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

	TRANSCRIPT OF PROCEEDINGS
Date:	20 July 2022
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
Under	The Inquiries Act 2013

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DR BRIGIT MIRFIN-VEITCH

Questioning by Ms Thomas Questioning by Commissioners

CLOSING STATEMENT BY THE ROYAL COMMISSION

CLOSING STATEMENT BY CITIZENS FOR HUMAN RIGHTS

CLOSING STATEMENT BY THE CROWN

1		Hearing opens with waiata Whakataka Te Hau and karakia by Ngāti Whātua Ōrākei
2		
3		Lunch adjournment from 12.54 pm to 1.56 pm
4	COM	MISSIONER GIBSON: Thank you everybody. Ms Thomas.
5	MS T	THOMAS: Thank you, Commissioner Gibson. Our final witness for this public hearing is
6		Dr Brigit Mirfin-Veitch and just before we start her statement if you could do the
7		affirmation.
8		DR BRIGIT MIRFIN-VEITCH (Affirmed)
9	QUE	STIONING BY MS THOMAS: So Brigit, can you please introduce yourself to us all and
10		tell us a bit about your qualifications.
11	A.	Tēnā koutou katoa, ko Brigit Mirfin-Veitch ahau. My name is Brigit Mirfin-Veitch, I'm the
12		director of the Donald Beasley Institute, the DBI, an independent research institute
13		specialising in disability research.
14		I'm a sociologist and have been working as a disability researcher since 1994. I
15		have a part-time role as a research associate professor with the University of Otago,
16		Christchurch, and I provided expert evidence as part of the contextual hearings at the
17		beginning of the Commission.
18		I think the other important thing to say is that I contribute to the Commission in
19		other ways, mostly through reference group involvement.
20	Q.	Thank you. And as we go through your evidence today, which is very important evidence,
21		we do need to speak slowly and take our time for the interpreters
22	A.	Sure.
23	Q.	to cover everything that you have to say. Can you tell us a little bit more about the
24		Donald Beasley Institute and what it is?
25	A.	Yes, the Donald Beasley Institute is an independent charitable trust. We have been on the
26		disability landscape and the wider disability sector providing disability research for
27		approximately, or nearly four decades. I have had the great privilege to work with the
28		institute for three of those nearly four decades and over the past 30 years the DBI has
29		witnessed both the closure of institutions and the evolution of the community-based support
30		system.
31	Q.	And has the DBI had quite an active role in research around the deinstitutionalisation
32		process?
33	A.	Yes, we have.

- 1 Q. Last week we heard from a witness Paul Milner who was involved working with the DBI during the Kimberley Project on deinstitutionalisation. Has the DBI done any other work in that area?
- 4 A. Yes, I think it's important to say that all of our work over the time that we've been in
 5 existence has prioritised lived experience and inclusive rights-based disability research.
 6 We seek to do research that challenges or has the potential to challenge and change the

system, the systems, and to make a difference in disabled people's lives.

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That work has included exploring processes used to move disabled people out of institutions, and documenting what life was like before and after they lived in those settings, and just like the work that Paul described last week around Kimberley.

- Has the DBI also been part of the call for the establishment of this Royal Commission that we're in today?
- 13 A. Yes, in 2017 we undertook a literature review-based project about the experiences of
 14 disabled children and adults in State care. Those research findings led us to title the report
 15 "Institutions are Places of Abuse" because of the prevalence of abuse that we found in
 16 publicly available documents that tell stories of institutional care.
- 17 **Q.** So, on the basis of the research that the DBI had undertaken, did you conclude that there was an absolute need for this Royal Commission of Inquiry?
- Yes, it would be very fair to say that on the basis of all of the research that we have done over the past 30 years, we held the view that a Royal Commission of Inquiry into Abuse in Care was long overdue.
- The focus of your evidence today that we're going to come on to is a research project that the DBI has just recently completed, the Tell Me About You project. Can you tell us how this project has come about?
- 25 A. Yes. The Tell Me About You project was designed to make sure that people with learning
 26 disabilities and people who identify as neurodiverse had the same opportunity to share their
 27 experiences about State and faith-based care as other survivors. We really wanted to make
 28 sure that their voices were heard in this Commission.
- Q. So, did you and your research colleagues work in alternative ways to engage with disabled survivors and people with learning disability and people who are neurodiverse?
- A. Yes, we did. Fundamentally we drew on our long history of inclusive narrative-based research to craft a sort of unique approach that had the potential to engage with people with learning disabilities, people who are neurodiverse in a way that enabled them to tell their own stories in their own way and we partnered with other people to achieve that goal.

- I know you would like to make some acknowledgments before we get underway in the depth of the report. Would you like to make those now?
- A. Yes. At this point it's important to acknowledge my co-researchers and colleagues on the project, so Kelly Tikao, Hilary Stace, Umi Asaka, Eden Tuisaula, Robbie Francis Watene, and Patsie Frawley, most of whom are here today. While I'm the spokesperson today, it
- was definitely a collective effort of disabled and nondisabled researchers.
- 7 Q. Would you also like to acknowledge and name the members of Te Kahui Arataki?
- A. Yes, I would. I would like to name the members of Te Kahui Arataki, our Māori
 governance group whose wisdom and experience both guided and supported our mahi, so
 ngā mihi nui ki a koe Huhana Hickey, Gary Williams, Bernadette Jones, Kirsten Smiler,
 Tania Thomas, Kerri Cleaver, Matthew Whiting, and Tuari Potiki, all of you people
 constructively pushed and challenged us to get things right for tāngata whaikaha and we
- 14 **Q.** What were some of the important aspects of the research design?
- One of the most important aspects of the research design and I think the thing that the
 Commission was interested in in us doing the work was our use of individually responsive
 methods, what we refer to as IRM.
- Q. Can you tell us what is IRM, what does that mean?

learned a lot.

- 19 A. IRM was developed by researchers from the DBI and our colleagues as a way of including 20 the voices of all disabled people in research.
- So, often, researchers are committed to values of inclusive research, but-- don't offer a range of methods that might make research more accessible to disabled people.
- Q. So how is the IRM, or the individually responsive method, different from the more traditional approach of research?
- A. Instead of offering one pre-determined way of taking part, IRM offers people lots of different ways to participate in research about a particular topic.
- 27 **Q.** And did the people that engaged in this research project take up that opportunity to engage in these different ways?
- Yeah, they certainly did. In our project people could choose from a list of different methods to tell their story. So, they could choose Kaupapa Māori methods, they could choose to just sit and talk, they could choose walking methods, so being on site at the place, the former institution or care setting, they could bring or use personal archives, things that were important to them or told something about them in their lives. They could use art-

- based approaches. They could tell their story with the help of a trusted person. They could tell their story online or using assisted technology as we saw with Lusi yesterday.
- 3 Q. And was this IRM approach also aligned with the trauma informed approach?
- 4 A. Yes, it was. So IRM is aligned with trauma, the trauma informed values of safety,
- trustworthiness, choice, collaboration, empowerment, but most importantly requires us as story gatherers to build relationships of trust.
- 7 **Q.** Throughout the life stories in your report, you've used the term "storytellers" rather than the term "survivors". Can you talk to us about that?
- Yes, first of all we want to make it very clear that we deeply respect the kaupapa of the
 term "survivor" and "support" that's used in relation to the Royal Commission, and you'll
 hear me use it later. However, we were also aware that some of the people who might want
 to take part and who would eventually choose to take part in the research would tell stories
 of abuse in care, --and they would not necessarily recognise the actions towards them as
 abusive, nor use the term "survivor" to describe themselves.
- So, your research team used the term "storyteller" and in terms of the research team going out to work with all these individuals, were they all called "the story gatherers" effectively?
- 17 A. Yes, yeah, so "storyteller" is a term that DBI has used in previous narrative inclusive
 18 research with people with learning disabilities and our research team were referred to as
 19 "story gatherers" to indicate that the story tellers had the power, and we were simply there
 20 to help them put the story together.
- Q. And given the sensitivity of the topic and what was being discussed throughout this research, how did the team make sure that all of this research was safe?
- A. First of all, I'd like to say that as a research institute that specialised in disability research and particularly learning disability research for a very long time, we're 100% committed to disabled people being able to freely participate in research and to be presumed to have the competence to do. But we're also very committed to ethics and so before the research got started, our project was assessed by no less than two ethics committees, one the Research and Ethics Advisory Panel within the Royal Commission, and by the Health and Disability Ethics Committee, New Zealand's national Ethics Committee.
 - **Q.** And what about informed consent?

A. We were also really committed to as many people as possible being able to take a part in the research, even if they were people who others might have thought didn't have the ability to give informed consent. So we made sure that we were as inclusive as possible by taking a supported decision-making approach to informed consent and working very carefully at

1	each stage of the process to make sure people were very aware of what was going to
2	happen if they took part in the research, particularly what would happen to their story.

- So the life stories in this research report, the Tell Me About You report, is it correct, or accurate to say the heart of this report are the life stories?
- 5 A. Yes.

Q.

A.

- 6 Q. Can you tell us a little bit about, yeah, that heart of your report, the life stories?
- A. So I'm conscious today that we're not going to do justice to those stories, we are probably going to focus on parts of people's stories, so I do want to stress that yes, those stories are the heart of our work, there are 16 stories, they are highly individual and personal stories, and they make up the bulk of this report. It will be available very soon.

We also wanted- Te- Kahui Arataki, our Māori governance group for the project and our research team view these stories as precious taonga or gifts. So this report and my evidence today is dedicated to all the storytellers who had the courage to share intimate details about their lives before, during and after being in care. Their resilience and their continuing resistance is remarkable. And it's also dedicated to disabled people across Aotearoa who have never had the opportunity to tell their own stories about their experiences in care.

I said that the last time I gave evidence and I think the statement is still correct, we haven't got to everyone yet.

Thank you. I can just reiterate, having read all of those 16 life stories, they are essential reading and just such an important part of this work. We will today in your evidence be asking you to call on those stories as we take you through the rest of the report, primarily the findings and the discussion parts.

In terms of the findings taken from these life stories in the research, you and your research colleagues have applied the ecological model of disability violence and abuse as a framework to analyse the life stories. Can you tell us what do you mean by this ecological model of abuse?

A challenging question and there's probably a better expert in the room than me right now. But yes, we did apply an ecological model of disability abuse and violence. And to try and explain simply the ecological model of disability violence and abuse provides a framework for exploring and for understanding the factors that impact on disabled people, to create environments where violence and abuse is able to occur. And it encourages us to look at the way these different factors interrelate and influence each other.

- Q. So this ecological model of abuse, is this an international model for disability violence and abuse?
- 3 A. Yes, it is.
- 4 Q. So is this an appropriate model for Aotearoa New Zealand to be using to address disability violence and abuse?
- The ecological model has been used right around the world and so it's very highly valued 6 A. internationally. We think it has potential here and it's certainly provided a really useful 7 instructive lens for us to look collectively at the stories we collected as part of Tell Me 8 About You. But it's a reasonable question to ask, Ruth, and our team and some others, 9 other researchers have just been funded by the Health Research Council of New Zealand to 10 conduct a project about how we can develop an approach to violence prevention that is 11 founded or based on the Te Tiriti o Waitangi, but that is inclusive of the principles of the 12 ecological model. So we will be able to answer that question more fully in a couple of 13 years' time. 14
- 15 **Q.** So, it's a watch this space?
- 16 A. Mmm.

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Excellent. Over the past eight days at this public hearing survivors and former staff 17 Q. members have shared abuse that they've experienced in care, and some themes have just 18 consistently and repeatedly come out, and I'll just list a few: For example a lack of love, 19 separation from whānau, lack of understanding of what abuse is, environments and spaces 20 devoid of privacy, culture where staff may consider watching abuse as entertainment, 21 people have complained but not been believed, complaints may have been investigated but 22 not eventuated in any formal response, there's been a culture of fear among residents to 23 make a complaint for their own safety, and a culture of fear among staff to say something 24 25 for fear of their own jobs and personal safety.

So these themes and topics have come up repetitively. How does the ecological model of abuse help us all to consider those separate factors?

- A. Because it provides a way to explore the examples that you've given according to four separate but interrelated levels or areas that all have the potential to create the context or environments where the abuse that you've described is able to occur.
- 31 **Q.** So what are the four levels?
- 32 A. The four levels are individual, relational, community, and societal.
- 33 **Q.** So how does analysing disability violence and abuse across those four different levels help us in our work?

1	A.	I've sort of pondered this and the most straightforward way I can use to describe it is that
2		the ecological model gives us a framework that can help us to understand why abuse
3		occurs, what responses are needed to address it, and what strategies are likely to be most
4		effective for preventing violence and abuse from occurring in the future.

- Is there a common misconception about, inverted commas, disabled people and a causative factor of abuse or violence?
- 7 A. Yes.

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- 8 Q. Can you tell us what is that misconception?
- A. This is also something that I knew I'd be asked and have spent some time thinking about.

 But the misconception as I see it is that disabled people are inherently vulnerable and therefore disability abuse and violence is inevitable. So both aspects of that misconception to me are distressing and morally wrong.

The reason for that is that the first part places blame for the abuse on disabled-- on the disabled person, and the second part suggests that there is societal acceptance of disability violence and abuse and a complacency.

- O. Did one of the witnesses just yesterday speak to this?
- 17 A. Yes, Leeann left us with a very strong challenge at end of the day yesterday, at the end of
 18 her evidence, and I agree, I think turning the tide on the persistently high level of abuse
 19 experienced by disabled people will take the commitment of all New Zealanders as Leeann
 20 challenged us with, and that's because this abuse is grounded in the attitudes and
 21 assumptions that we all hold about disabled people.
- Q. What does the ecological model do to challenge that "vulnerable victim" label and misconception?
- A. That model offers us a way to challenge these assumptions that link disability identity and lived experience to being somehow inherently or automatically vulnerable to violence and abuse.
- 27 **Q.** How does it challenge this?
- A. It requires us, at the risk of sounding too much like a researcher, but it requires a really close and critical examination of how those assumptions interact or have interacted at the individual relational, community and societal level to create the environments where abuse is able to occur.
- Right. And so we're now going to go through some of those levels in a way that we can hopefully all gain some understanding from.
- 34 A. Hopefully.

- 1 Q. We'll start with the individual level of this model. How does the individual level challenge,
- what we've just discussed, this misconception that places blame for violence and abuse with
- 3 the victim of that abuse?
- 4 A. So I think it requires a little bit of background before I answer that question properly.
- 5 Q. Sure.
- 6 A. But some approaches to understanding and responding to violence and abuse, either
- 7 intentionally or unintentionally, place blame for violence and abuse with the victim. So in
- 8 other words, personal characteristics or individual characteristics of disabled people
- become the reasons why other people think the abuse has happened.
- 10 **Q.** Right, yes.
- 11 A. So in other words, reasons for abuse get put forward, like "disabled people don't know the
- difference between right and wrong", or "they are hypersexual" or "they don't feel emotion
- in the same way as non-disabled people", or "they can't give consent because they haven't
- got capacity." These are all things that are used to explain away abuse in many ways. And
- so that leads us to ways of responding to abuse that also put the responsibility for fixing the
- problem on the person.
- 17 Q. Right. So again, the assumption that a disabled person is more vulnerable to abuse because
- of their disability is completely wrong?
- 19 A. In my opinion, yes.
- Q. When the Donald Beasley Institute analysed the life stories in the Tell Me About You
- 21 project, what did the researchers find in relation to this individual vulnerability?
- 22 A. We found that the storytellers were not inherently vulnerable and did not inherently lack
- capacity, but while they were in care, they almost universally experienced a lack of agency,
- a lack of rights, will and preference, and a lack of recognition of their personhood.
- 25 **Q.** Right.
- A. And in our view, they experienced a lack of all of those things because other people
- assumed that they lacked competence because of their disability label or identity.
- Q. And then the report then goes on to consider each of those sub-themes under this individual
- 29 level?
- 30 A. Yes, it does.
- Q. So if we could just go through those themes now and start with the first one that you've
- mentioned which is lack of agency, and I'd like you just to simplify and tell us what is lack
- of agency, what does that mean?

- 1 A. In plain language "agency" simply means having choice and control over your own life, and
- those of us that are immersed in the disability world will hear those words frequently.
- 3 Shannon, who gave evidence yesterday, did a really excellent job of explaining agency
- 4 when he talked about his desire to determine the direction of his own life, and to make his
- own decisions about how to get where he wanted to get to.
- Right. When in institutions or care settings, what did the storytellers tell your colleagues
- about the agency that they did over their lives?
- 8 A. In bald terms people didn't have any control over their lives. The care settings they lived in
- 9 determined the course of each day and people had very little choice and control over any
- aspect of their daily lives, while they were in those settings.
- Q. Can you give us an example from one of the story tellers in your research, Graham P, after
- he got out of Cherry Farm?
- 13 A. Yes, Graham's example or what he talked about when he was talking about his person
- about his life now was when -- he said, "I like my room here, it's comfortable, I have my
- own things in my room, I have a TV set, I have more control and I can be myself, look after
- myself, I do my dusting, it makes me happy, I can relax in my room."
- 17 **Q.** Right.
- A. So these are seemingly very small pleasures and decisions that he's taking, but you can see
- 19 how highly valued they are when he'd had the experience of them being taken away.
- Q. Right. I'm sorry but I'm going to have to ask you to move maybe even the base of the
- 21 microphone even closer.
- 22 A. Sure.
- 23 **Q.** There we go. It's quite intrusive but it's right there, the microphone, thank you.
- 24 What did the storytellers say about their independence when they had come out of
- 25 the institutions?
- A. This was interesting as well. When people emerged from the care system for some
- storytellers at least they felt as though they had changed, so now they were able to do things
- for themselves. For example, one person said, "Living out of Templeton now has changed
- me. I go down to the supermarket, have coffee with friends, they make me coffee in my
- cup, and I go and sit by the table and drink it. I tell staff where I'm going. I can just say I'll
- 31 be back any time."
- 32 Q. So when you hear this evidence, what does it show you or how do you interpret those
- responses?

- A. We interpreted it that people didn't recognise that they were always --well, they always had the right, but that they were always capable of doing those things and it was the system that had prevented them from doing that.
- 4 **Q.** Is that possibly similar to the evidence we've heard last week from Allison Campbell when she spoke of Sir Robert Martin saying to her, "I'm becoming a person"?
- 6 A. Mmm.
- 7 **Q.** I think she said, "You've always been a person"?
- 8 A. Mmm
- 9 **Q.** The second sub-theme at this level, this individual level of factors is a lack of recognition of rights, will and preference?
- 11 A. Mmm-hmm.
- Q. Can you tell us before we get into that, what is meant by the term "will and preference"?
- 13 A. Yeah, I have to give a small lecture here. So, the terminology is really drawn from Article
 14 12 of the United Nations Convention on the Rights of Persons With Disabilities, so I think
 15 everyone will understand about rights. But in Article 12 it talks about supported decision
 16 making and decisions being based on a person's will and preference. So, a person's ability
 17 to make decisions that are of their own choosing and that are not imposed on them by what
 18 other people think is best for them.
- 19 **Q.** Right. Why did the storytellers that you've engaged with have a lack of will and preference in their lives?
- 21 A. The answer to that is the same answer as to why people didn't have agency.
- 22 **Q.** Right.
- A. So, from our perspective storytellers' experiences indicated they weren't seen as rights holders and related to that, they were assumed to lack the capacity to express their will and preference or to make their own decisions based on what they wanted, in other words.
- Q. Can you give us an example from one of the life stories in the report about a storyteller who was not given her right to express her will and preference in care?
- A. Yes, and, you know, Lusi who gave evidence so powerfully yesterday springs to mind here.

 Lusi is someone who requires access to communication devices and technology to be able
 to communicate without restriction. For her, she was critically compromised in this regard
 due to a lack of tools and strategies to support her communication when she lived at

 Kimberley and without those strategies and tools and devices, she was unable to express
 her will and preference easily and clearly to people.

- O. So obviously yesterday Lusi used an electronic device, but historically other communication tools have been available, but they weren't made available in Kimberley?
- 3 A. Shannon, giving his evidence yesterday, also demonstrated that to us too, how important communication is.
- So, by not being provided the tools and support needed to communicate her will and preference, how did this impact Lusi's life, what did she say in her life story about that?
- A. Well, Lusi, again, told us very, very clearly yesterday, and it's been reported around the nation today, that she felt invisible to the world when she didn't have access to communication, and the devices she needed. That ability to freely express herself was not possible while she was in care and therefore, she couldn't show herself to the world.
- 11 **Q.** What was another example in the research gathered of will and preference being ignored?
- A. As someone who's done a lot of family research in my past, one of the things that really stood out clearly to me was, in terms of will and preference being denied or ignored, was the universal experience of being disconnected from family or whānau. So, it didn't matter what was going on for people at home, they all wanted to stay there, and what we heard, and have heard right across the eight days of this hearing, is that that desire to be with family and whānau or stay with family and whānau was often ignored, disrespected or, in some cases, actively kind of broken.
- 19 **Q.** Is there an example in the life stories from Michael on this point?
- Yes, the example from Michael really shows his ambivalence; the absolute desire to see his family but the absolute pain when they left again. And so, he put his feelings into words in the following way: "Mum and dad came up and visited me but it was hard leaving, saying goodbye to them," and his will and preference would have simply been for him to stay with his family, but the system decided for him and his parents that he would be better off in care. And that was due to his disability.
- Q. We've also heard in the course of the last eight days, and it's relevant in the life stories in this research project, about loss of identity. Do you have an example from the research project that you'd like to share with us?
- Yes. I think loss of identity was central to all the stories, and really starkly illustrated in the case of Sarah and her brothers.
- Oculd you give us a brief overview. -I know her story is very detailed and thorough in the -report -but to summarise, to an extent, her story for us now?-
- 33 A. So, Sarah's story is traumatic and, in our view, could serve as a case study of systemic abuse. Her story painstakingly tracks her journey to find her brothers, one of whom she

didn't know existed until she was an adult. So, integrating her efforts to find her brothers with inaccessible, incomplete and dehumanising records held by the system about them was 2 the way that her story was crafted. And she discovers that the reason, or she discovered that the reason that she couldn't find one of her brothers was because he'd been living in that system for many, many years with another man's identity, and this had occurred due to a series of failures in documentation and a system that didn't seem to care enough to find 6 out who he actually was. 7

In relation to this loss of identity, what does Sarah say about this in her life story? 8 Q.

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- A. This is directly from Sarah's story, and it says: "Sarah noticed that Paul's date of birth had 9 changed about three times over the decades. The admission application had the wrong date 10 of birth, his date of birth had changed in the institution on some documents, and decades 11 later the agency had yet another date of birth for him. It would turn out that the agency had 12 the birth certificate of a completely different person to Paul. The Christian and surnames 13 were correct, but the date and place of birth and the parents' names were all incorrect for 14 Paul. He had another man's identity. After Sarah managed to prove their sibling 15 relationship, a new birth certificate was ordered and the old one ripped up." 16
- 17 Q. To move on to the other theme that was mentioned, the lack of recognition of personhood. What does "personhood" mean? 18
- Like all of these concepts and ideas we're discussing, there could be a number of different 19 A. definitions used. But in the context of this research, we took "personhood" to refer to the 20 respect for an individual's essence of being, freedom to make choices and have autonomy, 21 or independence, freedom to love and be loved, and to belong and to relate with others. 22
- Q. Why does the Donald Beasley Institute report say that there was a lack of recognition of 23 personhood within the accounts of the research that you've gathered? 24
- 25 A. Because when we look across the 16 stories, all bar one really show repeated assaults on personhood or a lack of recognition of personhood. But one of as-- just one example, 26 personhood was challenged by medical practitioners and other staff in care settings as one 27 of the things we noticed in relation to personhood. 28
- Q. How did the medical practitioners or staff challenge a person's personhood? 29
- What we saw was storytellers being infantilised and devalued through the use and labels of A. 30 language, labels like "feebleminded" were common. Again, if people read Sarah's story, 31 you will see what we mean by these labels and language. 32
 - Q. When personhood was removed, what was the consequence of that?

- A. It was used when-- that sort of dehumanising language or people weren't seen as human occurred, it was seen as --or used as a justification for the removal of people's human rights, and their agency. So that's why it's really important to pay attention to things like language.
- Is it fair to say --when someone's not valued, or someone's been dehumanised then it's easier to see it's-- easier to justify the abuse that then is carried out against that person?
- 7 A. Yeah. And in my opinion, it continually circles back to a presumption of incompetence underwriting those things.
- When personhood was challenged by the medical staff or professionals and staff in the research that you gathered from the storytellers,-- what did the researchers observe about what disabled people did with those labels when they were labelled by these people?
- 12 A. Yeah, many, many times storytellers identified themselves by the labels that other people
 13 had attributed to them. So that is, their identity and their perceptions of themselves became
 14 echoes of those labels and attitudes that they were subjected to.
- Does the storyteller, a person called A, make a point on this?
- A. Yes. A is someone who was subjected to a lot of labelling and it impacted how he saw
 himself, and he tried to explain to me what it felt like to be him, and he said, "When I was
 at high school I wouldn't speak to anyone or anything or any person, any peoples, I was,
 what do you call it, I was sort of -- I wouldn't even speak to peoples or anything, eh, I don't
 really know why, but I was a bit worried people would tease me."
- 21 **Q.** Right.
- And for this person, in comparison to a lot of the other abuse and violence that he experienced, we might think this is quite a small thing, but to him it was something he spent a lot of time thinking about and talking about in his story.
- 25 **Q.** Another challenge to personhood that comes through in the life stories is inhumane treatment. Can you give us an example from the storyteller Graham P?
- 27 A. Yeah, so going from the example that I just gave of how people saw themselves or
 28 perceived themselves, the other end of the spectrum of assaults on personhood was
 29 violence, and Graham said about his experience of overt abuse, such as being locked up,
 30 was: "Sometimes I would get angry and yell out and put holes in the walls. I find it a bit
 31 hard to talk about being at Cherry Farm, I don't like thinking about it, I don't like Cherry
 32 Farm."
- Thank you. I'm now going to move us on to the relational level within the model. We've heard a lot of evidence particularly yesterday and even in the day's prior about power and

1	control in relationships, as a factor that enables abuse. Is there an important additional
2	factor at this relationship level of the model of disability violence and abuse?

- A. So the relationships or relational level of the model invites and enables a critical consideration of power and control in the relationships disabled people have with family and whānau, with peers, with intimate partners, with co-workers-, with people in the community, but importantly to this Royal Commission, it also asks questions about relationships disabled people have or are part of because of their -- the label of "disability", so that includes relationships with paid carers, with educators, with health and allied health professionals, and workers in the disability service system, past and present.
- Q. So how did the required relationships that disabled people have in their lives affect the rates of abuse of disabled people in Aotearoa when compared to non-disabled people?
- 12 A. We can unequivocally state now that research confirms that whānau hauā or tāngata
 13 whaikaha Māori and disabled people in Aotearoa experience violence and abuse at higher
 14 rates than non-disabled people.
- 15 **Q.** What are the key features of the relational level of disability violence and abuse?
- A. The key features of the relational level are that others have power over and are the
 decision-makers about the way relationships are conducted and managed. Other features
 are that there are limited opportunities for disabled people to form, to manage and to
 mediate equal and respectful relationships across their lives. And research has found that
 this is particularly the case in relationships that people are part of because of their lived
 experience of disability.
- Q. The research report also refers to the phrase "corruption of care". Can you please tell us what is this corruption of care?
- A. The "corruption of care" is a term used by a UK researcher Paul Cambridge. Paul
 Cambridge spent time in Aotearoa a number of years ago, speaking about these issues.
 And he found in research that within disability service environments disabled people are at risk of abuse due to the way these relationships frame disabled people as being of lesser value, and dependent and without agency or the ability to make their own decisions.
- Q. Are you able to give us an example to illustrate this corruption of care point based on one of the life stories or some of them?
- All of the stories bar one illustrated that while in care storytellers were seen as being of
 lesser value, as being dependent and without agency, and that these were relational features
 of the environments that they were in. But if I can only, give only one example, Graham
 P's is a good one, something that I've come back to a lot in his story. He said, when he was

- thinking about the relationships he had with staff in an institutional setting, he said: "I liked them, I treated the staff like family, they didn't treat me like family. Made me sad a bit, no one would comfort me when I was sad."
- Q. So is it fair to say that exposure to being in a care service or requiring one of these people in your lives increases a person's risk to being abused?
- A. Yes, for all the reasons that we've just talked about, but not because of the person themselves.
- No. The subthemes at this relational level that have been highlighted in your research are that others holding power over, others making decisions about their lives, lack of opportunity to form respectful relationships. If we go through some of those subthemes now and, firstly, the "others holding power over" topic, what was an example of this that was noted in the research report?
- A. Most of it. So, storytellers experienced direct and repeated physical abuse, emotional and psychological abuse and neglect, particularly in the form of forced seclusion, or in the form of sexual abuse at the hands of people they came into contact with because of their disability and their perceived need for care by professionals or the system. So these experience evidence that people who were supposed to care for them had power that they misused or abused.
- I'm going to move on to a question about the term "playing up". So what were the storytellers told by staff about why they were put in seclusion or why they had been assaulted?
- 22 A. The storytellers that described being restrained and locked up often used to talk about,
 23 when we would ask why that happened or when that happened, they would say, "It
 24 happened when I played up." So the consistency with which some of the storytellers, with
 25 learning disability particularly, linked incidents of abuse and violence against them by
 26 institution staff suggests that they were told that that violence that they were subjected to
 27 was justified because of their behaviour, that they were the cause of the violence.
- Q. Right. Today, what do people more readily understand about someone's behaviour when they might be playing up?
- A. As Dr Olive Webb explained during her evidence last week, contemporary understandings of communication and behaviour would tell us that playing up is a very common way for some disabled people to communicate and to express their lack of power when other people fail to listen to them.

- When the storytellers in the research project describe their effort to communicate their distress or frustration or lack of power in a way that looked like playing up, what typically happened to them?
- A. Their efforts to communicate in those settings tended to result in punishment and that was most often meted out in the form of violent, physical restraint and forced isolation.
- 6 Q. Is there a quote from one of the storytellers Allan that you'd like to read on this point?
- 7 A. Yes. Allan's example isn't as extreme in terms of the response, but it is very illustrative.
- He said: "Because when staff didn't understand me and expect me to do things that I wasn't sure about, then they'd yell at me for getting it wrong and then I would explode. They would just see me as a person who was trying to be naughty or out to be dangerous. And that wasn't the case at all. I think there was a misunderstanding, and I wasn't being listened
- to, is what the problem was."
- 13 Q. Is there also an example that can be seen in Sarah's story about her brother?
- A. Mmm-hmm. This is a more horrific example, which is in Sarah's story and it says: "There are illnesses that sometimes take weeks to diagnose and reports of problematic behaviour, deemed to be Paul's growing aggression, including his waking early and screaming, which required his being put in a quiet room and medicated and that turned out to be physical pain requiring surgery for gangrenous appendicitis, and other times dental problems which were eventually identified."
- Q. The next sub-theme in this level is about others making decisions about their lives and dictating the rules of relationships. Can you give us an example of this?
- 22 A. This was particularly obvious in the management of family and whānau interactions and
 23 relationships, storytellers always shared how they missed their family while they were in
 24 care. However, decisions about when family members were able to visit or when they were
 25 able to return to their family were controlled by their care providers.
- Q. Is there an example that you'd like to read from Sarah's story on this?
- A. Mmm, Sarah said, the following Christmas, with different staff members on, they chose to eat separately to the residents and assumed that the sister would not want to do the same.

 Sarah was dismayed, she had worked hard, saved up money and travelled a long way to break bread with her brother again on Christmas Day. She said it felt like her brother was being separated out from her again and she realised that he and his peers would probably never be seen as true equals by others. She watched on as her brother and his peers were fed separately like cattle, apart from the people in charge.

- 1 **Q.** That part of Sarah's story is she travelled from another country to come back to spend Christmas with her brother and yet --
- 3 A. So even when Sarah was in the setting, the separation and the segregation and the controlling of the relationship still occurred.
- The next sub-theme at this relational level is the lack of opportunity to form and manage or mediate equal and respectful social familial peer and intimate relationships?
- 7 A. Mmm-hmm.
- You've said that the storytellers in the research shared an overall experience of having little opportunity to form respectful relationships. How do you describe the impact of this at a relational level?
- 11 A. Quite simply the deprivation of significant relationships for storytellers can be described as a covert form of violence and abuse.
- 13 **Q.** Is there a useful example of this from Lusi's story?
- 14 A. Yes, and I think Lusi spoke about this yesterday, with the example of, she said, "while I
 15 was in Kimberley Centre my mum never visited me. The first time she came was when she
 16 came to take me home. I didn't know who she was, and I felt nervous."
- 17 **Q.** Moving on to the community level of the ecological model now, can you tell us what is this, what does "the community level" mean?
- 19 A. The community level represents the places and structures that already exist or are formed 20 by society when people come together and contribute and participate.
- 21 **Q.** Are there differences in-- these places or structures where communities come together and contribute, are there differences for disabled people when compared to non-disabled people?
- 24 A. Yeah, so for many people the community is a place of belonging and civic contribution.
- 25 However, for many disabled people, the-- community is experienced as places of exclusion.
- As we heard yesterday in the evidence of Lusi and Matt and Shannon and the many other disabled survivors over the past eight days.
- Q. What does the community level of the model require us to do about this difference?
- 29 A. Like the other levels, it challenges us to think about how disabled people are framed in 30 communities, including how the framing impacts on and shapes how they're positioned and 31 responded to alongside other members of the community.
- Q. What do you mean by "how disabled people are framed", can you just expand on that?

- 1 A. How they're seen by the community, including how other people's perceptions of how
 2 disabled people belong or don't belong, or contribute or don't contribute, so how they are
 3 seen.
- 4 Q. What does this level and the analysis, what does it illustrate?
- A. It illustrates how the way communities position disabled people impacts on the experiences that are available to them, and the extent to which they experience the benefits or risks associated with being inside or outside of a community.
- Your report details some of the sub-themes under this community level as, for example, a lack of access to housing, employment, education, people being understood as non- or unproductive community members, understood as recipient of services and supports and, effectively, in servitude, and understood as non-citizens. Could you take us through some of those themes, starting with the lack of access to housing, employment and education?
- 13 A. Yeah. The stories in Tell Me About You illustrated a fundamental erosion of the right to
 14 make decisions about where to live and where to make a home. None of our storytellers
 15 had that right.
- 16 **Q.** How did this happen, how was the right to decide where to live eroded?
- A. Some storytellers described that they entered care due to a lack of support for their family or whānau. Others shared that they didn't know why or how they'd ended up in State care.
- 19 **Q.** Is Graham, does he comment on this?
- 20 A. Mmm, both aspects are present in this comment which was: "Then I was at Cherry Farm.
- I remember when I went but I don't remember how old I was or why I went there.
- I remember feeling angry when I got there because I didn't want to leave home."
- Q. Was there also an account from one of the storytellers around education as a reason for why siblings entered care?
- 25 A. Yes. This storyteller, family storyteller shared that her siblings entered care in part because 26 they were perceived as being unable to participate in education. The perception was they 27 couldn't be educated because they were mentally retarded. She said in the 1960s it was 28 widely considered that mentally retarded or autistic children did not have the capacity to be 29 educated.
- 30 **Q.** That was in the life story from Sarah?
- 31 A. Mmm-hmm.
- The theme of being understood as non- or unproductive community members, how was this reflected in the life stories of the research?

- A. Running through most of the stories was an understanding or social construction of storytellers as non-productive or unproductive, and this was clearly reflected in their work experiences or lack of work experiences, and particularly in the prevalence of unpaid or underpaid work.
- 5 **Q.** Did David make a comment about that in his story?
- A. Yes, he said: "I worked at the printers in Templeton, not paid though. I didn't really like my job in the printers, the ink stunk, and it made my hands dirty." But what he's really saying is that he had no choice over what work he did.
- 9 **Q.** Being understood as recipient of services and supports and in servitude to the state was another theme. By being in care, how were the storytellers perceived at the community level in this regard?
- 12 A. Many of the storytellers were fundamentally and permanently assigned to the role of 13 recipient of services and supports. And that started with that initial act of being placed in 14 care. So being the recipient of services and support sometimes meant they were placed in 15 different institutions or care settings one after the other, and as the quote just a little earlier 16 here indicated, not knowing why those changes in setting were being occurring-- for them.
- I'm just going to move on to the next theme of being understood as non-citizens, which was one of the themes at this community level. How were these storytellers in the research deprived of citizenship?
- They were deprived of citizenship by being placed in institutions and prevented from 20 A. 21 leaving; they were deprived of citizenship in being restricted in who visited and when they visited; through being expected to undertake unpaid or low paid work; they were deprived 22 of citizenship by --having limited access to life experiences, to education, to training that 23 might support their ambitions for the future; and due to their containment, they were 24 25 excluded from being authentic members of their communities, including being able to develop that sense of belonging that we heard is so important across these eight days, and 26 that is typically associated with being part of a community. 27
- Q. When you and your colleagues were gathering these stories did the storytellers reflect on their lives after the institutional care, and when they did this, did this give you an insight into some of the community level factors that were actually present during their time in the institution?
- A. So I think some of the most instructive comments about the erosion of community and belonging are seen when storytellers reflect on their life beyond the institution or care setting, and even Rosie who was quite-- had a particular experience of a care setting that

- was more positive than others, said: "We had a choice, when we were in the institution, of who we lived with, but when I got out I found it was great to be in the community and I didn't look back."
- 4 Q. Thank you. We'll move on to the final level of this ecological model of abuse, which is the societal level.
- 6 A. Mmm-hmm.
- 7 **Q.** How can we begin to understand the impact of the societal level as a factor contributing to disability violence and abuse?
- A. Like the other levels, understanding how social structures impact on and shape disability, violence and abuse, also requires recognition that the way society works and is structured is framed by privilege and power, which is embedded in our economic and political and social policies and practices, that focus on the dominant and most productive members of society, and the storytellers that we talked about certainly didn't fall into that category.
- 14 **Q.** How does society give some people the power and privilege and not others?
- 15 A. Through discriminatory or ableist laws and policies and through systems that give some
 16 people access to power and privilege, including access to education, and employment, and
 17 networks that enable access to valued social roles and opportunities. And again, these
 18 storytellers we spoke with and the survivors that have been speaking across this hearing
 19 have all talked about not having access to those things.
- Q. And can you tell us how this exclusion and discrimination has been able to occur?
- A. For disabled people there's a history of exclusion from those systems and discrimination within them.
- 23 **Q.** And the impact of ableism?
- A. Mmm-hmm, is embedded in society and operates in the way social structures are designed and accessed and used.
- Q. Why is the societal level of the ecological model so significant in terms of prevention of future abuse?
- A. So, while it's the furthest from the individual, it has arguably the most significant impact in terms of being able to shape the structures and ideas and attitudes that have a direct impact on individuals and that we need to change.
- So in terms of future prevention of abuse and neglect of disabled people in care, while all of the four levels that we've gone through need to be addressed, is it fair to say that the societal level factors may have the most significant impact. --
- 34 A. Yes.

- 1 **Q.** -To influence transformative change?-
- 2 A. [Nods].
- Your report goes through the societal level with some sub-themes. The first one that's covered is "Laws and policies that deny personhood rights". The New Zealand laws and
- 5 policies that led to the era of institutional care, what value system were they built on?
- A. I think it's fairly clear by now that the policies relating to support for disabled people in the era we're talking about were developed in response to a system which valued segregation or was based on segregation.
- 9 **Q.** How did one of the storytellers describe this in the report?
- I seem to be drawing on Lusi's wisdom quite a lot today. But she explains it perfectly by saying: "It is built on a system that dehumanises disabled people."
- 12 **Q.** What power did these policies have?
- 13 A. They had tremendous power. We are talking about a time when those policies provided the
 14 mandate for disabled people to be isolated in environments that were cold and dark and
 15 blatantly, so I'm talking literally and figuratively there, that blatantly denied personhood
 16 and positioned people away from communities and the wider society.
- 17 **Q.** Looking at the theme of societal factors around education, employment, and health models
 18 that segregate and specialise, what model of support was offered to disabled people and
 19 their families by society's structures and policies?
- A. The support offered, again, followed the model of segregation really. So people in this research and much of the other research that we've done around this topic consistently showed that families only had one option, they weren't being supported to care for their disabled family member very well at home and in the community.
- Q. Your report also lists as a theme here "The limited access to legal and social protections".

 In terms of this theme, what did your research show about access to complaint mechanisms or justice?
- A. It can reasonably be asserted that disabled people in care that we spoke to had little
 effective control over the way they were treated, they had no clear pathway to justice for
 seeking accountability for violence and abuse that they either experienced or they
 witnessed, and the stories attest to that.
- Q. And is there an example in the research, I think it might be drawing again on Sarah's account?
- 33 A. Yes, who shared about the over-medication issue for her brothers and at the time there was 34 no pathway to question or challenge the treatment regime being administered. And this did

1	not occur until they moved into the community. She said: "The decades of charted
2	medication records indicate a heavy regime of drugs for epilepsy, anti-psychotics,
3	behaviour control and sometimes pain relief. Only after deinstitutionalisation and the
4	involvement of psychiatrists were questions raised about psychiatric polypharmacy despite
5	there not being any record of any diagnosis of mental illness."

- And the last sub-theme under this level was framed as "Outsiders in society". What does that mean at this level of the model?
- A. For all storytellers' supporting treatment was provided outside or away from mainstream society. We've heard that repeatedly. Societal attitudes of the time meant that when support or treatment was sought, the person was placed out of sight in institutions that were geographically and relationally on the margins of their communities.
- 12 **Q.** Your report then weaves these four levels together, and by doing that, how does that assist when considering strategies for prevention of abuse and violence in the future?
- 14 A. I'll defer to an international expert on this, Andrea Hollomotz, who says:

"If we do that it enables us to understand how social and individual factors interact in the formation of risk of violence. This allows us to focus our gaze beyond the assumption of vulnerability and with this to move away from dominant explanations of individual cause."

So that issue we were speaking about earlier.

- Q. Right. Just looking now at if— we could move to the discussion aspect of the report where yourself and your colleagues analysed the collective body of all of the life stories. When you did that, what did your analysis confirm?
- A. When we used this model, where we got to was that we identified and confirmed that systemic abuse within care had a pervasive impact on the experiences of storytellers at all levels of the model.
- 26 **Q.** What is systemic abuse?
- A. Again, we don't have time to go into lots of detail, but in brief, it refers not only to direct physical abuse that a person experiences, but the violence inherent within and to a system.
- Q. And acknowledging that you could probably talk on this for a few hours, but what did you and your colleagues conclude in terms of the abuse and violence described in the life stories, was it systemic?
- 32 A. Yes.

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33 **Q.** And why did you conclude that?

A. It's probably, what I'm going to try to do is to give a composite story. So at, so- I'm
drawing on all of- the stories to provide an answer. So at the beginning of each storyteller's
care journey, the system granted power and authority to professionals to make decisions
about where that person would live and who and how they should be cared for.
Storytellers, and often their families, were almost totally voiceless in those decisions about
care.

When storytellers moved into institutions and other care settings, day-to-day carers continued to hold power over them, creating the potential for violence and abuse, the corruption of care we talked about earlier. And if we think about systemic abuse, it includes conditions and policies that are abusive. It -includes and-- these include inappropriate punishments and neglect and these were prevalent in the experiences of storytellers.

And the other thing that happened is that even if some institution staff and other people in caretaking roles didn't agree with what was happening, they were as powerless as the storytellers to challenge it. So all of this suggests ableism and disablism at play.

- Q. During your research report, you analyse the, also the experiences of survivors that have given evidence at the Royal Commission hearings, previous hearings, and I think you found that the evidence gathered in the life stories of the Tell Me About You report mirrored the experiences that the Commission has been receiving. What conclusions did the Donald Beasley Institute make about this in the research report?
- A. It was fairly stark. We said from survivor testimony it is clear the systems put in place by the State to support and protect children and young people catastrophically failed many of them repeatedly and we said that that constituted systemic abuse.
- Q. Does your report then go on to list how the State categorically failed to support and protect children and young people?
- 26 A. Yes, it does.

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- 27 **Q.** Would you like to just summarise those points that you made in the report?
- A. We said that children entered care needing support and protection either for their disability or due to circumstances at home, or both; that the lack of State support for children to remain in the families dismantled and fractured families; that children and young people who deviated or -- and I'll add adults there as well -- or who were perceived to deviate from the norm were not supported, and placed in State care; the impacts of abuse affected those children, young people and adults for the rest of their lives and often into the next generation; that staff members were often aware of abuse and remained complicit and

- complacent by not reporting it; and children and young people disclosed their abuse but were often accused of lying; and --
- 3 Q. Sorry, it carries on?
- A. And one more was the care system left survivors of abuse and neglect feeling unloved, unworthy, as deserving of being abused and suggesting that they had in turn internalised the ableism and disablism themselves.
- And for all of those reasons, your conclusions were that the State had categorically failed these children, young people and disabled adults catastrophically?
- 9 A. In my brief, yeah.

- **Q.** If we move now to your conclusions in the report. There is a comment made on the phrases
 11 that some people look back and say these things have happened historically, they were the
 12 practice of the day. What would you like to say in response to that phrase with reference to
 13 the examples in the life stories that you've gathered?
 - A. I think one of the challenges that we are facing in this Royal Commission is a repeated refrain that some people believe that or that is based on the belief that history shouldn't be judged by today's standards. However, what the Tell Me About You storytellers told us about their experiences might have been common but it doesn't mean it was right and it shouldn't be explained away as the practice of the time.

So what I would say to that is that taking young people away from whānau and fracturing cultural identity is not acceptable practice and never was; ignoring the rape of a child within foster care is not acceptable practice and never has been; administering medication using violence or as a punishment is not acceptable practice and never has been; locking people up and isolating them from others without lawful reason is not acceptable practice and never has been; punching people you were paid to care for is not acceptable practice and never has been; hanging disabled children from a clothesline is not acceptable practice and never has been; not knowing why you live somewhere and not being able to leave that place is not acceptable practice and never has been; and having clinicians encourage your peers to verbally abuse you in the context of therapy is not acceptable practice and never has been.

So these are just some of the stark examples of abuse and violence in the lives of disabled children and adults recounted by the 16 storytellers in Tell Me About You and they are all a denial of personhood.

Q. Just finally as we conclude your evidence today, I'd like to shift to look forward. In New Zealand currently we are on the crest of transformation in the disability support sector

l		with the Whaikaha, Ministry of Disabled People and the roll-out of Enabling Good Lives.
2		In drawing on your expertise in this area, do you have any comments or concerns around
3		these changes alone being sufficient to address the violence and abuse of disabled people?
1	A.	It's good to be able to focus on the positives for a moment. So Whaikaha, the ground-
5		breaking Ministry of Disabled People, the first Ministry designed and led by disabled
6		people and framed by Te Tiriti o Waitangi and the Convention is one major systemic
7		change that has the potential to improve and address this horrific record of systemic abuse
3		of the scale that has been described over the past eight days.

Related to that, commitment to the national rollout of Enabling Good Lives which is informed and influenced by whānau ora and underpinned by values like self-determination and person-centred, mainstream first, mana enhancing, etc. I know I've missed a few. That's a really important systemic transformation as well, that also has the potential to reduce systemic abuse.

But those measures alone won't fix the problem and those structures alone shouldn't have to fix the problem.

- Q. So in your expert opinion, what do you see in addition to these things we've just described as essential for real change?
- A. I'll go back to a point I made earlier and in my opinion what still needs to happen is for Aotearoa New Zealand to make a real commitment to the legislative and policy change required to fully implement Article 12 of the United Nations Convention on the Rights of Persons with Disabilities.

MR WHITING: Hear hear.

A. UNCRPD experts have long said that the realisation of all other rights asserted within the Convention hinge on Article 12.

So to continue with my lecture, if we think about the focus of the Royal Commission and analyse the evidence that disabled survivors have contributed, it's clear that if disabled people were recognised as having legal and mental capacity as per Article 12, and were supported to make decisions according to their own rights, will and preference, the violence and abuse in care that we have heard about over the course of the Royal Commission and this hearing would not have been able to continue unchecked.

So, yeah, in my view we should be using the powerful tool that we signed up to, the UNCRPD. Almost without exception every right expressed in the UNCRPD gives us a way to counter disability violence and abuse and its impacts. But at the very least, we need to fully implement and regularly and comprehensively monitor Articles 14 to 17 of the

- 1 Convention, which are arguably the most directly relevant to this Royal Commission and to
 2 the recommendations that will emerge from it. And obviously that needs to occur under the
 3 overarching framework of Te Tiriti o Waitangi and the United Nations Declaration for the
 4 Rights of Indigenous People.
- Can I ask you where to from here in terms of the evidence that has been gathered, the life stories, the survivor accounts? What do you say about this evidence that has been gathered?

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A. I've got a few opinions on that as well. The stories we have collected and all the others that have been contributed to the Royal Commission must be elevated from their previous status of invisible disability history. They need to be preserved and engaged with over time, and this Commission is just the tip of the iceberg, as has been referred to in evidence earlier in this hearing.

We need to think really carefully about how the evidence is provided, that has been provided to the Commission as preserved for future use. There are some examples we can look to, and we need to think about how we continue to provide pathways for people to report and record stories of their abuse in care over time. Not everyone will be ready to talk in the time frame of this Commission, we know that.

- 18 **Q.** And the Royal Commission of Inquiry's relevant period of investigation under its terms of reference is 1950 through to 1999. What would you like to say about that timeframe?
- A. I think we need to be very clear that abuse did not stop in 1999. It has not gone away and we need to continue to be vigilant, we need to be activists, we need to keep listening. And we need to critically ask ourselves if a contemporary examination of disability abuse is required. Whatever is decided, the end of this Royal Commission or the stated date of the end of this Royal Commission is not the end, or should not be the end.
- During the evidence and question time yesterday, there was a discussion about the need for disabled people to continue to be activists and to champion any recommendations that are made from this Commission. What would you like to say on this point?
- A. We need to celebrate the resilience and the resistance of survivors and their whānau and allies, but one of the things that we, one- of the messages that we're carrying forward from Te- Kahui Arataki is that we should not be using people's individual and collective strength as a reason to diminish or allow ourselves to put aside the horrendous impact of systemic abuse. We need to acknowledge and promote ongoing activism and the mana of disabled people and their representative organisations to highlight and respond to abuse, but in my opinion those individuals and those organisations need to be properly resourced with the

- formal mandate to implement and embed the recommendations that will undoubtedly come out of this Commission.
- 3 Q. It was also part of the discussions yesterday that this Commission does end at some point in the middle of next year. In your opinion, when does this important work in this area end?
- 5 A. Ultimately, the work of the Royal Commission will not be done until all New Zealanders
 6 understand that it is societies and systems that make people vulnerable to abuse; disabled
 7 people themselves are not inherently vulnerable to abuse.

So again, in my opinion, to continually recycle the notion that disabled people are somehow responsible for abuse, for the abuse they experienced, is dangerous and it will never lead us to the place where we can confidently assert "never again."

- 11 **Q.** Finally, Dr Mirfin-Veitch, would you like to finish your evidence today with your final two paragraphs from the Tell Me About You report?
- A. Sure, I think it's appropriate to take us back to the 16 individual storytellers who made this work possible. We ended our report by saying: "This report has captured the stories of only a small number of disabled people," and I think that's an important take home message.

"There are many more disabled people in Aotearoa New Zealand who will never get the opportunity to share theirs. The DBI research team acknowledges the bravery it took for every single storyteller to share their story and recognise that for some storytellers participating in Tell Me About You forced them to relive the mamae they felt while in care. We are deeply grateful for their contributions, but we think that justice for storytellers and the many others who undoubtedly shared similar experiences will only be achieved if redress is underpinned by Te Tiriti o Waitangi and implemented swiftly and universally in a way that is inclusive of and accessible to everyone."

24 **Q.** Thank you.

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- 25 A. Thank you.
- Q. I'll just see whether the Commissioners may have any questions.
- 27 **COMMISSIONER GIBSON:** Thank you, Brigit, thank you, Ruth. Commissioner Steenson, do you have any questions?
- 29 **COMMISSIONER STEENSON:** I do. Kia ora, Brigit.
- 30 A. Kia ora.
- Thank you for your statement. I just had one question around the definition that you've
- given on systemic abuse, which also says that it's interchangeable with institutional abuse.
- It just seems somewhat limited to an individual structure when it's defined that way as
- 34 opposed to a --

- 1 A. Yes.
- 2 **Q.** -- a wider system issue?
- 3 A. I think the interchangeability of the two terms happened a long way back and so we would
- 4 recommend dropping the "institutional abuse" term and just use "systemic abuse". But
- when you track its history back, it's used in the same way, it means the same thing. So
- 6 just- yeah-.
- 7 Q. Okay, that's quite interesting, because my understanding was institutional abuse referred to
- a particular institution and the abuse that occurred within that institution.
- 9 A. Yeah, and it can be used in that way too.
- 10 Q. As opposed to the wider attitudes, legislative policies (inaudible) of systemic abuse?
- 11 A. Yes.
- 12 **Q.** Okay. That was --
- 13 A. So my recommendation is simply go with "systemic".
- 14 **Q.** It should be wider. Kia ora.
- 15 A. But we were just acknowledging some of the origins of that term.
- 16 **Q.** Thank you. That's all my pātai.
- 17 A. Great.
- 18 **COMMISSIONER GIBSON:** A lot of the korero reading the stories is about care in what might
- be called support services, some of it's in education. Do you think that the lessons that you
- talk about across the four levels of the ecological model, and also you talked about
- segregation, are equally applicable to both or is there some nuance?
- 22 A. I would have to say I would need to give it some more thought and apply it, but my initial
- response would be yes, it is applicable.
- 24 Q. And from your sense of what you learnt, the-- bulk of these stories comes
- pre--2000,- about- what's happening now, I think there has been a clear message that it's
- still ongoing but what would you say are the subtleties in what's changed, what's got better
- and what's got worse in the last 20 or so years?
- A. So what we saw was I'll-- reframe that. Our analysis identified some key themes that were
- very extreme within the care settings and within the time period of the Royal Commission,
- but we still see people not having the opportunity to fully enjoy all their rights. In today's
- current settings we see care provided in a way that doesn't enable people to always express
- 32 their will and preference about what happens for them. We see assaults on people's
- personhood, possibly in less overt ways, but not always, in the current setting.

So people were definitely happier about their moves away from the care settings we
explored, but we certainly indicated, as three people who gave evidence yesterday said, that
they still find it difficult to always have their rights met.

- 4 Q. A casual conversation last night with a survivor talked about, and this was in reference to survivors who had given evidence, but I think it perhaps applies to the same 16, how would we know that we've achieved anything, would it be useful come back in two years or a certain amount of time and collect some similar stories. Is there a methodology to know that we're actually making a difference and through that methodology to learn again and --
- A. I think the methodology well--, the framework of the ecological model that we applied could be used in that way. We've identified the factors in each of the levels that contributed to the abuse that people experienced. You could apply, you could apply the same analysis and see if those things are present or apparent in people's lives.
- You talked, almost lyrically, about the resistance and resilience of disabled people and about the complacency and complicity of those involved in care. I think that was more at the relational level. When does complacency become complicity at a community level, at a societal level?
- 17 A. That's a really big question and I don't know that I've got the answer to it. But I, -do- you want to answer, Matt? [Smiles at Matt]

But I think I go back to some central themes in the evidence that I've given today and one of those central themes was trying to challenge the notion that the community and wider society has, that disabled people are inherently vulnerable, that would be a place to start.

- Q. I think I can hear Matt's answer before I ask this question- so- would you say that society is complicit in the abuse and neglect of disabled people?
- 25 A. Yes.

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Q. Thank you. I have no further questions, it's up to me to thank you. I've learned a lot from 26 you over the years, it's been great to have read that the many reports- I- think I read 200 of 27 the 250 pages last night and, again, the stories, the heart of the research jumps out at you 28 that what has happened, the necessary change, the documenting of the history of what's 29 happened in Aotearoa New Zealand. I think we've made another step, another significant 30 step towards change. I'm hoping we get to that point where we can say "never again". And 31 thank you and all the team at the Donald Beasley Institute, who I know are here and 32 contributed to this research and the research on these issues over the years, we really 33

- appreciate it. It's not just academic, it is social change, it's challenging and it will make a
- 2 difference. Kia ora, and thank you.
- 3 A. Kia ora, Paul.
- 4 MS THOMAS: If we could take the afternoon adjournment until 4 o'clock, so 15 minutes?
- 5 **COMMISSIONER GIBSON:** Yes, 15 minutes, kia ora, thank you.
- 6 Adjournment from 3.44 pm to 4.06 pm