

**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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AUCKLAND

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TRANSCRIPT OF PROCEEDINGS

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Adjournment from 11.35 am to 11.48 am

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

33 **MS THOMAS:** Thank you, Commissioner Gibson. The next witness we'll hear from today is

1 Paul Milner. He is happy to take the affirmation before we start.

2 **CHAIR:** Thank you for coming and being available to give evidence, we appreciate that. Would
3 you take the affirmation please.

4 **PAUL MARK MILNER (Affirmed)**

5 **QUESTIONING BY MS THOMAS CONTINUED:** Thank you, can you please tell us your full
6 name?

7 A. Paul Mark Milner.

8 **Q.** Is it accurate to say that you are also a failed retiree?

9 A. Completely accurate, Ruth.

10 **Q.** And you have previously been a disability researcher?

11 A. Yes.

12 **Q.** Prior to your work as a researcher at the Donald Beasley Institute, you had been a
13 geographer and you'd taught at the University of Otago and you'd also done some work
14 supporting people who were moving out from Cherry Farm; is that correct?

15 A. That's correct.

16 **Q.** Do you have a memory about one of your first days supporting people leaving Cherry
17 Farm, moving out into the community?

18 A. Sure. So actually I can't remember the dates.

19 **Q.** You don't need to worry about dates.

20 A. No, no, my involvement in the disability sector, I tumbleweeded into it, gosh, when I was
21 quite young, but I had worked for a service that was resettling men and women from
22 Cherry Farm, which is a local institution in Ōtepoti, Dunedin, and on the very first day, as
23 five men who thought they'd played their get--out--of-jail card began to claim their
24 bedrooms, somebody I knew from a former life, they were a mental health service user, was
25 attracted by the furore and came across and leaned into the window and saw a man who
26 was clearly, some might say struggling, but it was part of who he was, who had mania, and
27 he leaned across the fence and he said to me, "Paul, when I look at that man- I see 100%
28 man", and gosh, from,-- I think probably from that date onwards I was always deeply
29 suspicious of places where the prerequisite to entry was that you be at least two standard
30 deviations away from 100% man.

31 So that was my first day in disability service provision.

32 **Q.** So that is a lesson that you've taken with you ever since?

33 A. It is, yeah.

- 1 **Q.** I just do need to ask that both of us speak as clearly and slowly as possible so that the sign
2 interpreters and the stenographer can capture everything.
- 3 **A.** Sure.
- 4 **Q.** And then at some point you did start working as a researcher for the Donald Beasley
5 Institute and you worked there for 17 years. Why did you choose that role?
- 6 **A.** Tumbleweeding is my habit. I think it would be fair to say that I burnt out of service
7 provision, I lasted nine and a half years, which I think is about three times the average.
8 I burnt out, I guess it's kind of inevitable if your engines are fuelled by something of
9 disquiet and the odd moment of outrage, and so I left.
- 10 Yeah, I'm a leaper rather than a looker so I leapt out of services at that point and
11 tumbleweeded into the Donald Beasley Institute thereafter.
- 12 **Q.** You said that you were outraged through your work in the service provision work, what
13 were you outraged about?
- 14 **A.** Perhaps "outraged" is too heavy, but in, -- so the deinstitutionalisation of Cherry Farm came
15 quite early in the deinstitutionalisation process, and I worked in a service that started from
16 scratch, and so it tended to be a heart driven - service, it was led by people who knew and
17 cared deeply about the people who were moving and were determined to make a better life ,
18 a life that they felt they were owed. And then over time the kind of services become bigger
19 and the big decisions about people's lives become made at a distance from a relationship
20 and knowing, and I think, too, that, you know, the kind of, -- over time they became
21 bureaucratised and process driven in a way that it was easy to forget that it was your role to
22 help people to become -self made- men and women, people could become chattels of
23 service delivery moved about, and so, yeah.
- 24 **Q.** So when you first started your role as a researcher, how did you initially feel about that role
25 and did that change over time?
- 26 **A.** So it wasn't an easy fit to start with, I think I had a healthy dose of imposter syndrome in
27 the first place but also given what I said about the 100% man, I worried, I worried
28 that -- about places where the prerequisite to entrance was 100% man, and so I worried that
29 the researchers' gaze was just another form of othering.
- 30 **Q.** Right.
- 31 **A.** But what I came to learn quite quickly is that ethically conducted research and in particular
32 inclusive research can give people with learning disabilities the tools and the information
33 that they need to effect meaningful change. And I think the Donald Beasley Institute

1 pushes the envelope in this respect and they rightfully deserve their reputation as leaders in
2 ethically conducted research.

3 **Q.** Thank you. Through your work as a researcher, you have carried personal stories of
4 people's life experiences with you. Why did you choose to share these stories with the
5 Royal Commission of Inquiry?

6 **A.** A simple explanation, Ruth, might be that most of them, men and women I met at
7 Kimberley have now passed and so we have lost, we've lost their stories without an orator.
8 But that would only be less than half the truth. The real reason I was motivated to meet
9 Thomas and Nathan was because they had,-- the people that I knew had become so
10 acculturated to Kimberley that I don't think they'd have recognised what they experienced
11 as abuse, and so we would have lost their stories that way.

12 **Q.** Right.

13 **A.** I don't think they would have appeared today even if they had have lived.

14 **Q.** Thank you. I'm just going to check whether the pace is okay. Just.

15 In addition to your own recall of your interactions with people at Kimberley, what
16 else have you drawn on as you've worked together with the Commission on your
17 statement?

18 **A.** So my statement is something of an amalgam. As you say, it's in part driven by kind of
19 personal experiences and observations that I made while I was at Kimberley but it's
20 also -- I've tried to contextualise it with some of the formal findings from the research
21 project that we were conducting at the time.

22 So, at the risk of over-spruiking the Donald Beasley Institute, both the long and the
23 short reports are available on the Donald Beasley website.

24 **Q.** And so you've drawn on the research reports which you were one of the authors of. Do you
25 have those reports there just so the Commissioners may see what they look like?

26 **A.** Sure, yeah. So this is the short abbreviated report, a kind of insult to the complexity of an
27 institution.

28 **CHAIR:** What's it called?

29 **A.** So "An outcome of the resettlement of the residents from Kimberley Centre".

30 **Q.** Thank you.

31 **A.** So this is the long report, but both are downloadable from the Donald Beasley website.

32 **QUESTIONING BY MS THOMAS CONTINUED:** When were they published?

33 **A.** 2012, I think. Sorry 2008, 2008, yeah.

1 **Q.** Thank you. So when you first started with the Donald Beasley Institute, you were assigned
2 specifically to work on the Kimberley Project; is that correct?

3 **A.** Yes.

4 **Q.** Can you please outline for us what was the purpose of this project?

5 **A.** So Kimberley was the last of our major institutions to close, and when it shut its kind of
6 doors in 2006 it brought to an end what had been a significant policy shift for the State, it
7 effectively ended the long history of State care of people with learning disability. And so
8 prior to it, it represented our very last opportunity to catch a closed population whose lives
9 were going to be bifurcated by the two dominant models of support. And --

10 **Q.** When you say bifurcated can you just explain what does that mean?

11 **A.** Sure. I think this is going to happen a wee bit.

12 **Q.** It's all right. It's just so we can all grasp your important evidence.

13 **A.** Yeah, sure. So bifurcated means kind of branching in two directions. So at the time
14 Kimberley was closing there were two model, dominant models of care: There was the
15 institution, the total institution, which through the work of the Commission that we know
16 that at certain places in the history, 40% of people with a learning disability found their
17 way to. And then the other model, of course, was-- the dominant model was the
18 community group home.

19 So these were the two models. But interestingly enough, deinstitutionalisation
20 added a third. And so as part of a concession to families that were concerned, we
21 developed an onsite cluster housing at Templeton and offsite cluster housing at Kimberley,
22 and so we added those as a strand in the research as well.

23 **Q.** So there was an option of cluster housing, onsite or just close to Kimberley, onsite for
24 Templeton?

25 **A.** Yeah, for Templeton and for Kimberley.

26 **Q.** And there were community group homes throughout New Zealand?

27 **A.** Yeah, already established. The service that I worked in, of course, had to establish to
28 evacuate Cherry Farm, yeah.

29 **Q.** What were you and your research colleagues aiming to document through this research
30 project into Kimberley?

31 **A.** Okay. So the real purpose of the research was to build as comprehensive a picture as we
32 could of life of Kimberley. To do that, we used a range of both objective and, you know,
33 kind of qualitative and quantitative methods. And so we took into the -- we took into our

1 research a kind of forensic look at people's files, we looked at --we used a quality of life
 2 measure, we used a measure of choice making- to determine people's level of self-
 3 determination-, we used an adaptive behaviour scale, but perhaps the most potent of the
 4 tools that we took in were a running record of observations of what people were doing
 5 moment to moment, and also the narratives of people themselves and their, -- the staff who
 6 were identified as a key worker and the families of the men and women who lived there.

7 And so the idea was that we replicate, we take the same battery of measure and see
 8 what life was like six months and then 12 months after their resettlement.

9 **Q.** Right. So all of that gathering of the data would happen through your observations and
 10 work in the Kimberley setting and then you'd do all those same measures again six months
 11 later and 12 months later in the community homes that people were then living in?

12 **A.** Yeah, in the vernacular of research it was a mixed method approach, kind of, known - it
 13 used a prospective research design. So prospective means -forward-looking-, and so it's
 14 one of the very few research,- most research conducted on institutions is retrospective,
 15 it's- people going back to reflect. Here we had an opportunity to catch it prior to the move.
 16 So yeah, it's unique in that respect.

17 The other unique aspect of it is people became their own measure of change. We
 18 were able to see for each individual there what this moment, significant moment in their
 19 lives meant.

20 **Q.** During that research and the collection of all of that data, did you see a missed opportunity
 21 with some of that data that was collected?

22 **A.** In the context of the work that the Commission is doing, you know, the kind of broad
 23 objectives of the research meant that, - and also- the constraints of ethical approval in terms
 24 of we could only work with those that we had consent to, meant that we couldn't properly
 25 kind of drill down or interrogate, you know, the kind of systemic abuse or the kind of
 26 narratives that we heard in place about moments, yeah, about incidents of abuse.

27 **Q.** On a practical level, just so we all understand, can you take us through how did you
 28 actually undertake this research project in terms of how often were you visiting Kimberley,
 29 how long did you spend there, what was your role in that?

30 **A.** Okay. So the project itself ran I think for just over five years, and so we followed people
 31 through -- so we were at Kimberley I think for about three and a half years and when it
 32 originally began the intention was to be there for every week, for a week of every month. I
 33 think towards the end we may have drifted towards once every two months. But in a sense

1 that gave it a kind of ethnographiquesque attribute too. Whilst we were clearly there as
 2 researchers, after two to three years you kind of became part of the landscape of the place
 3 itself, we kind of became a little less visible, yeah.

4 **Q.** In your statement you've said that when you arrived at Kimberley there were some chatter
 5 or some comments about physical abuse such as hosing downs or the Kimberley cringe.
 6 Can you please explain to us what do you mean by those terms?

7 **A.** Sure. I could have,-- jeepers. Those kinds of disclosures kind of punctuate a lot of
 8 conversation. They lie just beyond the surface of asking. So I could have chosen any
 9 number, but,-- so the hosing down, staff would tell you that their remembrance of people,
 10 the fire hydrants being used on people as a form of punishment, and the Kimberley cringe,
 11 some didn't know, but there was this kind of common understanding that for some people if
 12 you walked up to them really quickly they would cower and cringe, the clear implication
 13 being that they had been assaulted previously and in the vernacular of Kimberley this was
 14 kind of known as the "Kimberley cringe".

15 **Q.** So you've just described some examples of physical abuse that many New Zealanders
 16 might feel shocked by, but in your statement you have said that the overt physical abuse in
 17 an institution is just the tip of the iceberg. What do you mean by that?

18 **A.** If I could go backwards to go forwards.

19 **Q.** Sure.

20 **A.** No, that's fine. Like, I think the point about the stories are that they kind of normalise
 21 physical abuse as part of the legacy of an institution. You know, they become part of the
 22 vernacular and expectations of an institution.

23 In terms of,-- I said tip of the iceberg; that is what I said, isn't it?

24 **Q.** Yes, and then you referred to what you saw as the real insult of the institution.

25 **A.** Yeah. So to me that's a smaller part of the story. To me the real insult of an institution is
 26 the kind of depersonalisation, the kind of social construction that people live in, including
 27 their seemingly purposeless lives that kind of make the events that we more readily
 28 recognise as abuse almost inevitable. It's part of the second layer of that ecology of abuse.
 29 We talked before about abuse, the fiction of abuse being just a moment between a
 30 perpetrator and a victim, when in reality it's supported by a whole culture and social
 31 understanding of people and their rights.

32 So yeah, to me most of the iceberg of human rights violations sit beneath our
 33 common understanding of abuse and neglect.

- 1 **Q.** Thank you. When you and your research colleagues first arrived at Kimberley, how were
2 you received? What did the staff think you were doing there?
- 3 **A.** So I must say warmly by management but with deep suspicion by everybody else. So there
4 was a degree of resistance and hostility. We were known there as "The Beastleys" which
5 I kind of love and appropriated. And staff that didn't know us there would kind of
6 habitually ask us if we were there window shopping.
- 7 **Q.** What do you mean by -- what did you understand that to mean, window shopping?
- 8 **A.** There's no ambiguity about it. So staff in villas were used to, at that stage, people from
9 Human Services coming to meet or, in their world view, take residents to populate their
10 houses and, again, in the kind of gallows humour of an institution, this was known as
11 window shopping.
- 12 **Q.** At paragraph 2.14 of your statement you talk about your first impression of a locked
13 women's villa at Kimberley. What were those first impressions?
- 14 **A.** So that villa was the first place I entered to conduct the research. And it would be fair to
15 say that I was completely affronted by it. In walking in most particularly by the way that
16 people in the villa were spoken to, called across the vacuum of the space as they kind of sat,
17 and I,-- I kind of thought that, look, I went in there with a clipboard and dreadlocks and was
18 clearly somebody out of the ordinary and expected therefore somebody to have some
19 degree of curiosity about me and what I was doing, and I was met by nothing, there was an
20 emotional vacuum to the place.
- 21 Whilst I was sitting there somebody, a woman ran through, burst into the room
22 completely naked and nobody flickered an eyelid. She was chaperoned out of the room by
23 one of the other women that lived there to be tidied up.
- 24 And, of course, the villa was locked, and so the kaupapa of the place is that those
25 women needed permission to do absolutely everything. I was a complete fish out of water,
26 I had no template for the context in which these women lived out their lives.
- 27 **Q.** Right. And I will ask you some more questions a bit later in your evidence around the
28 locked villa and some other locked villas that you saw at Kimberley.
- 29 **A.** Yes.
- 30 **Q.** Yesterday we saw some images and some scene-setting videos about Kimberley and its
31 grounds. What were the institutions like Kimberley or other institutions, psychiatric or
32 psychopaedic, what were they supposed to convey to the rest of the world in the way that
33 they were designed?

1 A. So you'll have seen in the -- so Kimberley is a little atypical. My understanding of the
 2 origins of Kimberley is it began as a disused Air Force base after World War II. But the
 3 standard model of institutions were that they were intended to display the kind of attributes
 4 of permanence and authority and professionalism that would quieten families who were in a
 5 place of surrendering their children to the State, the kind of grand gothic architecture that
 6 Templeton, and formerly Seacliff, were kind of the baroque examples of.

7 In its day, Seacliff was the largest building in the southern hemisphere. I remember
 8 reading a report somewhere that said, "In Dunedin we take our institutions seriously."
 9 Yeah. The spires were deliberately built big so they could spot people who were trying to
 10 escape. In Kimberley they resolved this by dressing people in red. It was called runners'
 11 red.

12 Q. Wow. So you've talked about the architecture and the grounds of these places and the
 13 spaciousness of those, what was the reality of life for people living in those buildings or in
 14 those spacious places?

15 A. So the first thing you would notice as a family driving into Kimberley is the kind of wide,
 16 expansive and well-groomed gardens. Families would often talk about it as part of the
 17 important attributes of Kimberley institution, but in reality nobody walked the grounds,
 18 they were completely empty.

19 I mentioned before we did, - the running records we did was randomised and for I
 20 think it -was - 90-% of our 260 randomised observations took place in people's villas, they
 21 were,-- their lives kind of principally unfolded in these settings.

22 Q. I think you mentioned a percentage there, was it even slightly higher than that, 96%?

23 A. 96%, 4% of their time outside of their villa.

24 Q. Within these villas, what spaces were the people that you were observing spending their
 25 time in within the villa?

26 A. So their life space was even more constricted than that. 70% of the time -- of the
 27 observations were conducted in the villa day room or their dorm.

28 **CHAIR:** Could I just ask you about that for a moment. Did you ask people to come to you to be
 29 interviewed or did you just find them where they were and interview them where they
 30 were?

31 A. So our time, in order to make sure that we had a fair sample of, you know, a representative
 32 sample of times and there was nothing biased in our methodology, we randomised the time
 33 that we would conduct the interviews. So they took place at the time that was assigned

1 wherever the person was, yeah.

2 **Q.** Right?

3 **A.** So that was between the hours of 9 and 9. So, you know, like, ordinarily, wakeful hours,
4 yeah.

5 **Q.** So that explains your ability to reach a -- draw an inference about percentage of time in and
6 out?

7 **A.** Correct, yeah. I mean, it won't, as is the case with lies and damned statistics it won't be
8 completely accurate, but like it was a protection against our possible bias, yeah.

9 **Q.** Thank you for that.

10 **QUESTIONING BY MS THOMAS CONTINUED:** Paul, can you describe for us what a
11 typical villa day room looked like?

12 **A.** Yeah. So they were all slightly different, but on the whole the five, again in the vernacular
13 of the institution, the lifestyle villas. So if you were to walk into one what you were most
14 likely to see is all -- so 13 people to a villa, and so most of the time almost all of them
15 would be sitting against the back walls of the villa on second-hand furniture that they kind
16 of proprietarily claimed it was the same seat that they sat on the day before that and almost
17 every other day before that.

18 So people, you'd catch people either sitting or standing or snoozing or trapped in
19 their wheelchair by their tray.

20 **Q.** What were they doing there? So snoozing and sitting, was there any activities being
21 provided?

22 **A.** Yeah. So, yeah, we'll do that, and then we'll go back. I mean, it's important to know that,
23 so the population that I haven't named in there was the staff, and the staff would usually,
24 they were supposed to be -- there were supposed to be two on for every 13 staff [sic]. In
25 reality that often didn't happen, and so staff would sit at a desk and really their kind of role
26 was to moderate what was happening in those places, you know, to kind of keep the kind of
27 quiescence and that kind of stasis or equilibrium that everybody had adjusted to.

28 So your question was what were people doing?

29 **Q.** Mmm.

30 **A.** When we unpacked the running records what we discovered was 50% of the time -- 50% of
31 the time we coded sedentary, sorry, -yeah, sedentary activity, in order -- that category
32 required you either to be sitting doing nothing, standing doing nothing, snoozing, and then
33 if you added on top of that a kind of wandering and self-stimulation, that, -- gosh, I forget,

1 you're the statistics, 70% of the time -- no, 80% of the time they were doing no obviously
2 purposeful activity, 80% of the time.

3 Perhaps it's easiest to do by contrast, actually, Ruth. So to cross the threshold into
4 indoor active activity all you needed to be doing was flicking the top off a bottle, or
5 covering a page in ink with a pen that a staff person had given you until there was no white
6 left in it, these were,-- that would get you across the threshold into indoor active activity.

7 **Q.** Right, so if the residents were doing something like that, then they'd be categorised as
8 having active activity?

9 **A.** Indoor active, yeah.

10 **Q.** But you found from your observations 80% of the people you're observing, their time was
11 spent doing nothing, sedentary, purposeless?

12 **A.** Yeah, yeah. So I haven't included popping the top off a bottle or inking in a page as
13 unobviously purposeful.

14 **Q.** Right.

15 **A.** I think,-- we were talking before about the kaupapa of a villa day room and I think, like
16 I remember reading somewhere that unpacked all institutions, had a look over all
17 institutions to find their defining motif and it seemed to be true of Kimberley too that on a
18 good day nothing happened.

19 **Q.** I'm going to ask you about -- I'm on page 5 of your statement now. At the top of
20 that -- you've mentioned already that there were things that happened beneath the surface at
21 an institution, or what you observed. Would you like to talk to the Commissioners more
22 about that?

23 **A.** Beneath the iceberg?

24 **Q.** Mmm.

25 **A.** And what constitutes a human rights violation or the kind of -- the thing that I think kind of
26 interests me is that in the first place this kind of neglect of someone's human promise or
27 their potential in any other custodial relationship would have been considered grounds for
28 State intervention. If you had been a parent displaying this kind of ambivalence and denial
29 of personhood there would have been a clear case for custodial removal.

30 But to me it's so much more than that. Because you can only imagine what the
31 accumulated weight of this kind of form of social knowing must have had on the people
32 who lived there and the people who worked there. The fact that for some reason that they
33 represented a population for whom it was acceptable for them to live in a locked villa and

1 unable to access the kind of sights and smells and human relationships, and Sir Robert
2 Martin talked about not being even understanding news, he had no understanding of the All
3 Blacks despite knowing rugby, that,-- all of which would have been available, readily
4 accessible if people had just been able to step out of the oppressive quiescence of the villa
5 they were in.

6 **Q.** In your statement at para 2.24 you've stated the sociologist Erving Goffman?

7 **A.** Yeah.

8 **Q.** Could you read to us what you've said there?

9 **A.** So Goffman was writing in the 1960s, 1961, his book on asylums about American
10 institutions and he said "the loss of a progressive personal identity through restrained and
11 regulated circumstance represented the defining attribute of institutional life."

12 So it goes so much deeper. On the surface of it people will tell the Commission that
13 they had no clothes. At Kimberley when we went they did have their own clothes, but for
14 almost all of the entire time at Kimberley people didn't, they wore others, except for a pair
15 that they kept for when parents came, they could dress them up. When we were there,
16 people had few possessions, they couldn't write themselves into place in the same way that
17 we do with our homes because their possessions would be stolen or taken. Yeah.

18 Sorry, I've drifted off the --

19 **Q.** No, that's fine.

20 **A.** Yeah.

21 **Q.** I'm going to ask you a question now as we go through your evidence we're about to move
22 on to some examples of particular individuals that you grow to know. But as we do that,
23 what would you like the Commissioners and the members of the public to keep in mind and
24 ask themselves as we go through the examples of people's lives that you'll talk about?

25 **A.** It's a very simple question, and that is that, would this be morally defensible for any other
26 person? I,-- this question has always framed itself as important for me. In my early days in
27 service provision, I fell across a poem by Les Murray, an Australian poet, it's called Dog
28 Fox Field and in the poem there's a line that goes, -- that reads, "Paul who grew large but
29 giggled small." And Paul,-- so what you learn in the poem is Paul and other people who
30 have just failed an IQ test in which one of the elements of it was that you were required to
31 make a sentence that contained the words "dog", "fox" and "field". What you learn about
32 the van is that it's being used to trial the cyclone gasses that would eventually flood the gas
33 chambers of Nazi Germany and their T4 euthanasia programme, it is the same eugenic

1 imperative that sat behind the 1911 Mental Defectives Act that saw the construction of
2 institutions and their population by people that the State now had the right to determine
3 were socially defective.

4 So it was that act of carrying your name into places. And part of the, -- and talking
5 about these people that I met at Kimberley today, one of the requirements of ethical
6 approval is that we have to anonymise them and so it's this - potentially the same kind of,
7 arguably, another form of depersonalisation that makes it difficult to imagine you taking
8 your name into Monowai or Rotoiti or Hawea- or Palm Grove, but that's the invitation:
9 Would this be morally defensible for anybody else that carried that name?

10 **Q.** Thank you. So, keeping that in mind, would this be morally defensible for any other
11 person, I'm going to ask you first to start by talking to us a little bit about a person that is
12 referred to in your statement as "P"?

13 **A.** Sure. So much to my embarrassment in my statement I began by saying that P was a
14 nonverbal man, as if that was an appropriate form of introduction. P was a man who had
15 the brightest blue eyes. He was perhaps one of the kindest men I've ever met. P had lived
16 almost his entire life in Kimberley. His story was that his mother, as retold to me, was so
17 stigmatised in the first place possibly by having a son with a learning disability, completely
18 consistent with social construction of the time, but almost certainly as a mother, of having
19 to have given up her son. And so, as a consequence- she hid the fact that she had,-- that she
20 had a son that was living in Levin and so P couldn't get out of Kimberley. His sister who
21 loved him and couldn't fathom how the life of her brother had taken such a radically
22 different trajectory to hers couldn't get him out until his mother died.

23 **Q.** Did P have a nickname?

24 **A.** P's nickname was Hardie.

25 **Q.** Why was he called Hardie?

26 **A.** Because back in the day, maybe it's still true now, they had a building product called a
27 Hardie plank and P was Hardie because he was thick as a plank.

28 **Q.** What did you think about his nickname?

29 **A.** So immediately prior to going- actually, I- don't know, the fictions of life, but at some
30 point, in my time at Kimberley I watched a documentary on how Chinese prisoners were
31 treated by their Japanese captors and so in order to legitimise the kind of treatment of these
32 men they had to have a depersonalising lexicon, and so these Japanese guards would call
33 them "logs", not even human. And so that was my remembrance when I heard the rationale

1 for calling P "Hardie", thick as a plank. It's kind of an understanding of someone's
2 personhood that contributes not just to the way you treat them, but it insulates you from
3 thinking too deeply about it.

4 **Q.** How did you communicate with P?

5 **A.** So, we tried to interview everybody, whether they had words in them or not, and so for
6 some of the time that I was at Kimberley I would sit down, I would sit down with P and
7 look into his electric blue eyes as he tried to look into mine.

8 **Q.** When you sat across from him doing this, what did P do, what did he do sometimes to
9 himself?

10 **A.** So, P was in the habit of hitting himself. So, he'd hit himself in a way that not only must
11 have hurt, but must have,-- in all probability was harming him. So that's the way some of
12 our interviews were transacted, with P hitting himself and me desperate to try to stop him
13 from doing it.

14 **Q.** So, what did you try to,-- what did you do to try and stop him hitting himself?

15 **A.** Naturally I felt complicit, I felt there was something about our interaction that was causing
16 P to strike himself that way, despite the fact that he was kind of intent on knowing me. So,
17 I tried everything, I tried holding his hand down, I tried distracting him, I tried everything
18 I could think of, but in desperation, in absolute desperation, I hit myself the same way that
19 Hardie did.

20 **Q.** Right. So, when you started hitting yourself in the same way, what did Hardie, or P do
21 then?

22 **A.** So, when nobody else moved, P reached out and held my hand and pressed it gently to the
23 table. So, we stayed like that, because I knew for as long as P held my hand, he couldn't hit
24 himself. I think the other thing that's important to know about P is how,-- so P was perhaps
25 hardest to find at Kimberley, because if he wasn't in the villa day room where you expected
26 him, he was outside in a little enclave, which was about 20 by 20 metres I think, it had a
27 fence at the end, and it was grassed except there was a furrow in the grass that was left bare
28 and it took me a little while to realise that this was because P would walk it every day, he
29 did the same circular lap in that groove. He would stop by the carpark and I'm assuming
30 that he'd look for,-- he was waiting to see for somebody who arrived, but,-- so,- and then he
31 would move his circle and go back I think looking for some kind of stimulation - or to
32 escape the gaze or the surveillance of the villa day room.

33 So that's the way P's life unfolded.

- 1 **Q.** At paragraph 2.34 of your statement, you've quoted John O'Brien . Can you tell us who is
2 John O'Brien?
- 3 **A.** John O'Brien was an American, I think, he may be Canadian, but he was a leading
4 disability writer and thinker who's perhaps more than anybody responsible for what we now
5 know as person-centred planning and his five accomplishments that were supposed to be a
6 road map for services, providing services beyond the walls of an institution. John
7 O'Brien -wrote the-- reason I remember him, I once heard him say: Nothing of value
8 happens in productive time, it's most likely to happen in wasted time.
- 9 **Q.** What do you understand to mean by that, what is wasted time?
- 10 **A.** So as a researcher I was afforded the opportunity just to sit with P while he looked inside of
11 me, and I got a chance to inside of him. But the insult of an institution of 13 people lining
12 the walls with one staff person who's maintaining its quiescence is that there's no
13 opportunity to waste time with people; there's no opportunity for discovery; there's no
14 opportunity to be surprised by somebody's capacities or things that you didn't know about
15 somebody; there's no opportunity to contemplate what possibilities might exist in the
16 wasted time that you spend together, the time that we all discover new things about our
17 children and our neighbours and ourselves in the process.
- 18 **Q.** If it's all right with, you Paul, just in terms of where we're moving on your brief now,
19 I might ask you to talk to us first about the person referred to as "B" and then we'll see
20 where we get to in terms of our timeframes, if that's all right?
- 21 **A.** Sure. Could you tell me the page?
- 22 **Q.** Page 10 on your current version.
- 23 **CHAIR:** We don't have those page numbers; can you give us the para number?
- 24 **MS THOMAS:** Absolutely, the paragraph number for B.
- 25 **CHAIR:** I found it, 2.68?
- 26 **MS THOMAS:** Yes, that's correct, thank you.
- 27 **CHAIR:** Just to reassure you that although we are skipping, we have the full brief of evidence and
28 have read it already.
- 29 **A.** Yes, okay.
- 30 **Q.** So, we're not missing everything, except your dulcet tones.
- 31 **QUESTIONING BY MS THOMAS CONTINUED:** Depending how we go with the next part of
32 your evidence; I may well come back to another person's story as well.
- 33 **A.** Here's the curse of anonymising, they're not just "B" and "D", they've become page

- 1 numbers. Sorry, I'm struggling to with-- my alphabet. So, page 10?
- 2 **Q.** Bottom of page 10 on your version.
- 3 **A.** Sure.
- 4 **Q.** Okay. So, I'm going to ask you some questions about B who lived at Palm Grove villa.
- 5 **A.** Yes.
- 6 **Q.** Now, is this one of the villas that was also a locked villa?
- 7 **A.** Yeah, yes.
- 8 **Q.** Can I just ask you to describe to the Commissioners what does that mean, what is a locked
9 villa?
- 10 **A.** So, I think from memory there were four locked villas at Kimberley, so one was a women's
11 locked villa and the other three were, were set aside for men. A locked villa means that
12 even your egress from the building required you to ask permission of a staff person simply
13 to get out, yeah. Yeah, so these lives were highly routine and highly policed, yeah.
- 14 **Q.** Just can you describe for us visually what did this Palm villa look like?
- 15 **A.** Again, the ironies of an institution, my daughter Meg used to think I had the best job in the
16 world because once every month I'd catch an aeroplane and I'd go to Palm Grove. Palm
17 Grove was an abomination. I remember it as concrete, double locked doors, all of the
18 windows had glass mesh that meant even if you broke the window there was no escape, the
19 men in there were dishevelled- in a way that would not communicate to a mother any form
20 of love and care. Even in the lounge room, - even in the lounge there wasn't enough chairs
21 for the men to sit on. A good part of the windows were above eyesight. The television of
22 course was up high as well to save it from being ripped.
- 23 It was a place of real machismo. I was terrified of it and so were the people that
24 lived there. Palm Grove was used as a place of punishment for people who lived at
25 Kimberley.
- 26 **Q.** Do you have a particular memory about B, who was one of the people in this Palm Grove
27 villa, one day some staff asking you to come and see what he was doing when a trades
28 person was coming to enter the villa?
- 29 **A.** Yeah, sure, it actually isn't in my evidence, but whilst I was sitting doing, -waiting to do
30 one of the running record observations, one of the staff hurriedly called me over to come
31 and look at this, come and look at this. This tradie- was coming to do work inside of the
32 villa and what they were anticipating was the fact that B would rush them, he'd been kind
33 of socialised into this kind of unpredictable violence, and so exactly what they foretold

1 happened. He did, he rushed them and wheeled away laughing, much to the amusement of
2 the staff that were there.

3 **Q.** So, the staff had asked you to witness this, and they were amused by this?

4 **A.** Yes, yeah, it's,-- they saw it as part of the law, or yeah, it was just the culture of the place.

5 **Q.** You wrote a sentence and, Paul, I'm just at the very top of page 11 of your amended brief
6 here, you wrote a sentence in the Kimberley report that says, "A pervasive acceptance of
7 the reality that many residents had entered Kimberley speaking but would leave silent
8 represented a quiet but distressing everyday denial of personhood".

9 Can you tell us why you wrote that sentence in the report?

10 **A.** It's reflecting back conversations that I had with some of B's staff, and in particular when
11 I talked to his mum, she said that when B first went into Kimberley, he spoke but when he
12 came out, he didn't.

13 **Q.** What did B's mum tell you about B's life before he entered Kimberley?

14 **A.** So, I never really got a sense of it in the way that I could with others, but what she did say
15 to me was that he used to drive their tractor on the farm, that they'd weight down the
16 accelerator pedal, and they would throw hay bales off the back while B stared, yeah.

17 **Q.** What did you think about this change in B, the fact that he entered Kimberley able to drive
18 a tractor and speaking, but then he left Kimberley silent, and his behaviour had changed
19 significantly, what did you think about that?

20 **A.** It naturally struck me as a great injustice that the boy that entered Kimberley speaking and
21 could steer a tractor would ultimately live beyond the kind of intimate and ordinary
22 relationships out of State care. So, as I was saying, in addition to not being able to speak,
23 his proclivity for rushing people and frightening them and tearing off their glasses meant
24 that he was effectively estranged from relationships when he came out.

25 **Q.** What were your thoughts about the fact that B lost his language and no longer spoke?

26 **A.** I can't imagine the deprivations that would lead you to think that your language, - you had
27 no use for language. Actually, I- think you probably know the statistics better than I do,
28 Ruth, but we did have a look at a communication, so as part of the running records you
29 recorded when people were spoken to. People were seldom spoken to at Kimberley. The
30 average length of a conversation,-- they never,- most, the uncontrollable women spoke to
31 each other, but almost nobody else. And so, when we looked at the communication
32 events,- you'll-- know the number.

33 **Q.** I think,-- was it 63%?

- 1 A. 63% of conversations never lasted longer than two minutes. Moreover, they were almost
2 always initiated by staff and all of the, -- and most of the communicative intent was
3 instructive. There was never any invitation to deeper dialogue or something that would
4 lead you to a deeper knowing of somebody's personhood. Yeah, these were silent places.
- 5 **Q.** Further in relation to B, at the time that you were getting to know him at Palm Grove, what
6 was on the news that you considered to be relevant to the living situation that B was in and
7 any other people in this locked villa?
- 8 A. So Epuni old boy Arthur Taylor had just taken a case against Corrections, because of the
9 inhumane conditions that prisoners were experiencing. I think from memory it related to
10 either not being able to get outside to exercise enough or some of the facilities that were
11 missing in his cell. And like most of the cases that Arthur Taylor took, he won, and yet at
12 the same time I was sitting in Palm Grove with men who had nothing to do, who had done
13 nothing wrong other than to be born with a learning disability. These were men who spent,
14 in the case of Palm Grove, 90% of their time sitting in a room without windows and
15 without enough furniture. These were men whose liberty had already been taken from
16 them.
- 17 **Q.** Paul, if it's all right with you and bearing in mind that I can reassure you t he
18 Commissioners have read everything in your statement --
- 19 A. It's okay.
- 20 **Q.** - we might move now to page 12 and go through some of your concluding remarks.
21 So,- this is paragraphs 3.1 onwards in the statement.
- 22 A. Yeah, sure.
- 23 **Q.** What were the main conclusions that you had drawn from the Kimberley research?
- 24 A. So perhaps not surprisingly we found the kind of quality-of-life indicators or the kind of
25 battery of measures that we took in evidenced an improvement in people's life quality, but
26 what surprised us was that the single most important predictor was how close people had
27 moved to their welfare guardian.
- 28 It's important to say about that perhaps. In a way I'm kind of aware I'm dribbling
29 away time, but the people who lived at Kimberley, there was a decision by the State to give
30 blanket welfare guardianship and so rather than getting to know people and askin g them
31 and coming to an understanding of what they might like in terms of this critical juncture in
32 their lives, they were made by people some of whom had been estranged from their son and
33 daughter for decades, yeah.

1 **Q.** So, in terms of the factors that you observed that explained differences between how some
2 people's adaptive behaviours improved, and others did not, what was the surprise in terms
3 of your research there?

4 **A.** So, it's important to say, firstly, that across all of the indicators on the adaptive behaviour
5 scale that the men and women at Kimberley performed so much more poorly against their
6 normalised peers, the other people with learning disability in the community across all of
7 those competencies. Jeppers. And so, when they moved into homes the kind of adaptive
8 behaviour began to flourish because it was so much more easy for them to demonstrate
9 latent competence or for staff to recognise and build upon skills and capacity.

10 So, this was a finding that we kind of expected to happen, but what we didn't anticipate,
11 when most people kind of modelled or looked for these kinds of changes, they would
12 always look for elements of service provision or they would look for the personal attributes
13 of the person. But what we found almost by incidentally-, we put the distance that
14 somebody had moved, the geographic distance somebody had moved to their relative and
15 what the nature of the relative was, and the variables that explained almost all of - the
16 variations in these improvements was how close you moved to your family member and
17 whether that family member was your mum or dad.

18 **Q.** What did these findings mean in terms of support services design? So --

19 **A.** No, no, that's fine, I'm okay, I'm with you.

20 **Q.** -- I'm on page 13 now.

21 **A.** Yeah, okay. Two things. In the first place they will often get in the habit of distancing
22 family and that was the experience at Kimberley. Maybe we'll have time to talk about that
23 in a second, maybe not. But the worry is that services don't think deeply enough about how
24 to proximate the attributes of familial care, families can remain on the edges of service
25 delivery, but also, we don't work hard enough to find people who can carry into the
26 relationships a family's love and aspiration. Kaupapa Māori services get a lot better, but
27 yeah.

28 **Q.** Right. And in your statement at para 3.6 you've said that the staff at Kimberley, that "They
29 did love the residents for sure, but in their own institutional way, where the horizons of care
30 barely crept off the floor of Maslow's hierarchy"?

31 **A.** Yeah.

32 **Q.** I'm actually just going to ask for a diagram of Maslow's hierarchy to be put up on the
33 screen for you to explain what you mean by this.

1 Just so everyone is able to understand what we've put up on the screen there, it's a
2 triangle with five levels and, Paul, if you're happy to, would you mind reading out the
3 words that we can see on those five levels, possibly starting at the bottom moving upwards?

4 **A.** Sure, I'm not a psychologist, I'm somewhat a little out of my depth. However, the thing to
5 know about Maslow's hierarchy of needs, it had origins in, I think, Piaget's stage theory.
6 So, the way that it works is in order to progress up, in terms of the kind of complete
7 composite of needs, you need to have lower order needs satisfied in order to progress to
8 higher needs. And so, the most basic of all human needs are physical, are physiological
9 needs that we're fed and watered and that we're warm and we have a place -to a-- roof over
10 our head, and then --

11 **Q.** So, are they on the bottom level?

12 **A.** Yeah.

13 **Q.** Level 1 of this triangle?

14 **A.** Yeah. So moving upwards, once satisfied, people need their safety needs met in terms of
15 security and safety; and moving up are needs for a sense of belonging and love and
16 intimacy in relationships; and beyond that are esteem needs, the kind of prestige and the
17 things that we wish to communicate, you know, kind of the things that we want to
18 communicate about ourselves and then self-actualising, I'm not sure what that means,
19 I haven't made it that far yet.

20 So that's Maslow's hierarchy of needs. In the report we wrote that people loved
21 people- love people in the sense they would bring bottles with caps to pop, and they would
22 surrender their pen in order that somebody could ink in a page. So,- they saw them in that
23 respect, but,-- and their instrumental care I think probably you could say was exemplary,
24 but they fell at the very next hurdle in terms of meeting people's safety needs. People
25 weren't always safe at Kimberley.

26 **Q.** Right. So institutional life may have met the basic needs at level 1, food, water, warmth,
27 rest, but never really progressed above to the next level that it's essential to get through to
28 be able to,-- so you need security and safety before you can get to level 3, which is that
29 sense of relationship and belonging?

30 **A.** On a good day nothing happened, Ruth.

31 **Q.** And in terms of what you know about contemporary care settings, where would you say
32 they're at on this level?

33 **A.** That's the thing about models, they never capture life exactly, do they? I mean do- you

1 mean in our current -community-based- services?

2 **Q.** In our current community based.

3 **A.** Every now and again we'll fail at the most instrumental of services, we don't actually know
4 how often, just because we haven't got surveillance in any way adequate. I think you could
5 say that on the whole people's physiological needs are well met, community group homes
6 are safer but not always safer.

7 But in terms of progressing much further up the ladder, the kind of evidence is quite
8 damning. So, beyond family and staff, services still struggle to realise the importance of
9 supporting people into relationships of where-- their needs for belonging and where their
10 needs for love and intimacy can be met. So, I would say we fall at the second hurdle.

11 **Q.** Thank you. If we can take that diagram down now.

12 Just before I come to your very final concluding remarks, just another question
13 about the research work when you did attend to visit the people who had been resettled 12
14 months later. This is at the bottom of your page 13. What did you observe about the
15 residents 12 months later, because you've said previously that things flourished straight out
16 of Kimberley, was that maintained?

17 **A.** So, no. So, what we saw 12 months later was there was still a small increase in adaptive
18 behaviour gain and the rest of it, but pretty much it had stalled, it had stopped, it had
19 plateaued. Once we found it, we went looking, and other people had found a similar level
20 of plateauing. One explanation for it is because people had kind of slipped into patterns
21 where it was no longer possible to,-- for them to demonstrate or staff to continue to build on
22 evolving competence and all the rest of it. But there are two other possible explanations
23 that are more relationally bound.

24 The first is that when we went back families had already begun to report that they
25 felt marginalised, increasingly marginalised. They'd made this one important decision in
26 people's lives and --

27 **CHAIR:** Don't feel as though there's a race to the clock, we will listen to you, please feel, -- take
28 your time. You don't have to rush.

29 **A.** Okay.

30 **QUESTIONING BY MS THOMAS CONTINUED:** If you could take us through those two
31 other main factors.

32 **A.** Sure. Remember I said before that the thing that surprised us was how close you were to a
33 family member and the way that we began to theorise that was that people came within the

1 ambit of their, particularly their parents' love and aspiration. And so, what had happened
2 with the marginalised family, they reported to us that they had to manage their presence in
3 a way that, - they were managing the perception that somehow, they were intruding on what
4 was now -service led- care, yeah.

5 **Q.** Right.

6 **A.** And so, the effect of that was to kind of weaken their kind of access to familial love and
7 aspiration. And also, perhaps monitoring. You know, the fact that people coming into
8 these settings could monitor and hold services to account.

9 But the other reason had to do with a change that we saw in the disposition of staff.
10 So, when people first moved out of the institutions, the people who moved and the people
11 who met them in services met as strangers, and the kind of Kaupapa of that meeting was
12 that the relationship seemed to be enveloped by this Kaupapa of discovery. It was hugely
13 rewarding to staff to begin to see people, they were hugely excited by seeing the way that
14 they could restore their personhood. But when we came back 12 years later --

15 **Q.** 12 months later?

16 **A.** Sorry, 12 months. What did I say, 12 weeks?

17 **Q.** 12 years.

18 **A.** 12 years we-- need to.

19 **Q.** Yeah.

20 **A.** There was this almost antithetical care. People, - this ethic of discovery had been replaced
21 by an almost antithetical ethic of knowing people. So, knowing, predicting, managing. So,
22 residents had -reacculturated- to their role of the kind of passive recipients of knowing care
23 that was moderated by their staff. This, I think it's an under -explored attribute of the
24 impact of those two conflicting ethics of relational ethics, yeah.

25 **Q.** Paul, on page 15, your page 15 of your statement, at the top there, I'd like to ask you what
26 do New Zealanders who have been listening to your evidence today need to do or ask
27 themselves, in your opinion?

28 **A.** Jeez, we've missed a bit, haven't we? Gosh, without being flippant, I think the challenge
29 for all New Zealanders is, as I've stated before, to decide whether all of those deprivations
30 and displacements that survivors experience would be normally defensible for anybody else
31 that carried that name, but more than that. If it's not, why might we ever have thought so.

32 **Q.** What do you think the State needs to do or reflect on as a result of listening to all the
33 evidence from yourself and the other evidence that's coming through this Royal

1 Commission?

2 A. I might drift towards eyes down because it's important to get it right.

3 Q. Absolutely.

4 A. I love the Kaupapa of the Commission. I think it's,- and in particular its- ethic of fulfilling
5 the promise of restoring people to their full personhood. And I think it's to be particularly
6 applauded for the fact that it's not just for those who endured institutions, it's for all those
7 who continue to live in the long shadow of that set of beliefs that originally led to their
8 construction.

9 So, we know, for example, that many people with learning disabilities continue to
10 live in services and their lives almost entirely unfold in services, this time with the social
11 construction of consumer or service user or client, rather than patient. But as a
12 consequence, in terms of,-- we were just talking about Maslow's hierarchy of needs, they
13 can become equally displaced from community relationships that transcend mere knowing.

14 So, the real dangers of an institution are twofold. In the first place they normalise
15 othering, something different than the other, and then the second is at the same time they
16 put people, as Sir Robert Martin so accurately said, beyond sight.

17 And so, for me the State needs to consider whether the instruments that it uses to
18 determine whether the human rights of those who are most at risk and in their care are
19 sufficient to put people and their lives into plain and self-authored sight. We only need to
20 step outside this door and talk to Catherine to realise that Catherine with her cloth
21 swaddling sculptures that if you've experienced abuse and that you're met with, at best,
22 silence but, at worst, punishment, you keep your secrets, and that the prerequisites to
23 disclosure that might keep you and definitely the people that live beyond you safe is trust.

24 And so to this very day, we audit services, rather than come to a clear understanding
25 of how people live and how they experience their lives, as they look for us the way that as I
26 was afforded the opportunity looking into [GRO-B]'s eyes as he looked back trying to see
27 me, and so in this respect the Code of Health and Disability Rights and its models of
28 retrospective advocacy are almost completely useless to people with learning disability.

29 It would be difficult for them in the first place to even find their way, equally
30 difficult for them to see how a code of abstract rights might find expression in the
31 complexities of their lives, and certainly next to impossible for them to have the vocabulary
32 and to be able to communicate with any understanding how the culture of the places where
33 they are often still required to live in spite of Article 19 or have their vocational support, it's

1 impossible to make them transparent without those relationships of trust.

2 And, finally, I think rather than a single apology, I think we all need to own our
3 eugenic history and its impact by placing R and D and B, and all the alphabet we never got
4 to, not just that, the accumulated weight of all the stories that are going to be exposed
5 through the Commission's work in full sight of tomorrow's generation.

6 Having a sense of moral outrage that I described at the start is a prerequisite to, if
7 we're not going to build alternative versions of Kimberley, the first step is that we acquire a
8 sense of moral outrage about what happened. But it's insufficient by its own. We actually
9 need a sense of complicity, the same kind of complicity that I experienced when I went and
10 visited the women in the villa that I first went to and I had the sun on my back and I knew
11 all the personalities in the room, and I could predict what was happening and I noticed that
12 I'd stopped being outraged. Or the kind of complicity that we never got to, -- I forget his
13 alphabet attribute, but the man who I thought had locked in syndrome who completely
14 destabilised me on the last day of being there by shooting me a look that said,
15 "You- absolute arsehole, you've seen,-- I've revealed something of myself, and you just
16 walked away." That is the habit of institutional care, and it ought not to be a habit, the
17 knowing but walking away. Yeah.

18 **Q.** Thank you so much, Paul.

19 **A.** It's a pleasure.

20 **Q.** Thank you. If you could just remain there and I'll see,-- the Commissioners may well have
21 some questions for you.

22 **COMMISSIONER GIBSON:** Thanks, Paul. Commissioner Shaw, would you like to ask any
23 questions?

24 **CHAIR:** No, I wouldn't even start to try and ask you some more questions, Paul. Just know that I
25 have read carefully, listened carefully and will be watching, I also want to read that report
26 of yours, so thank you very much.

27 **COMMISSIONER GIBSON:** Commissioner Steenson.

28 **COMMISSIONER STEENSON:** Yes, I have a question. Tēnā koe, thank you for your
29 statement today. So just a clarification firstly. You're saying that your research found that
30 there was a correlation between whānau connection and flourishing competence, and you
31 briefly said that kaupapa Māori gets that very well and actually yes, mātauranga Māori has
32 always known that whānau centric improves.

33 **A.** Yeah.

- 1 **Q.** It was interesting that you showed the Maslow's, talked about the Maslow's needs. Would
 2 you say that the basic level, the physiological level, that the institutions were pretty much
 3 just focused on that bottom scale, providing that bottom scale?
- 4 **A.** I think the people that lived there got there because of a biomedical understanding of their
 5 personhood, that was the reason why they ended up in Kimberley, and I think the institution
 6 responded to that biomedical construction. And so instrumental care in terms of, well, it
 7 was always it-- was never so-- an institution beats to the rhythm of its own historical pattern
 8 and so it would have had systems in place to monitor and, - and- so those instrumental- care
 9 would have been built into that, do you know what I mean? So,- people would have been
 10 changed at appointed times, showered at appointed times, and medicated at appointed
 11 times, and there was a degree of, I think, surveillance about people's physiological needs in
 12 the institution.
- 13 **Q.** Yeah, we've heard from other witnesses that there is a need for consistency with the care.
- 14 **A.** Yeah.
- 15 **Q.** But there's clearly a fine line between what becomes regulation versus consistency, I think.
- 16 **A.** Yeah, yeah. It was most obvious, I mean, the nicest villas to be in were what they called
 17 the multis villa. They were multis, because people had multiple conditions. So, they were
 18 the nicest places to be because people understood their role as, they kind of interpreted their
 19 role as being attendant care whereas it gets more complicated.
- 20 When you think about somebody's personhood rising up that scale of Maslow's
 21 hierarchy of needs, you have to meet a whole lot more than their instrumental care. And so,
 22 in those villas, people, I think it would be fair to say, would be reasonably well looked to.
- 23 But I don't know. It was such a broad scope to our study; it was difficult to drill
 24 down into any one aspect of care.
- 25 **Q.** Okay. So, I guess I'd like to understand whether or not you'd agree that your research
 26 supports somewhat that a whānaucentric model, I'm not sure if you're familiar with Māori
 27 models of care, would improve from that kind of foundation thinking.
- 28 **A.** So, it's not unique to Te Ao Māori, so other cultures as well, so in Italy the model of care is
 29 familial as well.
- 30 **Q.** But for New Zealand, I'm talking about, Aotearoa.
- 31 **A.** Yeah, for New Zealand, yeah, yeah, no. I think being poorest anyone, it always confuses
 32 me why services kind of, to me, have a sense that they have to meet all people's needs by
 33 themselves rather than inviting the community in. The best place to begin with is family.

1 You know, it won't always be the case, but I think they are much safer repositories of
2 someone's care and,-- yeah.

3 **Q.** Okay, thank you very much, tēnā koe.

4 **A.** It's okay.

5 **COMMISSIONER GIBSON:** Thank you, Paul, a few questions from me. First, this happened
6 recently, this century you're talking about, we're not talking about back in the earlier days
7 of institutionalisation. And thinking about, you talked about the long shadow of
8 institutionalisation of eugenics and that ecological model. How do we change not just the
9 direct service, that support environment, but that background shadow of ableism, of the
10 attitudes that provide the basis for care as we still know it today?

11 **A.** We were talking before coming in about how the New Zealand Government is about to
12 introduce into the school curriculum, Paul, introduce to tomorrow's generation to the impact
13 of colonisation on Māori, and the parallels between Māori and people with learning
14 disability are somewhat striking, they were othered in similar ways and the difference for
15 people with learning disability, Paul, is that they were colonised by the medical profession
16 and the biomedical understandings of learning disability, that was their form of othering.
17 And I don't know the answer to you, Paul, but I do think that, you know, if the minds of our
18 next generation are introduced to the injustices that are so clearly obvious might be a really
19 good place to start.

20 **Q.** The histories of Kimberley and Cherry Farm should be taught in Levin and Dunedin and --

21 **A.** It's history, how this came to be, how a century's worth of institutionalised came to be, what
22 were the beliefs that understood it, and do they would- -they do-- they stand the scrutiny or
23 the light of a human rights focus.

24 **Q.** Another question. You talked at the time, in the early 2000s, about the two models
25 institutional versus the group home and we've briefly touched on how things have evolved,
26 the family role, person-centred planning, where do you see support, how it connects with
27 family in the future?

28 **A.** If it's jeepers-- So, I've stopped being I'm- the failed retiree, Paul. So, I worry a little
29 about families in terms -of I-- think enabling good lives is inherently safer by trying to
30 invert the professional gift model of support by empowering people and their families to
31 make important decisions about their lives. I worry about the load on families if that's what
32 you if-- that's where you're going, Paul.

33 The thing,-- gosh. When we looked at what precipitated the decision of families to

1 surrender their children to State care, one of the legacies of the Aitken Report was that
 2 there was no available support for families, and so the path to the institution always had a
 3 predictable trajectory. The only thing that was offered was respite care and the only place
 4 to get it was the institution.

5 And so, people had no alternative but to seek care from those places that didn't have
 6 the same kind of social knowing that they shared of their sons or daughters. Gosh, I'm
 7 drifting away.

8 I do worry about the need to throw support not just around a person but around the
 9 people who care for people. In answer to your question, I think of the rhizome, I think of
 10 we- say it takes a community to raise a child, and yet the lives of people with learning
 11 disability are so insulated from all of the other places that they might more legitimately
 12 receive support or, you know, satisfy all of the rungs of Maslow's hierarchy. They still kind
 13 of live quite-,- many just live quite siloed lives. Yeah. So, - it's a waste. You know, like
 14 drawing on the connectivity of family and, -- jeepers, the kind of liminal or in between
 15 spaces or the communities that connect, the infinite number of communities th at each
 16 connect, they still are so, I think, so, -- we don't find them in those places.

17 **Q.** Can I also ask, you went further than most people to actually deeply connect to people who
 18 otherwise had little connection. What is the role, what is the priority for communication in
 19 that sense? What should this Inquiry be learning and thinking about communication?

20 **A.** In terms of how to communicate? The cruel irony is those people who's, I -- always
 21 remember Byron's paradox, Paul. The people whose stories that we most need to learn
 22 from or hear are always those that are most difficult to access. It's having a real
 23 commitment to understanding that our real change agents in New Zealand are those people
 24 who most depend on others in terms of the realisation of their human rights, right?

25 So, it's a real, -- some of it comes from the wasted time, Paul, you know, the time
 26 and having a genuine commitment to people's, -- we still don't do alternative and assisted
 27 communication well in service settings, you know, staff aren't orientated to it.

28 I don't know, Paul. Yeah.

29 **Q.** You are sharing more you know so much and guiding us. One final question, I'm not quite
 30 quoting you right but it's almost like a question other than for the disability is this morally
 31 defensible, is this service setup morally defensible, would I want to be living in these
 32 places? Do you think people designing services, people working in Government
 33 departments are asking those questions and are, is the community capable of asking those

1 questions of itself? Are what we doing to people in care at the moment, is it morally
2 defensible, would we want to be there ourselves?

3 A. The short answer is no, isn't it, you know? Jeepers. In the same way that I was talking
4 about the man who carried, you know, the man who carried my name into the back of the
5 van couldn't be more distanced from my life, but the impact of that, -- just that one poem,
6 you know, like beginning by, - jeepers. So, I am doing some work with survivors, - and
7 I deliberately introduce them to my son, Levi, and I do that because that's a shortcut to
8 crystallising whether it would be in any way acceptable for these young people to, -- for me
9 to place my son and the richness and diversity of his life into one of those care settings.
10 Yeah.

11 Q. It's left to me to thank you, Paul, and can I thank you for teaching me now and for teaching
12 me over the years in the various reports and conversations we've had, which have been a
13 large part of leading to this Inquiry, and to thinking back to those who have taught you
14 inside Kimberley, inside Cherry Farm and other places, we owe them a debt as well, thank
15 you so much.

16 A. Pleasure, thank you.

17 **COMMISSIONER GIBSON:** It's now lunchtime. Just checking on a time to return. We're
18 scheduled for 2.15 or is that --

19 **MS THOMAS:** If that is possible -is- 2.15 suitable? We'll come back at 2.15.

20 **COMMISSIONER GIBSON:** Thank you.

21 **Lunch adjournment from 1.21 pm to 2.13 pm**