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

The Inquiries Act 2013

Under

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Venue:	Level 2 Abuse in Care Royal Commission of Inquiry 414 Khyber Pass Road AUCKLAND
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
Royal Commission:	Judge Coral Shaw (Chair) Paul Gibson Julia Steenson
In the matter of	The Royal Commission of Inquiry into Historical Abuse in State Care and in the Care of Faith-based Institutions

INDEX

ROSS CLARK – video	192
DR OLIVE JEAN WEBB	
Questioning by Ms Basire	195
Questioning by Commissioners	218
ALISON ADAMS - video	
Questioning by Ms Basire	226
Questioning by Commissioners	241
PETER KEOGHAN - video	
Questioning by Mr Thomas	243
CAROLINE ALICE ARRELL	
Questioning by Mr Thomas	267
Questioning by Commissioners	290

20	CHA	AIR: The last session of the afternoon, good afternoon. Mr Thomas.
21	MR	THOMAS: Thank you, Madam Chair. The next witness is Caroline Arrell, and she is
22		obviously here in person.
23	CHA	AIR: Yes.
24	MR	THOMAS: She'll be talking about her time as a training officer in the psychopaedic side of
25		Tokanui Hospital and also her involvement in the closure of Kimberley later in her
26		career. Caroline is very happy to take questions during her evidence.
27	CHA	AIR: Thank you. I'll just ask you to take the affirmation.
28		CAROLINE ALICE ARRELL (Affirmed)
29	QU	ESTIONING BY MR THOMAS: Caroline, can you start off by just telling us a bit about
30		your training and professional background?
31	A.	Sure. Kia ora mai, Caroline Alice Arrell. I've had a 35-year history of working in the
32		disability sector as Michael said, starting off as a young training officer at the age of 18 at
33		Tokanui Hospital.

Adjournment from 3.02 pm to 3.20 pm

I then graduated after three years of completing my psychopaedic training officer diploma to become a tutor training officer, spending probably eight to nine years in Tokanui during that time.

I then moved on to work for the Waikato Community Living Trust as a case manager for the de-inst [deinstitutionalisation] process of Tokanui Hospital, and I had a caseload of around 120 people that I repatriated to their chosen domiciles.

When Tokanui closed I was fortunate enough to join the pilot project of the very first NASC in New Zealand – that's Needs Assessment and Service Coordination Agency – called Accessibility in Taranaki, where I worked from Hawera.

I was then asked to join the IHC as a national trainer, with my background in teaching, which I took on and did that for a couple of years. And then moved to be the team leader for the behaviour support services in IHC for the central and southern regions. And had a team of about eight people and responsible for around 600 people that were referred to us.

After that I then was the project manager for -- from 2000 to 2007 I was the project manager for NZ Care in the deinstitutionalisation of Kimberley Hospital. I was responsible for 312 people from Kimberley who were being resettled back into their, or their families', chosen domiciles. I was responsible for the purpose building of the cluster housing models and the individualised housing models. I'll talk more about that in my evidence.

When that finished I needed to take a year off and have a break, and then I rejoined IHC as the national manager of self-advocacy for three years.

And then since then I've had two roles, one as a service manager with NZ Care, and then latterly area manager for NZ Care for the Greater Wellington area.

But for the last two years I've been travelling New Zealand looking for our piece of dirt, which we have found in Taupō, so that's where I reside now.

Q. Thank you for that, Caroline.

Did you want to make some opening comment about why you're here to give evidence?

Yeah, sure. I understand that my evidence augments and supplements the stories already told by people who have disabilities. Through the lens of their own experience they have been able to describe abuse and neglect in institutions or they've had very powerful advocates to tell those stories on their behalf, such as Margaret, kia kaha Irene.

But today my stories revolve around people who had no family involvement, who had a receptive understanding of the world around them, but could not express in any way

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1	using formalised language or any other type of language to convey, communicate the terror
2	the trauma, the abuse and neglect that they endured at Tokanui and Kimberley Hospital, so
3	perhaps the most vulnerable of vulnerable in my mind. So again, thank you for the
4	opportunity to do this.

- Thank you. Caroline, can I just get you to start, you mentioned you started at Tokanui as an 18--year-old- in the training centre. Can you just give the -- everyone an idea about what that training centre was like, how many children attended, just the set-up of that?
- A. Sure. The training centre, as you've heard from other evidence -- well, actually, the training centre at Tokanui was probably one of the newest training centres at that time, it was purpose-built, so it was a building that housed about eight classrooms, and predominantly drew children from the village part of the -- so Tokanui was three hospitals, so it was Te Mawhai Hospital for the elderly, then there was a psychiatric side of the hospital, and then there was the Waipā Community and Training Centre which was dedicated to children and young adults who had intellectual disability.

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So when I arrived at Tokanui, there was around about 3 to 400 children in the Waipā Community and Training Centre, of which approximately 42 came to the children's training centre. And the classrooms were designed as classroom sizes of four to five pupils per classroom with one training officer. Unlike Māngere, we did not have psychopaedic nurses in our classrooms. We were autonomous and overseen by clinical psychologists and/or senior training officers.

- 21 **Q.** Thank you. You mention the children's village and in your written statement there's also discussion of the other general wards so, just to clarify, would both children and adults from different wards in Tokanui attend the training centre?
- A. Yes, some did. So there was probably eight to nine wards within the Waipā Community and Training Centre plus the children's -- plus, sorry, the village complex. So yes, we did draw from other wards people who came to the training centre, yes.
- Q. Were most of the attendees at the training centre from the village, or were they drawn more widely?
- Yes, most of them came from the village. Perhaps, you know, four or five young people from ward 19, 16 and 17, yes.
- And by -- when we're talking about the children's village, that was a specific area within Tokanui?
- 33 A. Yes, it was, it was deemed -- it was -- they were a cluster of houses that look like, I liken 34 them to State houses, so they were in a circle in the middle of the Waipā Community and

Training Centre, and they were four- to five-bed houses that were meant to resemble more home-like living. So each of the children that lived there -- and so these children were between probably four and 18, so it was meant to resemble more of a family hom e-like environment. So each of the children had their own rooms, although some of them did share, from memory, as well, yeah.

- Q. Thank you. Can you tell us more about how children came to be at the training centre?
- A. There was a selection process around, the children that lived at the -- in the village complex

 were deemed to be more cognitively able, that they would be able to be educable in some

 way, that they had the ability to learn new skills and they were independently ambulant, so

 they walked over to the children's training centre each day or they rode tricycles or rode on

 scooters, but mainly walked over.
 - Q. Were families encouraged to place their disabled children at Tokanui?

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A. Well, initially as a young 18-year-old I wasn't privy to that information, but latterly when I joined the case management team with the Waikato Community Living Trust, I learned of their stories around why they placed their child into Tokanui Hospital. So, you know, like the stories you've heard, they were advised to place their young family member into care and to basically get on with their own lives.

For some of the families they didn't have the support structures back then that enabled them to keep their disabled child at home. For some of the mums they were on their own, and they couldn't cope. So there was no services available at that time for them to be able to do that. So that was a common theme of stories.

I also need to add that also in the Waikato Community Living Centre there was a ward where babies were, so young children that had been admitted as babies and who had no family contact whatsoever.

- Q. Your role as a training officer, can you just give us a bit more of an idea of what that involved on a daily basis?
- So each child was -- that came, was assessed on skill acquisition, what would support them A. 27 to live a more functional life, I suppose. Although, in reflecting back on it, I often wonder 28 how helpful that skill acquisition was. We taught things like money recognition, reading, 29 writing, spatial awareness, how to have a conversation, interactive techniques, yeah. And 30 adaptive behaviour, so daily activities -- sorry, activities of daily living such as how to 31 cook, how to dress for the weather, how to colour-coordinate clothes, how to make their 32 own bed. Again, all in a classroom setting which I'll talk about a bit later about how we've 33 34 kind of changed that.

- **Q.** Thank you. I just want to talk about briefly the different teaching techniques or theory that you used at the time at the training centre. Are you able to explain that?
- A. Yeah, sure. So this is in 1979 through to 1982, I believe. When I arrived, we employed teaching techniques from an applied behavioural analysis model, very stringent teaching practices that were based on a series -- based on the theory that behaviour and learning could take place through the process of rewards and consequences.

It was an extremely sterile and stark form of teaching. It was devoid of any love or compassion and I can describe it as extremely clinical.

Q. Could you give us an example of, say, a positive reinforcement technique or some other example of that?

A.

A. So I'll give you a concrete example of actually a teaching session. A child would sit opposite me and it looked like a regular classroom, and I would teach them money recognition. So I would have the money out on the table and I'd ask them to identify which was the \$5 note. If they got that correct they would get a teaspoon of yoghurt, as an example of positive reinforcement. Edible reinforcement was predominantly used as positive reinforcement. And, again, later in my testimony I raise ethical questions about that.

So that was reward token systems, and verbal praise, yeah.

- **Q.** Thank you. You also mention other techniques involving, you describe it as positive punishment, or that's the term you use?
 - It's incongruent, isn't it, positive punishment? For a lot of the children in the trial -by-trial teaching, in fact in any teaching situation, if they got a response wrong, say I'd ask them to identify or point to or show me the \$5 bill and they pointed to the \$1 bill, there was a technique employed, I suppose you could say an aversive consequence in the guise of positive punishment, where I would say "no" to the child, take them by their elbow and walk them to the purpose-built in-built -- so the training centre was designed to have time-out rooms in every single classroom. They weren't wooden boxes as described from Māngere, but they were purpose-built. They looked like closets, they had four walls, no windows, and they had doors that locked from the outside. So the child -- but they had a light switch that was left on. And they were escorted to the time-out room and they were left in there for three minutes with one minute of silence and then they were brought out and expected to resume a teaching session. Yeah.

I'm sorry to describe this to you like this, that's what it was. It was an expectation of our training that if we didn't comply with those techniques, then we wouldn't have a job.

1		So this was a common theme and common practice across most of the training
2		centres within Templeton, Mangere, Tokanui and Kimberley.
3		So yeah, that's one of the
4	Q.	Thank you sorry.
5	A.	positive punishment.
6	Q.	Thank you. Looking back or reflecting back on those techniques now, what do you think
7		about them?
8	A.	I think they were absolutely abhorrent. In fact, on one occasion I was asked a little boy,
9		he must have been four years of age, and I'll call him "T", and I was asked to conduct this
10		process with him during a session of clothing recognition and I refused. He was four years
11		old, you know, this was just an abhorrent process. And one it never sat well with any of
12		us this practice. But, I think as Olive described earlier in her evidence, it was just the time,
13		it was what we had to do, it was expected of us. And, again, if we wanted to see our
14		qualification through we had to comply.
15	Q.	You mention in your statement the use of ammonia capsules at other psychopaedic
16		hospitals. Do you want to discuss that?
17	A.	Well, we never that was never employed at Tokanui, I never, ever saw that used.
18		I actually think that that would have been a bridge way too far for any of us to consider.
19		That was but I do know from a colleague at Kimberley that it was used, without success,
20		on a young woman there as prescribed by a consultant psychiatrist that was visiting
21		Kimberley.
22	Q.	Caroline, can you tell us about what other forms of punishment were used at Tokanui?
23	A.	Punishment was pervasive, it permeated daily life for all the young people that I got to meet
24		and know and work alongside. I was indignant that the in-classroom style of teaching,
25		whilst important, I wanted to go and teach skills to these young children at the right times
26		of the day. So if I was teaching them, for example, to get dressed or recognise the weather,
27		I would go to the ward, or I would go to the villa and I would teach them at that time.
28		So I got to see punishment from two contexts, I got to see, you know, our clinical
29		teaching punishment, which I've described to you, and I also got to see punishment, well,
30		clearly intertwined with abuse on the wards.
31		Withdrawal of privileges we're going to go on to talk about some of that a bit
32		later, aren't we? So punishment
33	Q.	We will, yes. I was thinking about paragraph 2.16 of your statement where you discuss

food and water being used as a form of punishment. Do you want to mention that?

- A. Yes. So, I mean, the withdrawal of -- for non-compliance of behaviour, not getting ready in time to come to school, breakfast being withdrawn, social isolation, the punishment of threatening to tell families about behaviour, meaning that they would have to live longer within the complex. Having food withheld, again, without talking about all the indictments of what I witnessed in terms of abuse, that was some of the things in relation to my teaching time on the wards.
- **Q.** What about communication being used as a punishment?
- 8 A. So...

- **Q.** In the sense of not being allowed to communicate with family, was that used?
- 10 A. Yes, it was. So for any misdemeanours, I mean, these children lived in very regimented
 11 and rigid, you know, routines and timetables, and any misdemeanour against that was met
 12 with punishment such as no phone calls to their families, not being able to see their friends,
 13 having privileges to go out on picnics or outside of the hospital taken away from them, yes.
- **Q.** You wanted to mention a specific incident that you witnessed of electric convulsive therapy at Tokanui, do you want to describe that?
- A. There was a young woman that I worked with who was described and diagnosed at 10 years of age of having a type of schizophrenic melancholy, she was very taciturn, didn't have a great attention span, according to the paediatrician that worked on site. These days she would clearly sit on the autism spectrum. That would clearly be her diagnosis.

Now, I can't tell you if her parents were asked for consent or permission, but I supported her on three occasions to go down to this very small unit next door to the admin building at the entrance to Tokanui Hospital to have ECT [electro-convulsive therapy]. It was one of the most traumatising experiences I have ever had in my life and I have no idea how K survived this. She was taken into this small room and strapped fully clothed on the bed and, to me – and I could be quite mistaken with this – it was a technician who administered ECT.

The reason I say that is because sometimes we would see him around the wards acting as an electrician so, you know, I don't know what his qualifications were. There was a psychopaedic nurse in attendance and myself, and K had ECT administered to her twice on each occasion.

- **Q.** How old was she?
- 32 A. 10. She was 10.
- **Q.** Was she sedated?

A. Yes, she was sedated, she was sedated. And after she had ECT she was -- I would just describe her as like a zombie. She was in my classroom, I was responsible for her during the days and after ECT she would come over to the classroom and we would forgo all teaching. We would build a bed in the room, we would sing, tell stories, we would completely ignore the teaching plan and I would falsify teaching records so that she could have, just that time to relax and try to understand the world around her after that dreadful experience.

Q.

I also want to add to that that for the other people, the other young students in the classroom -- now, I had these same students for four years and we formed a very close bond. They also were very distressed at seeing K like this, and so we would -- which was interesting because four of these young people couldn't communicate using expressive language but they clearly understood what had happened for K and they, like me, were remorseful, sad and just wanting to take good care of her.

Q. Can I move on to talk about environmental abuse or neglect at Tokanui. There's a number of aspects of this in your statement, starting with – what about smoking in the environment?
A. So, as I said earlier, I was able to not only work at the training cen tre but I got to go teach skills such as bathing, eating, exercise, within the wards. Back then everyone smoked, all the staff smoked, and the wards were full of smoke, there was ashtrays everywhere. So people with disabilities that lived in these wards were subject to the inhalation of smoke all day. It was nothing to see four or five staff in a day room smoking and it was full of smoke, and I often wondered, you know, the impact that that had on the young bodies.

Gosh, environmental abuse. It was -- as other people have described, it was devoid of any activities, devoid of anything meaningful to do. I'm just going to look down at my ... Sure.

- 25 A. Oh, yes, so the TV; TVs were in every ward and in most rooms and were turned up very
 26 loud. They were TVs that were behind glass panels pinned on the wall with no remote, so
 27 it was always -- the staff had control of the remote, so it was always set to programmes that
 28 they wanted to watch and it was loud. For me, the neglect and abuse around that was that
 29 people never had any peace or quiet or -- so staff would play music of their own liking,
 - often reggae music, loud, so there was always a lot of noise, it was incredibly destructive
- for the well-being of people having to endure all day in those day rooms.
- **Q.** Several times in your written statement you talk about this theme of teaching relationships 33 being transactional rather than relational. I was just wondering if you could explain that for 34 the Commissioners, what you mean by that?

A.	Well, in all relationships that I witnessed in both Tokanui and Kimberley, it was all based
	on getting people up in the morning, getting them fed, getting them showered, all
	happening before 10 am so they had nothing else to do for the rest of the day.
	Transactional was "just what I have to do", conversations were never relational. In fact,
	I give examples in my testimony of showering and eating. Two things that should be
	incredibly pleasurable for young people to have and instead they were extremely devoid of
	any type of good interaction.

I'll give you a quick example. The bathrooms and the showers -- now, I was there teaching a young boy in the bathroom to -- how to bath himself. How to get undressed, how to turn the taps on, how to check the temperature, hop into the bath. So I was able to witness the bathing schedule of the other four to five baths that had no covering or privacy, and so what happened was, is that they were stripped off and they were bathed on type of a conveyor belt -- it wasn't a conveyor belt, but there was a staff member that put them in the bath, another staff member lifted them out, dried them, then another staff member dressed, all while the staff were talking amongst themselves, never to the child or never to the person that was receiving their support. So that's what I mean by transactional, it was a very transactional approach. I saw that in many interactions.

In fact, I use that term a lot, transactional rather than relational.

- **Q.** Thanks for explaining that. Can you tell us about over-crowding and clustering in the wards?
- A. Within the Waipā Community and Training Centre, like Tokanui Hospital, the wards seemed to be designed on kind of a thematic style. So, for example -- can I use the name of wards?
- **Q.** Yes.

A. So, for example, ward 16 was for people who used wheelchairs for their mobility, they had no ability to move any part of their body, very few of them were able to speak. Now -- and then there were other wards for young people who had more problematic or, as is described, challenging behaviour.

What this meant was, especially for people who couldn't speak or who used specialised seating and wheelchairs for mobility was they had no ability to converse with each other. It was -- they were clustered for ease of the working conditions for the staff so...

There was another ward that had men who were described as being -- maybe there was 32, 33 young men in this ward who were described as having challenging or aggressive

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to the stress, I suppose, or the lackadaisical approach of the staff, looking after them.

behaviour, and a fairly set staff roster in each of those wards. So in my evidence I describe that caring for or supporting 32 men who have these types of behavioural repertoires added

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CHAIR: Can I just ask you, was the food all pureed up?

A. Yes.

I think, though, if I can just go to people who were more dependent, there was an absolute void of conversation or interaction with these young people in those wards. It was: Get them up, get them dressed, give them their food which was a whole other place and activity that I found extremely distressing, and I made a point of getting permission to

work in ward 16 to teach a young man how to scoop his food up with his spoon.

The abuse that I saw during eating was that the food arrived, as you know, on a tractor and it was brought in in these large wheeled heated ovens and the food was spooned out, never tasted first, which is something that I want to talk about, and it was all placed into one plate and then stirred up. It resembled a cow pat pie, which is what we -- it's what, yeah, that's exactly what it looked like, it looked like a cow pat pie. And people were given their food incredibly fast. They used -- they didn't use specialised spoons and everyone had a plastic bib around them that had a catchment area at the bottom. So for the food that didn't go into their mouths and dribbled out into the plastic bib, it was re-spooned up from that plastic bib back into their mouth.

Now, it was cold, it was abhorrent, I spent a lot of time trying to advocate for the change in this, but it was purely based on convenience to get food quickly into people.

I'd also like to add that for many of the people who needed full support to eat, the y were extremely thin, extremely thin and underweight.

It took, especially for people who had cerebral palsy, a long time to form a bolus and swallow. Same for drinking. It takes a long time to take a sip, get organised in your own mouth to swallow it, and they were fed extremely fast. So, consequently, a lot of food didn't make it down.

Now, for me, that was a neglectful and abusive practice. The other part of that, and I come back to tasting, no-one ever tasted the food that came in. So when I was working on this particular ward, I would make a point of going and tasting it and I soon realised why it was so abhorrent for people to swallow, it was often over salted, and it -- some of it was inedible.

So whilst there were dieticians, the food across all the wards and villas that I saw was the same.

- **Q.** All the food for everybody?
- 2 A. Yes.
- 3 Q. Goodness.
- 4 A. In this particular ward, yes.
- **Q.** Oh, in that particular ward?
- 6 A. Yes, yes. So in the village clearly no.
- **Q.** Right.
- 8 A. Because they could -- it didn't need to be, they could chew, they could masticate.
- **Q.** But in that particular ward all the food was mushed together?
- 10 A. Yes. Look, in saying that also I have to say that in other wards, in another ward,
 11 particularly, there were people there who could actually support themselves to eat, but they
 12 were not given that opportunity.
- **Q.** Right.

A. And the food was mixed up. For people with disabilities, if they were reluctant to eat the food like that, their arms were restrained to the chairs that they were sitting in, and they were basically -- I would describe it as being forced to eat.

If the process became too hard for the staff, then they would be verbally abusive and say, "Well, you had your chance to eat it, too late now, you know, you're not going to get it." So that was quite common.

- QUESTIONING BY MR THOMAS CONTINUED: Caroline, you mentioned that there were -- you tried to change the eating practices. Can you briefly describe how you went about that.
- A. So I was often accused of having rose-coloured spectacles, and I suppose I did to a degree because I felt that I could go and role model good practice and -- but clearly that was met with resistance and attitudinal barriers from the staff. Basically they described me as being a bit of a Pollyanna and that it took too long, it took too long to serve the food in individual piles to let them taste the potatoes, to let them taste the broccoli, you know, to give them -- what does pumpkin taste like, to establish those individual and personal preferences, that was just way too hard.

I had very little impact on that. Yeah, for me meal times and bath times were extremely distressing experiences and I never got used to seeing that or experiencing that. So what I did, I guess I tried to be a good role model, I tried to talk to the charge nurse about, you know, what it must be like to have that experience.

One success we did have, though, was during my time as tutor training officer I got to teach a course called Effective Teaching and people from other organisations would come from outside of Tokanui to come and learn these modularised packages of learning. It was how to teach people with disabilities.

One of the activities that we did was we would restrain the participants in a chair and give them their food like I had seen it being given. I know that sounds dreadful, but it was actually a very cathartic experience for those participants because they realised how transactional and abusive the process actually was.

But I had very limited success in my advocacy for any change of eating practices within Tokanui.

- **Q.** Moving on to another topic, did residents physically hurt and assault each other at Tokanui, can you talk about that?
- 13 A. Yes, along with self-injurious behaviour which was prevalent, I mean, I'm sure we would 14 all engage in self-injurious behaviour if we were living in those conditions, but yes --
- **Q.** You talk about -- oh, sorry.

16 A. No, no, well, there were very vulnerable people who couldn't defend themselves living with
17 others who were described as having challenging repertoires or aggressive repertoires of
18 behaviour and they would hit out at the more vulnerable people or bite or kick or scratch.

So, to me, I likened it to living in an extreme domestic violence situation. It was never incident reported. There were some very serious injuries inflicted, particularly on one young man I remember, and I'll call him R, he couldn't move any part of his body, he was a very young boy of about 10 and he got bitten so severely that it drew a big chunk out of his arm.

So I asked what was going to happen next to minimise this happening? Again, there was no overt process for keeping people safe. It was never incident reported and that's something that, you know, I'd like to also focus on when you look at contemporary service provision today, is how incident reports are generated around this. But this was a very big issue, self-injurious behaviour and other accidents and injuries and incidents involving peers on peers, yeah.

- **Q.** What about sexual abuse at Tokanui, was that something you were aware of?
- 31 A. Yes, it was reported to me in a friendship that I had with a yo ung man who I worked with, 32 and I'm going to get to discuss him --
- Yeah, we'll come to that specific case in more detail, but I guess outside of that specific case, were you aware of any, yeah, sexual abuse occurrences?

1	A.	Clearly it was reported to me by people who with disabilities, but it was never believed
2		and it was never investigated. And when they would give me this information I would have
3		to pass it on to the charge nurse or I would have to relay it to others and nothing was ever,
4		ever done about that, to my knowledge. And I was always clear about following that up,
5		what had happened.

Q. Okay.

Q.

A.

- 7 A. "Oh, they just talk about being abused all the time, it never happens, they say that so -and-so has sexually abused them, but that's just them, they say that, it's not true." So it was never believed.
- **Q.** You wanted to talk about toileting practices at Tokanui, can you give some examples of that?
 - A. Toilet paper. Again, it reminded me that in most of the wards there was no access to toilet paper. So as described by others, the -- toileting was a very public affair, there was no privacy. In one particular ward people were strapped and restrained on potties until they had passed bowel motions. That could be up to 45 minutes.

The way in which people were cleansed was rough, and it was without -- it was devoid of any respect or dignity. In fact, often people were taken off the toilet, particularly people who could not walk but they could crawl, they were lifted off the toilet and left to crawl away from the toilet while the staff member was wiping their backside, yeah.

So it was devoid of any privacy and it was -- yeah, that's all I'll say about that.

What -- was dental care available for children at Tokanui, or residents, actually?

We had a dentist at Tokanui and he was described as a rough and unpleasant man, and no-one ever wanted to go and see him. Dental care was not proactive, it was only just needed as recognised. So often teeth had to be quite in a bad state of repair before they would go to the dentist and often that response was to whip one or two out.

One of the worst, I suppose -- well, it was all incredibly confronting, but particularly for one young man who was described as a biter, he had his teeth removed, all of his teeth removed for biting others, with no meaningful look at why he was biting, what led to this.

The dentist was an incredibly unpleasant place to go. Often sedation was required for the children and the young people to go to the dentist. And if anything more serious was needed, they were taken to Palmerston -- sorry, they were taken to Waikato Hospital, Palmerston for Kimberley, to be seen under general anaesthetic.

- 1 **Q.** Thank you. You talk about the lack of respect for people's sexuality at Tokanui. Do you want to mention that, or give any examples?
- A. People were described as being asexual. There was no acknowledgment around puberty, around young people's needs. There was no teaching around masturbation and privacy.

 People were taunted about their bodily functions, I suppose.
- 6 **Q.** Taunted by staff?

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A. Yes, taunted by staff. So there was a gentleman who had nowhere to go, he was -- he had no privacy and he would get erections and he would masturbate in the day room and the staff, and I witnessed this on many occasions, would stand around and taunt him and laugh and describe that the size of his appendage was wasted on him.

There were many young people whose body parts were openly discussed, especially during the shower process, discussion around the shape of their genitals, discussion around the shape of their breasts, and taunted about this.

Staff would show a level of revulsion about having to cleanse people's intimate parts and would say that quite loudly while they were showering the woman or the man.

- **Q.** Thank you. I'm going to jump ahead to another topic now, I just wanted you to summarise this topic, if you can. You discovered an unmarked graveyard at Tokanui. Can you tell us how that came about?
- A. I lived on the back of Tokanui Hospital on a Ministry of Ag and Fisheries farm and it was a 19 20 500-acre farm. My partner at the time was a shepherd on this farm. I had a hors e, named Alice, and black Labrador, named Lucy, and we had free range of the farm, and for my own 21 22 relaxation I used to saddle up Alice and we would go around the farm and on this particular day -- I'm sorry, Michael, I've forgotten the date, I know it was in 1991, I 23 believe -- interestingly, before that, I would jump my horse Alice over this fence into a 24 25 paddock and my black Lab Lucy used to run all the way around the perimeter of this paddock. She would never -- and all the other fences she would climb through the fence 26 and chase after us, but this particular paddock she would run the whole perimeter around 27 and would never come through this paddock with us. I jumped Alice and we landed on the 28 ground and her -- one of her forelegs went straight down a hole, we tumbled over, and as 29 I fell I felt my elbow hit something hard in the ground and sat up and realised that what 30 I thought was a rock was a headstone. It was a plaque. And it said, "In loving memory of" 31 and I won't repeat the name. And I picked it up and I was very confused about this, and so 32 I went, we went home and -- so when I say I lived on a MAF farm, it was a cluster of 33

housing at Tokanui what was for the staff of Tokanui, so the Area Health Board provided cheap rental housing for staff.

So I went across to my next-door neighbour who was a clinical psychologist, a close friend of mine, and showed her this plaque and I said, "What do you make of this?" And she said, "I think this might be part of the paupers' grave." I said, "What are you talking about?" I had no knowledge of this.

To cut a very long story short, on the following Monday this psychologist friend went to the bake house, which -- it used to be the old bake house at Tokanui but it turned into a storage area for medical and other historical records – and she found the name that was on this plaque who had been buried in the paupers' grave. Not only that, she found the plans at that time of just under 500 people who were buried in that paupers' grave.

So I had been riding, not just me, everyone who worked on the farm, had been -- that paddock had been grazed with sheep, it had been grazed with other animals, it was run as a working farm and there was no knowledge of these people buried there.

So when we looked at the plans it was incredibly shocking, they were arranged into "protestants", "catholics", "unknown", "Māori", and "other ethnicities".

What happened next was that the powers that be contacted the iwi and by their -- some of you will be familiar with the process that unfolded about getting this paddock re-fenced and erecting a memorial to the 500 people that were buried there.

- **Q.** And you've been back since, I understand.
- 21 A. Yes.

- Q. And that memorial is there. It's still largely just an unmarked paddock, it's fenced; is that correct?
- A. That's correct. I've been recently back there in the last couple of months. It is still -- there's a beautiful black stone memorial there with all the people's names on but essentially it still lacks the look of a graveyard. It is on the slope of a hill, there are no crosses or flowers or markings to identify that there's a graveyard there, just the memorial.

From what I know, the paupers' grave ceased being used in about 1967, so not so long ago.

Q. Thank you for sharing that. Just in the interests of time, we'll move on to another topic which is, I want to ask you about what would happen if you tried to report something that you witnessed at Tokanui, abuse or neglect. What would happen if you reported that to a senior staff member or anyone there?

A. Any type of advocacy or reporting was rendered illegitimate, because the unspoken was the difficulties caused for me and for others about reporting on your colleagues. So life for me became incredibly difficult. Because I did report up, I did report things that I had seen.

I also learned that it had an extremely negative effect on the people with disabilities that were living in those wards that I was reporting for. So I understand that my nickname was "the Gestapo" and when I arrived on the ward they would call out, you know, "The Gestapo's here, watch out!" And I understand from people who later could communicate, that I had taught to communicate, they would say that the behaviour changed completely when I came on the ward to do my teaching sessions.

But I was ostracised, I was called names, I was left out of staff parties, and on one occasion I had my tyres on my car slashed. So the innuendoes and the environment gave very clear signals: You are not to be a snitch, you are not to report up, because if you do we're going to make life incredibly difficult for you. And that was evidenced to me on a number of occasions. Blocking me from -- so I would go in to bath or -- sorry, to teach this little man to bath and he'd already been bathed and he was sitting there crying his eyes out. So I knew that that was one of the messages to me that, yeah, just to -- so I guess I had to calibrate that reporting into sort of a more covert collection of evidence which transpired, anyway, into not being able to be used.

Q. Thank you. Moving on to another topic again, I wanted to ask about augmentative communication systems that you used in your training officer role.

And we might bring up an exhibit, Madam Chair, exhibit number 601002. We'll have that up on the screen.

It's not the clearest photo to look at to see the detail of that, but do you want to describe to the Commissioners what we see there?

- A. So this is one of the, we call it augmentative communication, and it's something I became very interested in, how was I going to equip people with the skills in order to communicate. That became my focus in the last five or six years of my time at Tokanui. I developed a specialist expertise in working alongside people assessing them for a communication
- **Q.** Just slow down a bit.
- 31 A. Sorry. Yes, I get very passionate about it.

device that ranged from --

CHAIR: Yes, I hear that.

A. So what you see up here is an example of a communication device, it's a very poor example, I wish I had photos of the end product, of a device that we designed for Mr B.

- Q. Can you just describe it physically so those without sight can know what we're looking at.
- A. So it is an aluminium empty frame, attached to another equally-sized frame that within it held around 12 different coloured overlays. This is a very early example, so you only see three colours up there. This is called an eye gaze display system. It was one that was designed alongside Mr B, who was very clear about what he wanted. The person speaking to him would sit on the other side of the aluminium frame so their face could see a series of numbers that's on the outside, which you can't see, it's on the other side of the aluminium

This was a design that we worked on over three to four years. So, shall I just quickly show?

QUESTIONING BY MR THOMAS CONTINUED: Go ahead.

frame, numbered 1 to 9.

A. I know you can't see this but how it operated was a number of grid systems. I can pass it up to you. So Mr B would indicate one of the numbers on the other side of the aluminium frame, and it could be 1. So I would be following his eye gaze, he would look at number 1, and I'd go 1, which would mean that he was speaking about the first grid reference -- it's very simple, it sounds very complicated. The second number that he would give me with his eyes indicated which of the boxes, the messages that he was going to within that grid.

We get to talk about Mr B?

- Yeah, I think I should have perhaps done that first. Do you want to talk about him now and how you met him and, yeah, a bit about him. He was -- you picked up that he showed a need to communicate and you developed this for him?
- 22 A. That's right.

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- 23 **Q.** He had cerebral palsy?
- 24 A. That's right.
- 25 **Q.** And please, you describe, you tell us about him.
- A. He never came to the training centre, he was someone I passed every day in ward 16 when I
 was collecting other young people to come over to the training centre and every day I'd
 walk past him as he was draped over his wedge, he had a very contractured body, he
 couldn't move any part of his body apart from his mouth and his eyes and I could actually
 pick him up and carry him. We were the same age, we were both born in the same year.

But I would walk past him every morning and say, "Heya, how are you going?" And he would give me a great big smile, an open mouth. And one morning I walked past him, I said, "How are you doing?", and he had a very pursed mouth, and he closed it. It tweaked me, his eyes and his pursed mouth were saying, "Actually, things aren't okay", and

I went back to him and I said, "Can you say yes and no?" Which was a stupid question really. And I said, "Show me your yes", and he opened his mouth very wide. I said, "Show me your no", and he pursed his lips very tightly. So I immediately went back over to the training centre and said to the psychologist, "This man has to come to the training centre, he's going to be in my class and we're going to start him tomorrow." He didn't, in fact, meet the criteria because he had no viable way of being assessed.

Well, he came over to my classroom, and we developed this eye gaze display system that over probably eight years developed into him having a vocab of just under 3,000 words and phrases.

Now, how on earth did this man learn to read and write and spell? Yes, okay, he did spell phonetically, like, for example, he would spell my name K-a-r-o-l-i-o-n, Karolion, which we laughed about in later years because, indeed, I was a lion for him. But he would lie on the floor of the day room every day, like others, and he would watch Sesame Street, he would watch Play School, he would watch other educational programmes where he learned from.

So another training officer and I spent individual sessions with him every single day, including some weekend time, going through what this man could understand through his eye gaze display. And I know that some people in the audience have seen him in action using it and he was a very sophisticated user. But to be able to memorise the placement of words and phrases -- and this is how he went on to describe the sexual abuse that he had witnessed for himself and others in the ward.

This was one of about -- I suppose about 30-odd people that I worked with designing individualised communication devices. So when we just talked about punishment before --

- **Q.** Sorry, just slow down for the stenographer, thank you.
- 26 A. Sorry, I know --

- **CHAIR:** Remember it's getting rather late in the day and I am sure fingers and arms are getting a bit tired so just be a bit careful about that.
- 29 A. Of course. I am sorry.

So every device was individually designed. I met a carpenter at Tokanui that loved – had no idea what I was doing – he loved it – and he would design and build me things like clocks on an eye gaze display where the person had a switch and the clock hand moved around and stopped and he'd hit the switch again with his cheek to stop on what the letter was or the phrase was.

1		So it became my passion, but it also became a punishing process for people who
2		wanted to disclose information, who wanted to talk about their staff members, and
3		unfortunately on many occasions the communication devices were trashed or stolen or
4		somehow lost.
5	QUE	ESTIONING BY MR THOMAS CONTINUED: Thank you. And for Mr B, learning those
6		communication skills also put him in danger; how was that so?
7	A.	So he was able to report who had stolen the VCRs, who had taken all the good jerseys, who
8		were the perpetrators of abuse, and he would tell me this.
9	Q.	He reported a specific incident of abuse to you
10	A.	Yes, he did.
11	Q.	involving him; do you want to talk about that?
12	A.	Yes, he reported to me that the cleaner on his ward had taken the high-powered vacuum
13		cleaner and after he had had a shower they all thought it was a great joke to put his penis in
14		the vacuum cleaner while it was on and that clearly distressed him, so he reported that to
15		me and I the cleaner was fired over that one, thankfully. But yes, that is the incident that
16		occurred.
17	Q.	Thank you. Talking about another aspect of Mr B's life that you discuss in your statement
18		around paragraph 2.94 about - you were asking him what he wanted in life and you talk
19		there about him wanting to explore his sexuality. Can you tell us a bit about that, in
20		summary?
21	A.	Yes. In time I asked him about what he wanted in his life, and he said to me that he wanted
22		to have sex. So again, my naïveté took me down the track of showing him a birds and the
23		bees movie of what that actually entailed. And he was very clear from his body language
24		that that was not what he was seeking. But it was the only word he had to articulate the
25		broad needs he had around being handled nicely, about seeing his body naked, about havin g
26		some intimacy and caressing that was not of a transactional type. He wanted to know what
27		love was, but the only way he had to say that in his experience was to use the word "sex".
28		That was a very cathartic moment, that took us, what I'm describing to you was
29		hours of conversation and clarity and understanding from me trying to extrapolate what this
30		young man was talking about, that he was seeking to have love.
31		Now, he'd been watching Days of Our Lives, and he clearly thought that that's what
32		love and romance was all about. We had to do a lot of work on what that actually meant.
33		Now, coincidentally, I ended up being his case manager in the de-inst
34		[deinstitutionalisation] of Tokanui and in time he was able to procure the services of an

amazing sex worker who helped him to explore this intimacy and need for love. And for him to see a woman's, you know, body naked that was of a personal and intimate interaction.

Now -- I just about said -- Mr B died in 2012. We always had the conversations that I have his permission to tell you these stories, because he had always wanted to be here to deliver the stories of abuse and neglect around his sexuality. And there's also the video available for the Commissioners called [GRO-B] where he explains it himself on videotape.

Q. Thanks for sharing that, Caroline.

Can I now cover another example, I guess an example or instance of sexual abuse or suspected sexual abuse. You raised a complaint of suspected sexual abuse against a senior teacher at Tokanui. Is that correct?

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14 **Q.** The allegations were relating to boys who were at Tokanui who were being taken home on weekends by this senior teacher and were suspected of being sexually abused by that teacher. I understand you supported those boys and tried to obtain evidence of abuse. As explained in your statement, you weren't able to find physical evidence of that abuse, but staff, including yourself, did try and do something to investigate that, what happened, and also prevent any future potential abuse.

Can you tell us, was a Police complaint made about the abuse?

- A. I'd just like to make it clear, first of all, though, that this was an allegation against a sen ior teacher at the Education Department.
- 23 **Q.** Sure.
- A. So on Tokanui Hospital there was also a separate school not the training centre there was a separate Education Department school run by bona fide teachers and teacher aides.
- So it was an allegation against a head teacher in that environment.
- 27 **Q.** Sure.
- A. No, at that time I was not aware that a Police complaint was made.
- 29 **Q.** Did you subsequently become aware of that?
- 30 A. Yes, yes, some years later.
- Q. Did anything happen to the teacher at the time of the allegations?
- 32 A. Well, we couldn't find any evidence, apart from what the young men were able to tell us, 33 but it was never proven. A senior member from the Waipā Community and Training

- 1 Centre spoke with him and disallowed him from taking any more children home for the 2 weekends, but that's all I understand that the consequences were.
- 3 **Q.** And he was able to continue teaching?
- A. Yes, he taught the same boys, he taught -- he mainly, his classroom had six young -- I'll say boys, they were boys at that time, they were under the age of 16, so he continued to teach them on a daily basis. There was no changes there. The only change was he couldn't take them home at the weekends.
- You later learned in 2021 that this teacher was convicted criminally of sexual abuse of two young men at a different, a mainstream primary school. How did you feel when you learned about that?
- 11 A. I was absolutely, absolutely floored. I was extremely upset. The young men that went
 12 home with him have all since deceased, so finding out in 2021 that prior to his teaching
 13 commencement at the special school at Tokanui, there had been this incident. From what I
 14 understand, though, the evidence and the accusations and then the proving of guilt didn't
 15 happen until sometime I think in around 2019. But what it did do was validate clearly.

I was ostracised and banned from the ward for my suspicions based on information given to me by disabled people that they were being sexually abused. That was too much for the charge nurse. I was persona non grata, I was not to go back to that ward to make these stories up.

But to be validated in 2021, I think I walked about 12 k's from Pukerua Bay in towards Wellington crying my eyes out thinking, "What an absolute injustice", you know, I could be somewhat, I was convinced, I --

- **COMMISSIONER GIBSON:** Can I just ask a question to check that the teacher, after the allegations at Tokanui, he stopped taking boys home but he still was allowed to teach?
- 25 A. Correct.

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- Q. And was part of his role as teacher washing, cleansing, anything intimate with the boys?
- 27 A. Yes.
- Q. And that was after the allegations at Tokanui, he was still allowed to do that?
- 29 A. Yes.
- 30 **Q.** Thank you.
- 31 **QUESTIONING BY MR THOMAS CONTINUED:** Thank you, Caroline.
- And that -- learning that at a later date, that still haunts you, is that right?
- A. It does. For Mr B, he had some type of covert communication system with these other men that went to the school. Mr B was never allowed to go to that school, yet clearly he had the

cognitive function, the intellectual function to do very well at that school. I asked myself a
lot of times during that time why wouldn't he be going to the school? Because he could
accurately report and because he now had a very good communication system to be able to
report.

Now, I just have to go back on one thing I didn't say about Mr B in the ward.

Q. Sure.

Α.

- A. When he started reporting who had pinched the good knitted jerseys and the VCR and who was having affairs with who, you know, and who was hurting people, he was threatened. And he was threatened by a staff member that he named to me and said that if he ca rried on giving out this information they could make his death look like a choking accident. And Mr B clearly believed this, clearly believed this, and he was -- it was then that we made the decision together that I needed to leave Tokanui and I needed to become his case manager and I needed to help him move out. It had gone -- it was he was now seen as someone who could potentially damage a lot of careers, and he was in danger.
- Q. Thank you for covering that. We're moving towards the sort of last part of your statement now, Caroline, and before we get to the sort of more broader questions I want to ask you, are you able to summarise what barriers to disclosure, or barriers to making complaints existed for neurodiverse people at Tokanui if they wanted to complain about something? Can you articulate the barriers they faced?
 - Well, firstly, for most people they couldn't communicate or articulate it in an expressive way that made sense. So there was no complaints process. I'm sorry, there was a complaints process, it was posted on the walls: If you are unhappy in the receipt of your service, here's the complaints process. You had to be able to read that first, understand it, then you had to be able to action a complaint yourself. You had no allies to call on to help you to fill in the form. Nor were you believed. People were not believed when they alleged complaints of being mistreated or disrespected or supported in undignified ways, it was absolutely impossible for them to make a complaint.

It was easy for staff to make a complaint, and incident report injuries and -- but no.

- **Q.** Thank you. Do you want to very quickly cover your involvement with the closure of Kimberley Hospital?
- A. Only in just that, you know, the decision was made where could I have the most efficacy in helping people to be removed from a very unsafe and inhumane environment, and I joined the case management team and I was Mr B's case manager who -- coincidentally he fired

me after he moved because he said that I made a much better friend and advocate than a case manager, so I lost that job.

But I cannot tell you what that man taught me, but that was a joyous process, and I am thankful that the men who endured what I now understand to be sexual abuse, and for all the others, that they were leaving a place that was terrifying and traumatising.

- Thank you. There's something that you mention in your statement around section 5 about attitudinal traction in terms of changing things for people with disabilities. Do you want to make comment on what needs to happen in terms of attitudes?
- 9 A. Only in what, you know other evidence has provided is that there is still a huge barrier 10 around attitudes towards the competencies, the value, the humanity of people with 11 disabilities. Which I see still prevalent in service-provision today. I think Olive summed it 12 up very well in terms of why this is so.

I think that we have a long way to go in terms of shaping and in stating -- demanding a shift, even within the disability sector about the attitudes towards people with disabilities, their worth, their contribution and their competencies, yeah.

- 16 **Q.** Thank you. You wanted to, I know you wanted to mention a specific more contemporary example around baths. Do you want to talk about that now, it is at para 5.2.
- 18 A. Do we have time?

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- 19 **Q.** We've got time, I believe.
- A. If I was to cite examples, I think this is a good one, of indictments against human rights and against attitudes towards those human rights for people who are in service provision today, and I'd just like to read from my statement if that's okay.
 - Q. Please do. Just remember to keep your pace slow as possible, thank you.
- A. "In September 2021 IDEA Services Chief Executive confirmed via a media statement that they prohibited the use of baths and spas in all of their residential services. They also disallowed the use of any spa pools in residential homes and in other facilities owned or leased by IDEA Services. The reason cited was that there have been significant investigations and due diligence into the risk of using baths in services and a recent court ruling stated that their duty to minimise the risk of baths was greater than people's rights to choose to have one."

So I use this as an example from a couple of aspects. The first one is that there will be no dedicated complaints from people who use services about this. It was based on that there was a drowning in IDEA Services in a bath, so after the investigation this was the outcome. So, you know, there are no more baths or spas.

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4	Q.	Thank you. I wanted to
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7	A.	Just a couple of things.

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ous that this is a very contemporary example of dismantling sion-making, not allowing any autonomy or choice in a very aily need. So yeah, that's all I'll say about that.

give you the chance now, I guess, yeah, to offer your comments or at you want to see overall come from this Royal Commission and concluding thoughts you want to share with the Commissioners.

Paul, you've already touched on the inadequacy of needs assessments. That's something that absolutely needs to change. One of the pieces of work that I'm incredibly proud of with the case management team during the late '80s was the way in which we describe people's lives. The needs assessments currently are based on a deficit model, what people can't do. Their life histories have been lost. There is no description of where they have come from, what their family environment is, what their familial needs are, what their cultural identity is all about, and what their hopes, dreams and aspirations are, and how to achieve those.

Again, the needs assessment process has changed significantly to – as others have described – as an application for funding and support rather being about what a person actually needs in their life.

Also, I don't expect the Commission to solve the problems of the world, but one of the things that I think you could have a serious look at is the auditing process that goes on, the relationship between the Ministry and contractual service providers.

It is, again – if I use the term – very transactional rather than relational. It does not in any way try to uncover or try to dissect, extrapolate what people's personal experiences are like, how satisfied they are living in Government-funded service provision. It is mainly about how the provider is meeting the contractual service standards, the sector service standards. I think there is a lot of conversational work to do around that.

I would like to see in that that how people communicate and are able to make complaints is inherently given as much weight as anything else. In an audit you can prove with pictorial strategies, with other devices that in fact people have the opportunity to communicate, but in my experience, the auditors never, ever see them in use.

I hope that makes sense.

- Q. Thanks, Caroline. Oh, sorry.
- No, no, no, I mean, if I was to choose anything that we'd need to have ongoing 33 A. 34 conversations about, that would be my priorities.

- **Q.** Thank you. Did you want to talk about the apology, as a final thing, before I see if the Commissioners had questions for you?
- A. Just finally, and again, I'll just read from my statement. I wanted to call out to all the children who are now adults that I supported, that I taught, that I cared for, that entrusted me with a lot of personal and intimate journeys. I wanted to reach out to make an apology to these people and go visit them, give them my apology, return photos that I have of them, have a cup of tea with them and just ensure that their lives now are happy.

And I have spoken to managers of service provision about seeking contact details for those people concerned and I have been declined due to the Privacy Act. I just wanted to state that my motive for doing that, as I'm sure the Commission understands, is part of redress and just making sure that their lives are better than what they endured in State care.

So that's really all what I wanted to say, Michael.

- **Q.** Thanks so much, Caroline, and I'll leave you with the Commissioners, their questions, thank you.
- **COMMISSIONER STEENSON:** I don't have any questions, but thank you, very fulsome statement.
 - CHAIR: I just have one issue. So much of what we've heard from you and from others is the locking away of people with disabilities, the out of sight, out of mind attitude which we now know so well informed the placement of residences and the leaving of children and vulnerable adults there out of sight, out of mind. It would be easy for us to say, "Oh, that was in the old days." I'm just wondering, do you have any views at the moment? Contemporarily, has that attitude gone or do we still live with a lingering or even pervasive sense that it's better for disabled people not to be seen, not to be in the community?
 - A. I think we have a long way to go. And I think that we need to much better speak with people who have disabilities and understand more about what they want, alongside their families, what they want in their lives, that their personal autonomy can be recognised, that they can wholeheartedly contribute to this design of their own plan. I think that, though, there is a lack of professional training that allows the multitude of stakeholders that meet people in this journey to actually authentically have that conversation. I think there are still attitudinal barriers.
- **Q.** Yes.

A. I think in my lifetime I probably won't see that change. But I think that we have to get better at demanding that and I think we have some great, we have some great documents, the United Nations on the Convention on the Rights of People with Disabilities is a

1	benchmark that everyone should understand, that the evidence of their behaviour of their
2	service provision should be driven from that premise, that they should be able to
3	demonstrate their values in action, not masquerading them as self-evident when in actual
4	fact they're not. So I think we have a relational issue that can be solved over time with
5	these conversations that will shape and change attitudes.

- O. Do you think there's room here for civic training, civic education? I'm talking about the whole population here.
- A. I think so, and I think that, you know, we see that in small snapshots. But we don't see it as a campaign or we don't see it as inherently part of everyday life. If you look at people with disabilities as a valuable employee, there's very few people actually in valued paid work.

If we see the competencies that they have -- look, I think -- you're right, from a community perspective, from a civic perspective, I think we have our best hope, but I also think that the training and how we see values in action, I understand that very few of the service providers now provide training to their staff on the basic values of the organisation and how they expect to see that transmitted into actual physical action.

- **Q.** So that's training and educating people who are actually working with disabled people?
- 17 A. Yes.

- **Q.** But also the ecosystem in which those people operate and in which disabled people live needs to be, I would have thought, transformed as well?
- A. Yes. I also think that we have taken away, we have People First for example, a great organisation, but they're not given the right resource or accolades or development planning for them to become, for them to show some of the phenomenal work that they're doing.

 There are no other self-advocacy groups that are run by people who have disabilities.

It's something that Sir Robert Martin talks about a lot in terms of shaping change, and I think from Allison Campbell's testimony in terms of how, when people actually had the tools, the right tools and the support and the resource, how they also contribute to the dismantling of attitudinal barriers. And civic education, the best civic education happens in civic land.

- **Q.** Yes. That's right. And to all of us, and for all of us, I would have thought?
- 30 A. Yes.
- Thank you so much for that. I appreciate your answer to that and I'll leave you now with Paul.

- 1 **COMMISSIONER GIBSON:** Thanks, Caroline, just a few follow-ups. Civic education and civic land, does that mean in schools? Can it work, can civic education work if kids in schools don't see disabled kids alongside them within those schools?
- That's a good question, Paul. Yeah, it starts at school. I think civic land includes, 4 A. 5 definitely includes schools. I'm not a keen fan of special schools, however, so I'm finding 6 that a bit hard to grapple with. What I mean is that community presence is a priority for people to be out there seen being active, being seen as equally contributing members, being 7 supported by their support staff to do so, having active membership to regular membership 8 9 clubs, to authentically talk and demonstrate progress against this thing that we talk about which is community integration. You know, what does that actually look like? We're 10 nowhere near people having that community presence and being respected for what they 11 can contribute. 12
- 13 **Q.** Community presence is a form of civic education in itself?
- 14 A. That's right.
- You talked about babies in Tokanui, was there any consciousness at the time of, as horrific as it is, what happened in these places for five-year-olds and over, that if you went in as a baby, your intimacy needs, your needs for love in those first few years, if they were missed out, any consciousness about how to meet those needs or, later on, how to try to fill any gaps?
- 20 A. During my experience during that time I have to say no. No, there was no consciousness,
 21 just another indictment of that model, Paul. You know, it was never -- they had a revolving
 22 door of staff around them that all brought with them different attitudes and different caring
 23 techniques but there was never any consciousness about how to provide a salient
 24 environment or a nurturing or loving environment for these children, what needed to be
 25 replaced for them in terms of love and kinship and some type of connection to that, I don't
 26 remember any discussions happening about that, no.
- Q. A lot of -- some of the themes were of intimacy and privacy for men, for women, for those for whom it would be harder to otherwise get. Do you have any further thoughts on that?

 I notice one of the solutions for Mr B was a sex worker. What should the future of disability support look like in terms of meeting the intimacy and privacy needs of a range of disabled adults?
- A. Well, that's a personal approach, but what I would say we need to have the conversations, and at the moment the conversations are not being had about people's sexuality or intimate needs.

- Q. Can I ask about the cleaner and that incident, or those incidents, were there other people present?
- 3 A. Yes.
- **Q.** So it was almost like a group sexual abuse incident?
- 5 A. Yes.

- **Q.** The cleaner was fired; was there any prosecution or anything beyond that to stop that person or any others having any contact with any other disabled people in the future?
- 8 A. No, not that I'm aware of. They resumed their work, their shifts, they were there. No.
- **Q.** It was hardly recognised as abuse?
- 10 A. I think that if [GRO-B] --oh, I'm sorry, Mr B, had not disclosed it to me it would never have been reported. So what was traumatising about that is what went unreported.
- **Q.** Many people require some form of augmented communication or a greater degree of
 13 interest, curiosity from the people they're engaging with. What is to be learned now in
 14 2022 specifically in that area, how does this Inquiry make an impact on those people who
 15 may be able to communicate more than what others perceive them to be able to do for those
 16 who might not even be perceived to have some "yes or no" communication?
 - A. You're right, Paul, first of all it needs to be diagnosed as a need. Everyone has a need to communicate, every behaviour has a communicative function. In my view, everyone should have a way of being able to express themselves.

As Sir Robert says to us very clearly, the only way that you get support or be recognised as a need is behaving inappropriately. If you start engaging in significant challenging behaviour because your communication needs aren't being met, then you *may* get referred to a specialist provider. But if you are compliant, if you are labile, if you are quietly sitting in your corner rocking, you're never going to attract that attention or that referral process.

It's dangerous, Paul, because everyone needs a way in which to be able to speak or a recognised repertoire of behaviour that people understand means dedicated things. That's a huge gap, that's a huge gap.

So what is the solution to that? Well, I think that it becomes a mandatory auditing process, that's not the right word, but the audits at the moment don't focus on that level of personalised ability to communicate. In my testimony I ask the Commission to review how many complaints have been made by people who have disabilities within current service provision, and you will find very few, especially from people who receptively understand

what's going on in their world around them, but they cannot actively, expressively communicate.

Those are the most vulnerable, that's where the abuse will be happening; that's where the neglect will most likely be happening, but they have no way to report.

- Another area was around things that happen at meal times, processes for eating, feeding, but also you reported on the amount of PEG [percutaneous endoscopic gastrostomy a feeding tube that gives food and fluid directly into the stomach] feeding of people that left Kimberley and other places.
- 9 A. Yes.

- **Q.** What are the lessons today to people in support services. Do people making decisions understand enough about people's needs for food, for appropriate --
 - A. That's another good question, that's a big question. Firstly, I think that I question the number of people that had PEG feeding processes in place, and that's why I've asked that Explore [Explore Services, the multi-disciplinary team contracted to provide the health assessments and referrals at the time of discharge], provide that evidence as part of the deinst process about why they were used, because on a number of occasions they were used purely for being able to give people enough nutrients. It was about staff time. I'm not over-exaggerating that, that's what was found.

So your question, then, is around people's current nutrition and eating? Well, again, you know, that's something that needs to be – as part of an authentic look into the quality of people's lives, not from an auditing process, but from a more meaningful perspective about how people are bathing, even if they're not allowed to have a bath. So what else is happening for them? What is their nutrition like? You know, when did they last go to the dentist? When did they last have a mammogram, a cervical smear?

I think that your question is multi-faceted in terms of, how do we actually ensure that people are living a quality of life. The tools that are currently used are inadequate and they focus really on compliance and contractual obligations to disability sector standards. So, yeah.

- One final question. You literally stumbled across 500 graves of people who were otherwise lost and forgotten. We can only imagine there might be thousands of others across

 New Zealand, we don't know.
- 32 A. Yeah.
- We hear what's happened in Canada recently with changes in ground scanning technology.

 What do you think we should be doing here in Aotearoa New Zealand around these issues?

A. The other question I had when I went to the grave is how did they die? How did they meet this end? Because when you look at the ages of those nearly 500 people, there were some as young as 35, what happened? I think the oldest one was around 70-odd.

I'm sorry, Paul, I've just forgotten your question.

- There may be many unmarked graves around Aotearoa New Zealand, we're hearing bits and pieces of more, what do you think should be happening? How can we honour them, their lives, connect with their families, their iwi?
 - A. Well, I think there needs to be a dedicated look at the records of some of the institutions as to what happened to these people that died within institutional life. You know, some of the people that were buried in that graveyard were returned servicemen that had come back with shell shock, that had been so deeply traumatised they had been diagnosed as having depression.

The abhorrence of this needs another lens over it and it needs — even I would suggest for Tokanui. Yes, we've got a memorial, but we do not know the history, we do not know how each of those people passed away and why there was no family involvement.

Now, for the plaque that I've stumbled onto, she had a sister who also lived at Tokanui and I became her case manager. When I went up to meet her, the mum, she said, "Yes, my other daughter is buried in the cemetery at Tokanui." This was before I'd stumbled across the plaque, sorry. And I had assumed that it was a graveyard in Te Awamutu, or I had assumed it was -- when we discovered this, the mother had passed away so I wasn't able to -- actually, I was grappling with how I would even begin to tell her that her daughter was buried in a paddock that I had grazed sheep on.

Paul, I think that we need to go back to the — what do we call it? — the baker's unit where they keep all the records and there needs to be some acknowledgement and discussion with iwi about a solution or, as part of the redress scheme, how do we offer an acknowledgement of sorrow or an apology around the treatment of those people who ended up in those paupers' graves?

- Q. Thank you. It's just left for me to thank you, I think there's a great chorus of people standing behind us that wish to thank you as well. You did mention Mr B's name.
- 30 A. I'm sorry.

He resonates with many of us -- I'm actually glad you did, I'm glad that came out. Thank you for touching, transforming many lives, and thank you so much for coming forward.

I know it hasn't been easy, and I know you carry the personal burden of some of what happened in these places, but I hope that you can -- the sense of restoration, of

Hearing adjourned at 5.13 pm to Thursday, 14 July 2022 at 10 am

1		enhancement of your mana and well-being through this process as well, that we hope that
2		survivors get as well.
3	A.	Thank you.
4	Q.	And thank you for your expertise, your ongoing passion and commitment and for making a
5		difference in the lives of people with disabilities, people with learning disabilities, people
6		with the highest degree of communication needs, and I'm sure it will make a difference for
7		those in the future. Kia ora, thank you.
8	A.	Kia ora, thank you.
9	CHA	IR: We've come to the end of evidence for the day and I'll ask our kaikarakia to come
10		forward.
11		Karakia mutunga and waiata, Ka Waiata, by Ngāti Whātua Ōrākei