

**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

Venue: Level 2
Abuse in Care Royal Commission of Inquiry
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Lunch adjournment from 12.54pm to 2.28pm28 **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**