16 **MS BASIRE:** So you've just said that people -- we need to respect that different ways of being are
17 equal to able-bodied ways?

18 **SHANNON:** Society.

19 **MS BASIRE:** That society needs to respect that different ways of being are equal to able-bodied?

20 **SHANNON:** Yes, and that our homes and lives need to be designed around for us and why do we
21 have to fit into able-bodied boxes?

22 **MS BASIRE:** Right, so you want society to know that your homes and lives should be "designed
23 around for us because why do we have to fit into able-bodied boxes"; is that right?

24 **SHANNON:** Hell yeah.

25 **MS BASIRE:** Hell yeah?

26 **SHANNON:** Yeah. I am sick of people saying I am wrong.

27 **MS BASIRE:** Yeah. So you're sick of people saying that you are wrong because you are
28 different. That's what you mean, isn't it?

29 **SHANNON:** Shit yeah, you got it.

30 **MS BASIRE:** You said, "Shit yeah, you got it."

31 So, Shannon, what do you want to tell the government about how the government
32 should be treating people like you?

33 **SHANNON:** Stop making the rules fit your ablest thinking and let us design our lives.

- 1 **MS BASIRE:** So what you were saying is stop making the rules fit your ablest thinking and let us
2 design our lives. That's right, isn't it, Shannon?
- 3 **SHANNON:** Yeah, and work with communities to change their thinking of us.
- 4 **MS BASIRE:** Right. So you want the powers that be, I guess, to work with communities of
5 people who have disabilities to change people's opinions of people like you -- no?
- 6 **NICK:** "Work with able-bodied communities".
- 7 **MS BASIRE:** Oh, work with able-bodied communities, got it. Okay, so you've just said "yes".
- 8 **SHANNON:** Yes.
- 9 **MS BASIRE:** So Nick was on to it. So what you're saying, it's us able-bodied people in our
10 communities who need to understand you, so you can live the life you want to live.
- 11 **SHANNON:** Accept that your way isn't best.
- 12 **MS BASIRE:** So you want the able-bodied community to accept that our way isn't the best,
13 particularly for you?
- 14 **SHANNON:** It's a way and everybody has the right to be different.
- 15 **MS BASIRE:** Right, so it's accepting that everyone has the right to be different. So one of the
16 things that we know happened to you is the Lightwriter that's in front of you got taken off
17 you in 2012, do you remember that?
- 18 **SHANNON:** Hated it, all communication taken away.
- 19 **MS BASIRE:** So you hated it because all your communication was taken away. Do you
20 remember who did it?
- 21 **SHANNON:** Management.
- 22 **MS BASIRE:** So, it was [GRO-C] and- the management of the [GRO-C].- And what I
23 understand, and tell me if I'm right or wrong, Shannon, it was taken away from you because
24 able-bodied people thought that this technique wasn't authentic or true anymore; is that
25 what happened?
- 26 **SHANNON:** Yeah.
- 27 **MS BASIRE:** And you didn't have a say in it, did you?
- 28 **SHANNON:** Shit no.
- 29 **MS BASIRE:** And this is despite the fact that many people had helped you use this keyboard over
30 the years. That's right, isn't it?
- 31 **SHANNON:** Dozens had, I went through Massey.
- 32 **MS BASIRE:** Yeah, so what you're saying is dozens of people helped you with it and you went
33 through Massey University?
- 34 **SHANNON:** Yes.

1 **MS BASIRE:** And still able-bodied people at the Mount Cargill Trust were able to take it away
2 from you and you didn't have the power to take it back, did you?

3 **SHANNON:** Lee kept FC.

4 **MS BASIRE:** Lee kept --

5 **LEEANN:** Facilitation.

6 **MS BASIRE:** Oh, kept facilitating but not with the Lightwriter -- or with the Lightwriter?

7 **LEEANN:** No. The Lightwriter actually went missing, a staff member lost it before 2012 and it
8 was never replaced.

9 **MS BASIRE:** Right.

10 **LEEANN:** This is a different Lightwriter to the first one.

11 **MS BASIRE:** Right. And am I right that the staff replaced the Lightwriter with laminated pieces
12 of paper with just "yes" and "no".

13 **SHANNON:** Lee kept FC, yep.

14 **MS BASIRE:** Yeah. I can see that you've just typed "yep", so you agree that the staff gave you
15 pieces of paper with just "yes/no"?

16 **SHANNON:** Yeah.

17 **MS BASIRE:** How did that feel to be treated like that?

18 **SHANNON:** Shit.

19 **MS BASIRE:** Do you think that able-bodied people should be able to control you like that?

20 **SHANNON:** I'd love to tape their mouth up.

21 **MS BASIRE:** Right, so you'd love to tape their mouth up as they did to you?

22 **SHANNON:** See what it's like.

23 **MS BASIRE:** So they could see what it was like to have no voice.

24 **SHANNON:** Yes.

25 **MS BASIRE:** Now the voice that we hear coming out of the machine, is that a voice that you
26 chose from a menu?

27 **SHANNON:** Kind of, this machine has a limited selection. I used to have Betty.

28 **MS BASIRE:** So was Betty the voice you had on your old machine?

29 **SHANNON:** Yes.

30 **MS BASIRE:** Do you have a name for the voice on this machine.

31 **SHANNON:** Can't remember.

32 **MS BASIRE:** And you're having a problem with funding, aren't you, Shannon, to get --

33 **SHANNON:** There is none for computer equipment.

34 **MS BASIRE:** Right.

1 **SHANNON:** There is none for computer equipment, I want to write again, but I don't have
2 funding.

3 **MS BASIRE:** So you really want to start writing again but you need new computer equipment?

4 **SHANNON:** Specialised.

5 **MS BASIRE:** And I know that you said to us last time that [GRO-C] - who's one of his caregivers
6 is learning to facilitate, but you're the one who has to teach him; is that right?

7 **LEEANN:** Correct. Which is fine, I don't have a problem with that.

8 **MS BASIRE:** Shannon, how's [GRO-C] going with facilitation?

9 **SHANNON:** Not the best, but that's me not letting him in.

10 **MS BASIRE:** Right. So you are saying that part of the issue with getting a new person is you feel
11 uncomfortable with them being your -- helping you be your voice?

12 **SHANNON:** Yes.

13 **MS BASIRE:** And the reason why it's so comfortable Leeann is because she's your sister and has
14 been doing it a long time?

15 **SHANNON:** Sister, mum, teacher.

16 **[Video paused]**

17 **MS BASIRE:** That's an appropriate time to take a break because the next part of the interview had
18 been done the next day.

19 **CHAIR:** All right, shall we come back at, what time, four o'clock?

20 **MS BASIRE:** Four.

21 **CHAIR:** Yes, thank you.

22 **Adjournment from 3.44pm to 4.06pm**

23 **CHAIR:** Yes, Ms Basire.

24 **MS BASIRE:** Thank you, we'll now play the second-half of the video.

25 **[Video played]**

26 "(Narrator): The camera angle and scene change slightly to be closer up onto Shannon, it is
27 now the next day. Leeann is slightly off camera assisting Shannon, while Shannon is sitting
28 at the table and giving his evidence, by pressing the speech device. Shannon wears a black
29 motorcycle-style jacket and a salmon pink shirt."

30 **MS BASIRE:** Shannon, I just wanted to ask you some questions about just random stuff really,
31 like I like watching TV. Do you like watching TV?

32 **SHANNON:** Shit, yes.

33 **MS BASIRE:** "Shit, yes". So what's your favourite TV programme?

34 **SHANNON:** I like lots of stuff, a good action piece, a period piece, a comedy.

- 1 **MS BASIRE:** So you said you like lots of stuff like an action piece, a period piece, a comedy?
- 2 **SHANNON:** Jane Austen books.
- 3 **MS BASIRE:** Right, because you like reading, don't you, Shannon?
- 4 **SHANNON:** Jane Austen books love.
- 5 **MS BASIRE:** Yeah. We've heard that you volunteer at the Fringe Festival here in Dunedin. Can
6 you tell us about that?
- 7 **SHANNON:** My fave.
- 8 **MS BASIRE:** It's your fave, your favourite?
- 9 **SHANNON:** I deliver pamphlets and posters.
- 10 **MS BASIRE:** So for the Fringe Festival you've just told us that you deliver pamphlets and
11 posters; is that right?
- 12 **SHANNON:** Yeah, and I do a great job.
- 13 **MS BASIRE:** You've just said, "Yeah, and I do a great job," and I'm sure you do. And I think
14 that on the Facebook page for the Fringe Festival there was a photo of you, is that right?
- 15 **SHANNON:** Through Volunteer Otago.
- 16 **MS BASIRE:** It was on the Volunteer Otago Facebook page, is that right?
- 17 **SHANNON:** Yes.
- 18 **MS BASIRE:** Shannon, have you ever taken music lessons?
- 19 **SHANNON:** I have a wonderful singing teacher. Her name is Molly [GRO-C]. She is my
20 rhythmic soul beat I create tunes with.
- 21 **MS BASIRE:** She is your rhythmic soul beat who you create tunes with, is that right?
- 22 **SHANNON:** Yes.
- 23 **MS BASIRE:** What do you use to create the tunes on?
- 24 **SHANNON:** Keyboard. Yes, keyboard, my keyboard.
- 25 **MS BASIRE:** Thank you for telling us about that.
- 26 So yesterday, Shannon, we were talking about that time that you were in the Mount
27 Cargill Trust from 2012 to 2016 when you couldn't facilitate and you didn't have the
28 Lightwriter.
- 29 **SHANNON:** That's right.
- 30 **MS BASIRE:** And you told us yesterday how bad that made you feel. So what I want to talk to
31 you about is whether any other bad things happened between 2012 and 2016 when you
32 were in the Mount Cargill Trust before you came to live with Leeann.
- 33 **SHANNON:** Yes.
- 34 **MS BASIRE:** Would you be comfortable telling me and Nick what those things were.

1 **SHANNON:** Okay, some.

2 **MS BASIRE:** So what are the things that happened that weren't good?

3 **SHANNON:** I got spoken badly to sometimes and grabbed. And they treated me like a moron
4 sometimes.

5 **MS BASIRE:** Thank you for telling me about that.

6 **SHANNON:** I wasn't allowed to go out like I could do with Leeann, I was not free.

7 **MS BASIRE:** So just for the camera so that the people who are going to be listening to this
8 recording are clear what you've just told me, you've told me that when you're in the Mount
9 Cargill Trust after 2012 you were spoken to badly and you were grabbed, you were treated
10 like you were a moron sometimes and you weren't allowed to go out like you had done with
11 Leeann and you weren't free.

12 **SHANNON:** Yes.

13 **MS BASIRE:** When people spoke to you badly, what type of words did they use?

14 **SHANNON:** Tell the camera I am using my voice too.

15 **MS BASIRE:** And you are using your voice through the Lightwriter, aren't you?

16 **LEEANN:** Are you talking about when you --

17 **SHANNON:** Tell the camera I am using my voice too.

18 **LEEANN:** Are you talking about when you're saying "yes"?

19 **MS BASIRE:** Yes.

20 **LEEANN:** When he goes (nods) -- just that there.

21 **MS BASIRE:** So you're using your voice through the Lightwriter but also through your actual
22 voice, which we can see and hear.

23 **SHANNON:** Yes.

24 **MS BASIRE:** Great. So my question was, when you were spoken to badly, can you remember
25 some of the words that were used towards you?

26 **SHANNON:** Yes, swearing. Yes, swearing.

27 **MS BASIRE:** So the staff would swear at you?

28 **SHANNON:** Occasionally.

29 **MS BASIRE:** Yeah, so occasionally they'd swear at you. And you talked about being grabbed.
30 Where would they grab you on your body?

31 **SHANNON:** Shoulders, arms.

32 **MS BASIRE:** So they'd grab you by your shoulders and by your arms?

33 **SHANNON:** Yes, I would be getting frustrated so they grabbed me.

- 1 **MS BASIRE:** How did that make you feel when the staff spoke to you badly and grabbed you
2 when you were frustrated?
- 3 **SHANNON:** Shit.
- 4 **MS BASIRE:** So you felt shit. Now, you talked about them treating you like you were a moron.
- 5 **SHANNON:** That's why Lee is great. I can be me.
- 6 **MS BASIRE:** Right, because it was your sister, Leeann, who got you out of that situation and
7 took you to live with her in 2016.
- 8 **SHANNON:** Best move ever.
- 9 **MS BASIRE:** Just one other question, which is a slightly different subject, but it is the same time.
10 Were you ever given drugs to make you sleepy, or to sedate you?
- 11 **SHANNON:** Not sleepy but stupid.
- 12 **MS BASIRE:** So the drugs didn't make you sleepy but they made you feel stupid; is that right?
- 13 **SHANNON:** Yeah.
- 14 **MS BASIRE:** What -- did anyone ask you whether you wanted those drugs?
- 15 **SHANNON:** No. I don't know.
- 16 **MS BASIRE:** Right. So you know that they were giving you drugs and it made you feel stupid,
17 but you don't really know what happened that made the change and they stopped giving
18 them to you? That's okay.
- 19 **SHANNON:** Lee stopped it because she said I didn't need them. And I don't.
- 20 **MS BASIRE:** Yeah. So when Lee got you moved to her house, she stopped the drugs because
21 you didn't need them and you know that you don't need them.
- 22 **SHANNON:** Yes.
- 23 **MS BASIRE:** We know that you spent about three-and-a-half years living with Leeann from
24 2016.
- 25 **SHANNON:** Yes.
- 26 **MS BASIRE:** And then from probably early in 2020 until now you've been living in your own
27 flat, haven't you?
- 28 **SHANNON:** Yes.
- 29 **MS BASIRE:** Is that the first time you've been able to live in your own flat without having to live
30 with other people with disabilities?
- 31 **SHANNON:** Yes.
- 32 **MS BASIRE:** How does it feel to live in your own flat that's just your flat?
- 33 **SHANNON:** Yes, it's not a flat, it's a home, and I love it.

- 1 **MS BASIRE:** Right, so you're saying it's not a flat, it's a home and you love it. Why is it better
2 that you don't have to live with other disabled?
- 3 **SHANNON:** Yes. I can't cope with people all the time and why does it have to be a PWD?
- 4 **MS BASIRE:** Right, so the reason you like living by yourself is you can't cope with living with
5 other people all the time and why does it have to be a PWD? You might have to explain to
6 me.
- 7 **SHANNON:** Person with disabilities.
- 8 **MS BASIRE:** Yeah, so why should you have to live with a person with disabilities because you
9 have a disability? That's what you're saying to me, isn't it?
- 10 **SHANNON:** Yes.
- 11 **MS BASIRE:** But most of your time in care you've had to live with other people with disability,
12 haven't you?
- 13 **SHANNON:** Yes, yeah.
- 14 **MS BASIRE:** So now you have a caregiver all the time, just one person in the house during the
15 day and one person at night?
- 16 **SHANNON:** Yes.
- 17 **MS BASIRE:** Do you control your own money now? That says "yes/no", so I think you're telling
18 me that you've got one-on-one carers but you are still not allowed to control your own
19 money?
- 20 **SHANNON:** Not want to too much.
- 21 **MS BASIRE:** Right, so that doesn't really bother you that you can't control your money, it's easier
22 for other people to do it?
- 23 **SHANNON:** Yep. Lee's job.
- 24 **MS BASIRE:** It's Lee's job to look after your money. Always the big sister.
- 25 **SHANNON:** She's my big sis extraordinaire.
- 26 **MS BASIRE:** I think she means "she's my big sister extraordinaire"; is that right?
- 27 **SHANNON:** Right.
- 28 **MS BASIRE:** So what else is good about your life at the moment, Shannon?
- 29 **SHANNON:** I have my space to be me and I get to make decisions, not Lee and not anyone else.
- 30 **MS BASIRE:** So you've just told us that one of the best things about your life at the moment is
31 you have space to make your own decisions and it's not Leeann or not anyone else.
- 32 **SHANNON:** Y, and I am in control.
- 33 **MS BASIRE:** So you feel in control of your life at the moment? That's really great.

1 **SHANNON:** More or less. So what I want everyone to know, that it is not right to expect us to be
2 and live how you think we should. I want everything you have in life.

3 **MS BASIRE:** You don't think it's right for able-bodied people to expect things and you want to
4 live just like everyone else.

5 **SHANNON:** Us get lesser life because that's how it is.

6 **MS BASIRE:** Yeah, so you don't think it's right that a person with a disability gets a lesser life
7 because that's what it is?

8 **SHANNON:** Yes. Yes, Lee has given me the best life but it's not everything I should rightfully
9 have.

10 **MS BASIRE:** When you think about it, Shannon, what sorts of things would make you have what
11 you rightfully should have?

12 **SHANNON:** A community that fully accepts me, computers I can use, a job that's paid lots, able
13 friends who aren't paid.

14 **MS BASIRE:** That's a brilliant answer, Shannon, and I'm just going to voice it for the camera.
15 You've just told us what rightfully is yours is a community that fully accepts you.

16 **LEEANN:** Keep going.

17 **MS BASIRE:** Computers I can use, a job that's paid, lots of able friends who aren't paid.

18 **SHANNON:** And my own home designed for my needs.

19 **MS BASIRE:** And your own home designed for your needs.

20 **SHANNON:** Yes. Want more.

21 **MS BASIRE:** Shannon, when you say you want lots of able friends who aren't paid, what you're
22 really saying is that the people you see all the time are just paid caregivers, isn't it?

23 **SHANNON:** Mainly.

24 **MS BASIRE:** How do you think things could be different so that you get to meet able-bodied
25 friends?

26 **SHANNON:** I don't know exactly.

27 **MS BASIRE:** So you're saying you don't know exactly, but you know that's what you'd like?

28 **SHANNON:** Yes.

29 **MS BASIRE:** Shannon, while you've got the chance, what other things do you want to tell the
30 Commissioners about what it's like living with Autism?

31 **SHANNON:** It's great, I wouldn't want to not have it.

32 **MS BASIRE:** So you've just said to me you want to tell the Commissioners that living with
33 Autism is great and you wouldn't want to not have it; am I right?

34 **SHANNON:** Hell yeah.

1 **MS BASIRE:** What else do you think that the Commissioners and the New Zealand public need
2 to know about people like you who, for various reasons, are what we call non-verbal?
3 **SHANNON:** We are just people who see the world through a different lens. That lens isn't wrong
4 and we aren't less.
5 **MS BASIRE:** And "that lens isn't wrong and we aren't less"?
6 **SHANNON:** Yes. Thanks.
7 **MS BASIRE:** Is there anything else you would like to tell us before we finish today?
8 **SHANNON:** No.
9 **MS BASIRE:** That's a wrap then.
10 **LEEANN:** Great, my arm's sore.
11 **MS BASIRE:** Hopefully from that – [reads screen] – yay.
12 **SHANNON:** I'm happy.
13 **MS BASIRE:** I'm pleased that you're happy.
14 "(Narrator) The following segment shows Shannon facilitating with Nick Baker,
15 solicitor for the Royal Commission. Nick had no previous experience in facilitated
16 communication. The scene has changed and now Nick is sitting next to Shannon. Nick has
17 glasses and wears a dark collared shirt, Leeann is standing next to Nick and is half in frame.
18 Nick is assisting Shannon by holding his arm while Shannon directs what is typed."
19 **LEEANN:** So can he type with you?
20 **SHANNON:** Yes.
21 **LEEANN:** Okay, you're trying to clear it, aren't you? Pull it right back, Nick, right back like that,
22 right.
23 **NICK:** Yeah.
24 **LEEANN:** Okay?
25 **NICK:** Okay.
26 **LEEANN:** Clear it, Shannon.
27 **SHANNON:** Yes.
28 **LEEANN:** Woohoo.
29 "(Narrator): Shannon and Leeann are now back sitting next to each other. Nick is
30 off screen."
31 **SHANNON:** Takes time but we could find a groove.
32 **NICK:** Yeah, I felt like we could find a groove as well. It's just not something that's instant, is it?
33 It takes a bit of practice and figuring out how to work with each other, eh.
34 **SHANNON:** Yeah.

1 **NICK:** Yeah, but even just with the "yes" or "no", I feel like we had that working well, which is
2 cool.

3 **SHANNON:** Yeah, I like talking with someone else.

4 **NICK:** Yeah, it must be nice to talk with someone else because you're probably just used to Lee
5 facilitating with you.

6 **SHANNON:** Yep.

7 **NICK:** Exactly.

8

[Video ends]

9 **MS BASIRE:** Mr Baker's just going to get Shannon. But that last portion of the video, that came
10 about when you were out of the room and Shannon indicated to us that he wanted Nick to
11 facilitate with him.

12 **LEEANN:** Yes, I had left the room, I came back in, Kathy was sitting on one side of Shannon,
13 Nick was on the other side. Kathy asked Shannon if he would facilitate with her, they were
14 both, they had written "yes" and "no" on a piece of paper and he was clearly facilitating that
15 way with them. Kathy said, "Shannon, can I facilitate with you?" He said, "No". "What
16 about Nick?" "Yes." So he took a liking to Nick and the facilitation, he likes men, because
17 he doesn't have that many men, hasn't had a huge amount of men in his life.

18 **MS BASIRE:** Yeah, so he was pretty clear he didn't want Kathy, he wanted Nick.

19 **LEEANN:** No, he likes you.

20 **MS BASIRE:** Oh, he likes me.

21 **LEEANN:** He just doesn't want to talk to you.

22 **MS BASIRE:** He was probably sick of talking to me by the end of that.

23 **LEEANN:** Can we just actually state to people, that's 40 minutes, that's actually about three-and-
24 a-half hours' worth of filming.

25 **MS BASIRE:** And many more hours of interviewing.

26 **LEEANN:** Yes. Days.

27 **CHAIR:** Can we just fill in the moment by thanking you for the amount of time that you
28 personally have put into this. I know you're doing it for Shannon, but you're also doing it
29 with Shannon, aren't you?

30 **LEEANN:** I actually would like to turn that back on to you and say thank you for the opportunity.
31 You've no idea the difference, this man is someone else since this process has begun.

32 **CHAIR:** We will do that, let's save our thank yous to the end, shall we?

33 **LEEANN:** Yes.

34

[Shannon joins the room]

- 1 **CHAIR:** Hello, Shannon.
- 2 **SHANNON:** Hi.
- 3 **CHAIR:** Hello, Shannon, thanks for coming in.
- 4 **SHANNON:** Hi, everyone.
- 5 **CHAIR:** I'll leave it to you.
- 6 **MS BASIRE:** Shannon, I'm just going to hand you over to Judge Shaw who's going to talk to you
7 and there's some questions; is that all right?
- 8 **SHANNON:** Okay.
- 9 **CHAIR:** You have no further questions?
- 10 **MS BASIRE:** I've got no further questions.
- 11 **CHAIR:** Okay then, all right. Shannon, Commissioner Julia Steenson's going to ask you a
12 question, she's over here.
- 13 **COMMISSIONER STEENSON:** Hi, Shannon. It's nice to meet you. Thank you for your
14 statement today. So my question is what safety measures do you think could protect people
15 with disabilities in care?
- 16 **SHANNON:** That's a wide topic, one is that the able-bodied leave us to run our organisations.
- 17 **LEEANN:** Did you understand that?
- 18 **COMMISSIONER STEENSON:** I think I heard that it's a big topic.
- 19 **LEEANN:** He said, "It's a wide topic, one is to leave" --
- 20 **COMMISSIONER STEENSON:** To an organisation dedicated?
- 21 **LEEANN:** "Leave able-bodied people to let us run our own organisations."
- 22 **COMMISSIONER STEENSON:** Yeah, that's great, thank you.
- 23 **SHANNON:** And independence of our lives.
- 24 **COMMISSIONER STEENSON:** Do you know, I think it's actually the accent that I'm --
- 25 **LEEANN:** It's totally different to the other machine.
- 26 **COMMISSIONER STEENSON:** Yeah, thank you, thank you, Shannon.
- 27 **LEEANN:** Her name's Rona.
- 28 **COMMISSIONER STEENSON:** Thank you to Rona and Leeann. I'll pass it back now.
- 29 **CHAIR:** Now Commissioner Paul Gibson's going to ask a question.
- 30 **COMMISSIONER GIBSON:** Thanks, Shannon, for your answers and the power, the
31 independence behind them, it's really important.
- 32 **SHANNON:** Hi Paul.
- 33 **COMMISSIONER GIBSON:** My question comes from some of what you said about you want
34 to tell the Commission it's great living with Autism, and you also talked about wanting to

1 change communities. So my question is, what would you tell parents who have just found
2 thought they've got an Autistic child?

3 **SHANNON:** First, I'm not Autistic, and rejoice.

4 **LEEANN:** He said, "First, I'm not Autistic, and rejoice." Do you want to explain that?

5 **SHANNON:** I have Autism. It's great and full of new adventures, just a few hard bits at the start.
6 Next.

7 **LEEANN:** He said "next", as in next question.

8 **COMMISSIONER GIBSON:** Thank you, it is full of adventures. My next question, should
9 communication devices, augmented communication systems, facilitated communication
10 systems, should people be entitled to having those? If so, how do we make that happen?

11 **SHANNON:** Hell yeah, computer equipment and speech and language therapist. Government
12 fully fund. Access to internet. Next.

13 **COMMISSIONER GIBSON:** That's the end of my questions, but thanks very much, Shannon,
14 and thank you, all, and the voice that's talking to me in my ear is called Reid, so tha nk you
15 to Rona as well.

16 **CHAIR:** I don't have any questions -- sorry.

17 **SHANNON:** I like.

18 **LEEANN:** He's saying to Paul "I like".

19 **CHAIR:** Does he want to say anything else before I start?

20 **SHANNON:** Yeah, I just want to add that I am worthy and capable of being [inaudible] Just
21 because people like me talk in a different way, doesn't mean you should exclude us.

22 **LEEANN:** Did you understand that?

23 **CHAIR:** I did understand that.

24 **LEEANN:** NZ.

25 **CHAIR:** It's a message to New Zealand.

26 **LEEANN:** Yes.

27 **CHAIR:** I'm sure it's been well-heard.

28 Shannon, I don't have any questions for you, but I want to let you know a couple of
29 things. First of all, I think we've got here a room of admiring fans who have sat and
30 listened, without making a single sound, to everything that you have told us today. And I
31 think they admire your tenacity and your courage and your willingness to come along and
32 tell us and all of New Zealand your reality. So we want to thank you for that.

33 Now I want to talk about Jane Austen, if I can. One of Jane Austen's novels you
34 might know is called *Sense and Sensibility*. Do you know that?

1 **SHANNON:** Go for it.

2 **CHAIR:** So I think I'm going to use those two words to -- as I thank you. First of all, you have
3 shown us --

4 **SHANNON:** Great book.

5 **CHAIR:** Do you want to say something?

6 **LEEANN:** "Great book."

7 **CHAIR:** A great book, and that's why I'm referring to it. First of all, you have shown us your
8 sensibilities. You have allowed us, by coming today and speaking so frankly, you have
9 allowed us to see just a glimpse into your life, your clever, your complex and your creative
10 life. And we have learned from you that you value what everybody in this world values,
11 and that is freedom, being able to be independent, having your own thoughts and making
12 your own decisions, people respecting your voice, whatever it is called, Rona or Betty, and
13 your absolute need and right to have free communication.

14 So those are all the matters of sensibility that I wanted to mention.

15 And then the second thing I wanted to talk about was your sense, your very good,
16 common sense. And I know that we've heard it a couple of times but I think it's important,
17 if I might be allowed to be your voice for a moment, just to read two of the final paragraphs
18 in your evidence which you prepared. I think this is the message for New Zealand that we
19 must all hear.

20 "First of all, our homes and lives need to be designed around and for us, because
21 why should we have to fit in to able-bodied boxes? Everybody has the right to be
22 different."

23 The second, not the only but the second, great message that I would like to
24 emphasise and let you know we have heard well: "Living with Autism is great and
25 I wouldn't change a thing. We are just people who see the world through a different lens,
26 the lens isn't wrong, and we aren't less."

27 And for me, those are the most sensible words that we've heard for a long time.

28 And we thank you for that. Thank you for the time and trouble you've taken to give your
29 evidence to us, to total strangers, but I can't tell you how valuable they are. So thank you
30 very much, Shannon.

31 **SHANNON:** Thanks, I want to speak like this more. I feel real.

32 **CHAIR:** You are real, Shannon, and we know that, so thank you so much.

33 The second person who's sitting next to you must be thanked as well and that's
34 Leeann. Leeann, thank you very much, I've already said it, for enabling this whole process

1 to happen. Cooperating with our people and helping Shannon to have his voice in the
2 safest way that I think is possible. So we're very grateful. And also for your extraordinary
3 insights and revelations about what it is like to work with and beside a disabled person, I
4 think that's going to help us a great deal in our deliberations, so thank you for that.

5 **SHANNON:** She's my sis.

6 **CHAIR:** She is, and your mother, I think, and your friend.

7 **SHANNON:** [typing.]

8 **LEEANN:** You got told not to call me that.

9 **SHANNON:** Wench.

10 **LEEANN:** Sorry, he has me on about that forever.

11 **CHAIR:** It's wonderful to see, yeah, thank you.

12 Now, you wanted to say something before we finish, because we're just going to
13 finish now.

14 **LEEANN:** There's a couple of big things I just really want to get across, and I want to reinforce
15 what Shannon has said. People with disabilities need to run organisations, whether they're
16 private or public. The issues I am still having with the current provider who has for the
17 second time gone back on their word and decided that his staff members can't facilitate with
18 him, despite the Ministry getting involved, despite two speechies, one who has 40 years'
19 experience, saying it's okay. The lack of accountability for these agencies, the lack of
20 independence of anybody out there, all the Ministry can do is pat people on the head and
21 say, "Now, now, dear, don't do that again, we'll help you fix it." There's no accountability,
22 there must be criminal accountability.

23 Other Government departments that do have the ability to do something about it
24 need to step-up to the plate.

25 But I really cannot emphasise, people with disabilities need to run. I live in that
26 world personally. I may not have ever been in state care, but if I hadn't had the parents I
27 had, my injuries were so severe I could very well have ended up in there and been sitting
28 alongside where Shannon was and yeah, we, even with lesser needs, we don't have the
29 independence. So for him, if he didn't have me, and remember I'm his foster sister, he
30 would be in a much worse place.

31 **CHAIR:** We salute you, we really salute you for being his enabler.

32 **LEEANN:** I don't want to be saluted, though. I think this is something people should do because
33 it's the right thing to do and I think that -- sorry, the last thing I want to say, is that it doesn't
34 matter what this Government or any future Government does, it doesn't matter how

1 remarkable your recommendations are and how many are picked up, until New Zealand
2 society, and I'm talking to the whole country here, every able-bodied person out there stops
3 thinking of people with disabilities as a nice fluffy little "other" or something to be scared
4 of, nothing will change.

5 **CHAIR:** That is a fine note for us to end on, thank you, Leeann. Thank you very much. And
6 thank you again, Shannon. So on that note, we end today's proceedings.

7 **SHANNON:** Ta.

8 **CHAIR:** You're welcome.

9 We end today's proceedings and we end the survivor evidence that we've heard over
10 these last few days. I just, again, acknowledge all of those survivors, the two who we have
11 here with us, those in the audience and those watching, and those who would like to be
12 speaking but can't for one reason or another, we salute you all and thank you all.

13 Tomorrow we go into a panel discussion. I won't be here, but Paul Gibson will be
14 chairing it and I'll be watching from afar and we're looking forward very much to a very
15 fruitful day of open and free discussion about the big issues related to Māori and disability,
16 so that's going to be a good day tomorrow.

17 So thank you all very much for your attendance today. Matua, kei a koe te tikanga,
18 kei a koe te karakia.

19 **Waiata Pūrea Nei and karakia mutunga by Ngāti Whātua Ōrākei**

20 **Hearing adjourned at 5.02pm to Wednesday, 20 July 2022 at 9.30am**