



TRANSCRIPT OF PROCEEDINGS

THE HON RONALD SACKVILLE AO QC, Chair
THE HON ROSLYN ATKINSON AO, Commissioner
MR ALASTAIR JAMES MCEWIN AM, Commissioner

**THE ROYAL COMMISSION INTO VIOLENCE, ABUSE, NEGLECT AND
EXPLOITATION OF PEOPLE WITH DISABILITY**

9.30 AM, WEDNESDAY, 23 SEPTEMBER 2020

DAY 2

MS KATE EASTMAN SC, Senior Counsel Assisting
DR HAYLEY BENNETT AND MS MELINDA ZERNER, Counsel Assisting

CHAIR: Good morning, everybody. I commence as we customarily do by acknowledging and paying our respects to the traditional custodians of the lands on which we participate in this public hearing. We pay our respects to First Nations elders, past, present and emerging, as well as to all First Nations people who are following this public hearing.

Today is the International Day of Sign Languages, and I invite Commissioner McEwin to make comments about today.

COMMISSIONER McEWIN: Thank you, Chair. Today is International Day of Sign Languages which is officially recognised by the United Nations. This is recognised annually for its celebration of the linguistic identity and cultural diversity of deaf people and sign language users around the world. The theme for this year's day is "Sign Languages are for Everyone!" This day is also part of International Week of the Deaf.

Auslan is the natural language of the deaf here in Australia. Auslan is one of more than 300 sign languages used around the world today. Some people believe that sign languages are the same all over the world. However, this is not the case. Like spoken languages, sign languages have their own unique syntax and grammar. Sign languages also evolve naturally when people come together to use sign language. Sign languages are also as diverse as the communities to which they belong to. Sign languages are used by deaf people, their families and friends, professionals and community members. There are many variations of sign languages, including the many First Nations sign languages and also tactile sign language which is used by deafblind people.

Access to sign language is a human right. Sign language ensures all people can access the world. The Disability Royal Commission is very proud to celebrate this important day and also to recognise the true beauty of sign language and deaf culture across Australia.

Sign languages are for everyone, and they play a part in achieving a truly inclusive society for all.

Happy International Day of Sign Languages.

CHAIR: Thank you, Commissioner McEwin. It's appropriate for me to take this opportunity to express appreciation to our own Auslan interpreters who are doing an outstanding job of interpreting throughout the work of the Royal Commission. We are much grateful to all who are involved in interpreting the work that we do in the proceedings of these hearings. So thank you.

Ms Eastman.

MS EASTMAN: Good morning, Commissioners and good morning everyone following the Royal Commission proceedings this morning. Our first witness this

morning is Rosemary Atherton.

5 CHAIR: Good morning, Ms Atherton. You have appeared on our screens and I very much hope that you will continue to appear on our screens. Can I ask you to follow the instructions of my associate who will administer the affirmation.

MS ROSEMARY ATHERTON, AFFIRMED

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CHAIR: Thank you, Ms Atherton. Ms Eastman will now ask you some questions.

EXAMINATION-IN-CHIEF BY MS EASTMAN

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MS EASTMAN: Your name is Rosemary Anne Atherton?

MS ATHERTON: Yes.

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MS EASTMAN: And you provided your address to the Royal Commission?

MS ATHERTON: Yes. Correct.

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MS EASTMAN: And you are a farmer, a dairy farmer in Victoria?

MS ATHERTON: Correct.

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MS EASTMAN: You've made a statement dated 8 September. Is the statement true?

MS ATHERTON: Yes, it is.

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MS EASTMAN: Commissioners, you will find a copy of the statement in Tender Bundle A behind Tab 16, and there are a few annexures to the statement which you will find in tab 17 and tab 18. And, Commissioners, could I ask you to mark those documents as Exhibit 6.6 and the annexures as 6.6.1 and 6.6.2.

CHAIR: Yes. Thank you.

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EXHIBIT# 6.6 - STATEMENT OF MS ROSEMARY ANN ATHERTON

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EXHIBITS# 6.6.1 THROUGH TO 6.6.2 - ANNEXURES TO STATEMENT OF ROSEMARY ANN ATHERTON

MS EASTMAN: Now, Ms Atherton, I was going to ask you about you first. But I'm not. You've got in the background some photographs of your brother Glen and your evidence today is to talk about Glen and some experiences that he had when he
5 moved to Australia. So can I ask, before I ask about you, what would you like to tell us about Glen?

MS ATHERTON: So Glen, if he was still alive, would be sitting over my shoulder right now, seeing his face on the big screen, laughing at probably not the right time.
10 So I felt that he needed to be shown as he wasn't just a name on a piece of paper. He is and was a real person.

MS EASTMAN: He sadly passed away on 5 December last year and he was 37
15 years old?

MS ATHERTON: Yes. He actually would have been 38 this Friday.

MS EASTMAN: Our condolences to you and your family for your loss.

20 MS ATHERTON: Thank you.

MS EASTMAN: So can I come and ask you some questions about yourself and then we will come to talk about some of the experiences in Glen's life.

25 So you grew up in New Zealand with your parents, a twin brother and Glen is your youngest brother; is that right?

MS ATHERTON: Correct.

30 MS EASTMAN: And you then moved to Australia, but Glen lived in New Zealand with your parents and then he moved in to some accommodation in Christchurch, is that right, where he lived, he had a job and he was part of the local community in Christchurch?

35 MS ATHERTON: Yes.

MS EASTMAN: Glen was born with an extra half chromosome and had an intellectual disability. What can you tell the Royal Commission about Glen's disability and the impact that it had on his life and the things that he did as a child
40 and as a young man growing up in Christchurch?

MS ATHERTON: Glen was growing up, he always had a smile on his face. Glen was cheeky, he liked joking with people. He had a great memory with phone numbers, and he also would ring a couple of times and he would remember the
45 number. He was great with dates or events. Yet, as I said, he had a loud booming voice and he took things literally. He made an everlasting connection with people he ran into, and he never forgot people that he met.

Glen could comprehend most things and he had a connection also with the older generation as they would give him the time of day and have that chat with him. He - growing up, he turned around and he was always wanting to do something. Out
5 on the farm, you know, with my grandparents, he turned around and he moved into supported accommodation. So he actually ended up catching two buses to his day placement in Christchurch and two buses home. Occasionally he wouldn't actually get home on time because he would shop, window shop, and then miss the bus and get home eventually. He always rang, every night, Mum and Dad or me or my
10 brother. And he was very much on the phone, you know, just telling us what happened or who he bumped into. He had a job at the local supermarket every Saturday morning, and he would do that come hail, snow, sun. He loved it. And again he would tell us who he bumped into.

15 MS EASTMAN: He was an independent person, he could make his own decisions. There was no guardianship order or power of attorney?

MS ATHERTON: No.

20 MS EASTMAN: He managed his own finances, is that right?

MS ATHERTON: Yes, he did but when he came over to Australia, I helped him manage those. Because one time Mum and Dad put a cheque into his account for a cow they sold and he withdrew that whole the \$600-and-something out. So he didn't
25 have the understanding with finance, so that's where I wanted to make sure that he wasn't being taken by a ride for everyone as well. So we had a co-signed bank account detail so he couldn't do too much damage.

MS EASTMAN: Now, I want to come to February 2011 and many people may recall the very significant earthquake in Christchurch. And the earthquake was a turning point for Glen. He went missing for 13 hours, and while there was no physical injury, the earthquake had a really significant impact on him. And what was
30 the impact on him?

MS ATHERTON: Yeah. So as you said, he was missing. We didn't know where he was. He was at an evacuation centre. When Mum went and picked him up he couldn't hardly get off the bed, and Mum took him back to live with her because his house where he lived in the supported accommodation had no power, no sewage, nothing. And his day placement that he was going to was deemed unfit. So he had
40 nowhere to go. So he had no routine. So Mum was due to come over here for a holiday, so I turned around and said to her, well, just bring him with you. All the aftershocks he was beside himself, just in time he had turned quite anxious. Then yeah, Mum --- they came over and he turned around and said "I don't want to go back to New Zealand, I want to stay here." I was lucky enough that the day centre, our
45 local day centre where he attended, I actually rang them before he came over and said you know, what had happened, and they said look, he's more than welcome to come in here for a couple of days to give him routine and stability, which he did.

And then when he decided he didn't want to go home I said to Mum, "We can't force him, we can't force him to go back to New Zealand if he doesn't want to." Then he stayed with me until we managed to find somewhere for him to live.

5 MS EASTMAN: We will talk about that in a moment.

MS ATHERTON: Yes.

10 MS EASTMAN: Can I ask you, juts in terms of your knowledge of Glen, how would you describe his physical health and his mental health prior to the earthquake and then any changes that you observed following the earthquake?

15 MS ATHERTON: So physically he was really - it was more his attention span he couldn't keep. So physically-wise there was nothing wrong with him, he was quite big, big-framed but physically he could help out with anything. So, you know, he wasn't impacted physically-wise. Mentally he was fine apart from, you know, he was on Ritalin for his ADHD, but then the earthquake when he came over, he was very much withdrawn. Very much went back into himself, you know, and I feel too, I don't know how I would have coped going through that, let alone someone like
20 Glen.

MS EASTMAN: Now, because Glen was a citizen of New Zealand, was Glen able to access the NDIS or any particular supports from the Australian system?

25 MS ATHERTON: So he got a package called an ISP, an individual support package which has now changed to COS, a continuity of support package, I can't quite remember the right wording. So he got paid by New Zealand and also Australia by his pension. So through the ISP he managed to get funding for his day placement, and then eventually we managed to get funding for his accommodation.
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MS EASTMAN: And in terms of his accommodation, by 2013 he had lived with you for a while and you thought that maybe living a little more independently from the family might be a good thing for Glen, and was Glen supportive of that approach as well? What did he want?
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MS ATHERTON: He wanted that, and he wanted find a job. He needed that to have that brother/sister relationship rather than that brother/carer relationship. It took us that long to get through the process of finding out where to even start looking to start with.
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MS EASTMAN: And so your expectation and as far as you know Glen's expectation was that moving into some supported accommodation would be an avenue to independence?
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MS ATHERTON: Yes.

MS EASTMAN: So he moved into his first group home in 2013, and at the start

there was a little bit of a transition, and you were advised just to allow him to stay in the home, settle in, and to just allow him to find his feet. So did you have a lot to do with him when he first moved to the group home?

5 MS ATHERTON: We actually did. We still kept in contact, he would still ring every night and we would see him on the weekends as well. So, yeah, we always - because he was only five minutes away from us, you know, we could still access him easily.

10 MS EASTMAN: Okay. And he told you after being there for some time that he felt he was being nagged by the staff to do things like have a shower, brush his teeth, clean his room, make his lunch, and he didn't take too nicely to being nagged so he dug his heels in a little bit. And did Glen tell you he felt that the staff members were treating him like a child?

15 MS ATHERTON: Yes. Yes, he did.

MS EASTMAN: And what was the impact on Glen in terms of the way in which he felt that he was being treated? Did he talk to you about that?

20 MS ATHERTON: He did, but he kept digging his heels in and just didn't want to do things. Like anyone, I suppose, if you keep getting nagged you do the opposite.

MS EASTMAN: And he told you he wasn't allowed to go out on his own, he couldn't go for a walk up the street, and did he tell you that caused him some frustration as well?

MS ATHERTON: Yeah, because he had no independence. There always had to be staff, and even sometimes on a Sunday we would turn around and go and pick them up and the staff would say he's not allowed back until a certain time because they then were going out. Where initially, because it was a group activity normally on a Sunday, I said to him well, what are the house doing, and he would say nothing, but the time we went to go and pick him out the house decided they were going out, and we couldn't take him back until a certain time. So he had no access to his house independently.

MS EASTMAN: In the house that Glen lived in, he was the most independent person of the residents and some of the other residents were non-verbal, they didn't communicate much. Some of them were significantly older than Glen; is that right?

40 MS ATHERTON: Yes.

MS EASTMAN: And you say in your statement that some of the residents had difficulty with Glen and he clashed with them and there were conflicts from time to time in the house; is that right?

45 MS ATHERTON: Yes. Correct. Yep.

MS EASTMAN: And what did you notice in terms of the impact on Glen with respect to those conflicts?

5 MS ATHERTON: Well, at one stage he packed his whole room and he actually wanted to move out.

MS EASTMAN: And the staff complained to you that Glen wanted too much attention and that he liked annoying them. You found that out later, didn't you?

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MS ATHERTON: Yes.

MS EASTMAN: But you think that he just wanted to have a chat to them, he wanted to talk to them and feel like he was living in a regular home where you could talk to the people who were there?

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MS ATHERTON: He had more connection with staff or colleagues than the actual clients in the house.

20 MS EASTMAN: You were concerned about the lack of continuity of staff at the home because as the staff changed, the opportunities for Glen to build the relationships with them and have the communication that he wanted dropped off; is that right?

25 MS ATHERTON: Yes. That's correct.

MS EASTMAN: And so you observed that Glen became quite unhappy in that home, and he wanted to leave. And I think as you say on the benefit of hindsight it just wasn't a good fit for him, that first home?

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MS ATHERTON: Correct.

MS EASTMAN: Now, while Glen was living at that first home, what were the arrangements in relation to his medical care? Did he have any supports following the earthquake and the anxiety that he had following the earthquake?

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MS ATHERTON: When he first came over he was living with me, of course. So I took him, so over here in Australia I was told by his GP that he had to go to a psychiatrist to get the Ritalin. So to start with, I went with him to all of these medical appointments or Mum would go if I was busy on the farm.

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When he moved into the house, the house said to me that they wanted to take him to all his medical appointments as they were now living with him. So I didn't actually have to worry about that and I suppose I took a step back. But in hindsight I probably should have carried on.

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MS EASTMAN: Does that mean that you were unaware of any health problems that

might have arisen for Glen over that period of time?

5 MS ATHERTON: Sometimes, yes. I only found out, you know, later on rather than, you know - he would go to the GP quite regularly but there was no follow-up meetings or reports or information given back to me.

10 MS EASTMAN: And over time you observed some changes in Glen's behaviour and you say in your statement that you've got a very clear memory of Christmas Day in 2017. What can you tell us about that day? And if you get upset and you need a breather, let me know.

15 MS ATHERTON: So that day, like before then he had actually, as I said, he was like clockwork and ring every afternoon. So there was times leading up to that Christmas where he actually stopped ringing and I was a bit concerned because he always rang. 3.30, 4 o'clock. And if he couldn't get me, he would ring my mum. Or if he couldn't get Mum, he would ring me and say, "Where's Mum?" So he stopped.

20 Christmas Day he came out to our house and he turned around and honestly, he looked like a zombie. There was no - no facial expressions. He was dribbling, he wasn't interacting with the dogs which he normally loved. He just sat there. He just looked like an old man and everyone actually commented that day, "What's wrong with Glen?" And that's when I'd said to Mum, "We've got to do something here, I want the old Glen back."

25 MS EASTMAN: So what did you do?

30 MS ATHERTON: And that's when I rang the psychiatrist and I said, "I need to come back and see you and see what's going on" and that's what started the process. And when I did go back to see him, he said to me, "I always want a family member with Glen when he comes to the appointments." And from then on Mum and I did.

35 MS EASTMAN: And was it the case that when you attended the appointments, did you find out as to whether Glen was prescribed any particular medication and the purpose for that medication?

MS ATHERTON: Look, in hindsight, yes, he did. But I can't remember what they were. But then the psychiatrist backed off the medication because he even said to me, "Where's the old Glen?"

40 We'd seen one psychiatrist first, and I wasn't happy with the way he treated Glen. And he didn't have a connection with Glen, so that's why we changed to the second one, and he had a real rapport with Glen and really interacted and really cared for Glen.

45 MS EASTMAN: And there was a period of time where the psychiatrist removed some medications, is that right?

MS ATHERTON: Yes, and that's when that happened after that Christmas, and then he started ringing us again. So there was definitely something there, but I can't quite pinpoint what the medication was, sorry.

5 MS EASTMAN: But you were contacted some time in the following year, 2018, from a staff member of the group home and they said they wanted Glen to go back to the psychiatrist as they felt his behaviours were escalating and the staff thought it might be that Glen was having a psychotic episode. So were you involved in what happened after that contact with the staff member and any treatment?

10 MS ATHERTON: Oh yes. I turned around and actually rang the psychiatrist receptionist, and said that they had made an appointment. So Glen would say yes to say yes, if that makes sense. So I turned around and said to the receptionist, the house are coming in, they want to change his medication, can he actually - the
15 psychiatrist have a one-on-one with Glen and have a chat to him rather than all of us being in there and Glen feel under that pressure. So we sat out in the waiting room for five, 10 minutes while he had a chat with Glen and he got us all in there and he said he does not need any more medication. You need to get a behavioural specialist involved.

20 MS EASTMAN: Did you know about behavioural specialists?

MS ATHERTON: No.

25 MS EASTMAN: Had you had any involvement with them?

MS ATHERTON: Not until that point. He gave us a name, both myself and the house, the name of Renee to contact, and I had a piece of paper.

30 MS EASTMAN: The person who you were recommended and who you went to see is a psychologist and behavioural specialist, and she is based in the same region as you, that's Renee Dela Cruz, is that right?

35 MS ATHERTON: That's right.

MS EASTMAN: Then around that time a few things came together. There was an incident for Glen on a bus trip and you also got access to what you found out to be some behaviour support plans that had been written by the staff at the group home around the same time as the incident on the bus.

40 Do you want me to cover the incident on the bus or do you want to tell the Royal Commission?

45 MS ATHERTON: You can.

MS EASTMAN: You put this in your statement, and it's a pretty traumatic issue I think to talk about. So I will go slowly and again if you need a break, let me know.

So we go to 21 November 2018. And around 4.30 in the afternoon you were contacted by a support worker to say that an incident had occurred that morning with between Glen and one of the female residents at the home.

5 They were going on the bus to be taken to their various day placements. And Glen was sitting at the back of the bus and he asked the female resident to move her bag. His account is that when he asked her to do that, she then reached over and took the glasses or tried to take the glasses off her face. He reacted and he then hit her, he punched her.

10 You were informed of the incident later in that afternoon and you immediately contacted Glen to ask him what had happened and he was very distressed. You got a call a couple of days later from a supervisor telling you that the female resident's family wanted to take some action and that they had made an application for a
15 personal safety intervention order against Glen. You got a further call from the supervisor to say that the family had been successful in getting an interim order against Glen. You knew that this wasn't right and you felt that there had been no other options offered to Glen, other than being on the end of an intervention order. This meant that Glen was taken to the police station so the intervention order could
20 be served on him.

MS ATHERTON: Sorry, they wanted me to take him to the police station. Yep.

25 MS EASTMAN: Yes, thank you.

No one really knew what was going on and you were all concerned that you're in a legal process without having any idea what this meant. So, at that point, can I ask you to take up from here what happened to Glen and what did the effect of the order mean on him and his accommodation. Because, as you say later in the statement,
30 you went through a fairly lengthy court process to have the intervention order removed, and that was engaging lawyers and following processes. I think you say in your statement, "We ended up in this system that we never expected to be in". But can I come back to Glen. What was the impact on Glen in terms of being served with the intervention order and what it meant for where he could live?

35 MS ATHERTON: So the house, as you said, they rang me and they actually asked me, the supervisor asked me to take him to the police station to get served the papers. And that's when I also rang the advocate to help me because, again, it is was all new to me and I didn't know where to turn. I needed help and support. And he turned
40 away round and said to me if I take him to the police station, I'm admitting that everything is right. So the cops - the police sorry, turned around and served him that night at the house. There was no independent witness there, just by himself. The supervisor, the house supervisor that night rang me --- or the worker, sorry, and she turned away round and said, "I've been served the papers, I can't get hold of a
45 supervisor so he will have to stay within the 5-metre rule."

So he stayed there that night and the next morning they went in different buses, I

think he caught a taxi to the day service and that night at 5.30 I had a call from the house supervisor to say that no one had told her that Glen had been served the papers. She said he has to go immediately, and we will place him in the respite house for now. And I said well, how does Glen feel about that? They hadn't told
5 him at that stage. So within only half an hour to an hour, he was packed up with a couple of bags or bag or and moved to the respite house. They then turned around and told me he would be there for three days and relocated to another region, away from his family and day placement. I said, how can you do that? She turned around and said to me, "Well, he has done it before when he moved from New Zealand, and
10 he can do it again."

And I thought this is someone who is a supervisor in a disability - how could they say that? You know? Would they do that to their own?

15 MS EASTMAN: The three days turned into 11 months.

MS ATHERTON: Correct. Because with the advocate and me pushing to say he needs to stay locally, how can you - it - for us, yes, it's an only an hour, but being on the farm away, too far. But, yes, he loved it there. He had a great connection with
20 the staff there and he had no behaviours of concern.

MS EASTMAN: And the strange thing that was happening then was that while he was in respite care, in terms of looking at a permanent home the discussion was about getting him back to the original group home?
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MS ATHERTON: Correct.

MS EASTMAN: And that caused a lot of tension and stress because Glen liked being in the respite home and he would liked to have stayed there, but there was
30 always this ongoing conversation about "how do we get him back to his first home"; is that right?

MS ATHERTON: Yes, that's correct, because he was - because all the houses down this way, the [audio distorted] had rolled over to NDIS, because Glen couldn't get to
35 the NDIS, this was his only place of residence. So if I took anything out of his room or packed his room up, I would have lost his placement in supported accommodation.

So that's why they were trying to get him back, and we had care team meetings with Renee, advocate, DHS, the houses, to try to get him back there. And all the time he
40 was saying, "I don't want to go back."

But unfortunately his voice still didn't get heard.

MS EASTMAN: While he was in the respite home he had to navigate, as you say in
45 your statement, the doctors on his own?

MS ATHERTON: That was the other group home. Yes.

MS EASTMAN: That was later.

MS ATHERTON: Yes.

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MS EASTMAN: Eventually he did move into a new home but he was only there for a very short period of time; is that right?

MS ATHERTON: Correct, yes.

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MS EASTMAN: Because he had a medical assessment that was done shortly after he moved to his group home or was it just before? So he moved to the second home in June but he had a medical assessment that identified a fairly significant heart problem for him; is that right?

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MS ATHERTON: That's right, so he had a CHAP assessment and that happened --- or down here anyway, every year. So it's a great big health assessment that they do, and on that they picked up that he had a heart problem, so this afternoon he was at the house and they were short-staffed, and he was asked to go up to the doctors by himself to get an echocardiogram done. They turned away round, and I thought it was strange that night because he was back ringing us quite regularly, and I was like "He hasn't rung me tonight, he might actually be doing something" and at quarter to 8 I got a call from the house saying they had just been to the doctors, and said, "Someone needs to come up and pick Glen up, we think he's having a heart attack. His levels are too high." They rang me and said "He needs to go to emergency, we've got a letter here, we can't take him. I can drop him at the door for you but we can't take him." I'm like "No, I'll come in" because you just can't leave somebody at the door of a hospital not knowing what they were actually going through. So I went and picked him up and took him.

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MS EASTMAN: And he eventually had to have some surgery in relation to the heart condition and he had the open heart surgery on 4 December.

MS ATHERTON: Yes.

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MS EASTMAN: And then an allergic reaction after the surgery that then led to his death last year?

MS ATHERTON: Yes.

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MS EASTMAN: I want to finish by asking you two things.

First of all, coming back to the support that you had from Renee Dela Cruz and the behaviour support plans that you saw, and then finally I want you to tell the Royal Commission what you think, having gone through these experiences and speaking for your brother here, what should change? So around the time of the bus incident and because the psychiatrist had said, "I think you need to speak to a

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behaviour support specialist", Renee became involved and you were able to get hold of a behaviour support plan that had been prepared by the group home. And as I said earlier, this was a staff member. And you've provided in the evidence for the Royal Commission a copy of the behaviour support plan, and in the time that we've got this morning, I won't go through it and the Commissioners I know have read the document, and when your evidence goes up on to the internet, other people can read the document. But when you read the behaviour support plan and when Renee read the behaviour support plan, you were both quite shocked; is that right?

10 MS ATHERTON: Yes.

MS EASTMAN: About what it described about Glen's behaviour and also the way in which the behaviour should be addressed. And you've included, in your evidence, Renee's report in relation to her review of the plan. And you've kindly shared that with the Royal Commission. Can I just --- if you want to comment on this let me know, but can I summarise what Renee found --

MS ATHERTON: Yes. Thank you.

20 MS EASTMAN: --- was that the plan did not document when particular behaviours of concern arose. That there was no incident report recording what incidents had occurred, including any prior incidents. There was no behaviour tracking data where the suggestion in the plan that Glen can be verbally aggressive towards co-residents could be demonstrated by reference to any particular incident or events. Likewise, the behaviour plan that's described Glen as threatening and/assault to hurt other co-residents if they disagreed with him, there was nothing to indicate when such incidents had occurred or why the incidents might have occurred from looking at the behaviours or the lead-up to the behaviour.

30 Renee noted that one of the concerns about Glen described in the plan, that he would abscond from the house or refuse to return to the house. And it said Glen will abscond when he's not getting his own way, and then can be gone for up to two hours. And Renee said:

35 *Glen appears to be capable of making a decision that he wants to go for a walk and take a break from interactions in the house. Perhaps this could be reshaped as a proactive behaviour to assist calming down.*

40 And so throughout her report, and she makes a range of recommendations, she is critical of the language that's used to describe Glen's behaviour. She is critical about the lack of communication between the house and your family regarding incidents and behaviours. She's critical that there were no clear strategies that appear to have been implemented, and she's critical that the personal intervention order seemed to be inappropriate as a model for dealing with behaviours. And she says this:

45 *The AVO has had a significant negative impact on Glen's emotional and mental health. With Glen suddenly being removed from his home, cessation of*

contact with his known support workers and no transition to support him to adjust to his current accommodation.

And she says this:

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A strong behaviour support plan and positive behaviour support training for his support staff is required to influence long-lasting behaviour change.

And she says that she queries this:

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Glen does not demonstrate behaviours of concern described by his day program or at the respite accommodation.

And she says:

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It is likely that Glen's behaviours are largely environmentally triggered and this can be sufficiently addressed through a behaviour support plan that sets out strategies to make sufficient adaptations to his environment.

20 And then she makes a range of recommendations.

Reflecting on what Renee's advice was to you, what do you think would have been a difference for Glen if he had been provided the support that Renee has described in her report?

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MS ATHERTON: So Renee was - built a wonderful relationship with Glen and listened and provided the much-needed support, and also engaged with him on working on his emotional regulation and using visual charts, and also assisted him to articulate his needs and break down what he was feeling.

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Glen, as you said, Glen's behaviour improved and, you know, it was great to see. They worked so well together.

35 MS EASTMAN: And you don't know, do you, the extent to which Glen may have been prescribed any medication, psychotropic or otherwise, to manage his behaviour but you've got an ongoing suspicion that that's the case?

MS ATHERTON: Yes. Yes. Especially like he was because he never used to be like that. So in that time period, something changed.

40

MS EASTMAN: All right. So finally can I ask you to tell the Royal Commission about some of the suggestions for change that you think come out of the experience of Glen?

45 MS ATHERTON: Yes. I'm just going to put my glasses on so I can read it.

I thought by placing Glen in supported accommodation, he was in the hands of experi

enced professionals who would provide him with the required quality of care that he needed. My view is that while he was there, some staff that do perform to expected standards but sadly they were in the minority.

5 In my experience, the organisation that provided my brother supported
accommodation let us down. I lack of confidence in them and I felt I got treated - he
got treated as an outcast by the organisation and staff members that were supposed to
be supporting him. After Glen passed away, I felt they were still continuing to
disrespect him and show a lack of care, empathy, and compassion to us as a grieving
10 family. I was absolutely gutted. Even then, it seemed that I constantly had to be
proactive in order to get anything done for Glen, such as keeping on following up
with the service provider about resolving Glen's financial issues and money that was
owed to us.

15 Some of the questions that I have that need to be considered are: what level of
training are staff required to have to enter into this field? And, are the qualifications
set too low? Do staff get specific training to deal with all situations they are faced
with? And how often is training provided? Are staff who write behaviour plans
actually qualified to do so?

20 There needs to be more follow-up from staff at group homes, when issues arise, with
the family. Mediation options need to be explored, and there must be regular
communication with family. Staff in group homes need to treat clients with
compassion, dignity, empathy and respect like they would their own loved ones.
25 They need to have appropriate training and they need to have great resources to assist
the voices of people like Glen to be heard. Human rights for clients need to be
upheld and not forgotten.

I also think there should be more consideration for New Zealand citizens living in
30 Australia to be able to access the NDIS. The NDIS could have given Glen a different
life. He could have lived anywhere and had the supports he needed. His behaviours
of concern would have perhaps been addressed a lot earlier.

I am hopeful that from my experiences, some considerations may be enforced to
35 provide a better level of care for everyone. As Glen had a voice, Glen was able to
tell us what he wanted. But he didn't really get heard. I am doing this for him and
also for all the other people that can't speak up or have no voice. People with
disabilities just want to be treated like everyone else.

40 MS EASTMAN: Ms Atherton, thank you for your evidence today.

CHAIR: Ms Atherton, I've got a couple of questions if you don't mind.

MS ATHERTON: Yes.

45 CHAIR: You said in your statement that Glen had decided to become a permanent
resident by 2011 but he was unable to get assistance from the NDIS because he was

not an Australian citizen. Was there a particular reason why he did not become an Australian citizen between 2011 and the time the NDIS came in?

5 MS ATHERTON: Yes. He wasn't able through all the categories. I went to an immigration agent and I was trying to bring him - because my mum is also living here in Australia. But Mum unfortunately didn't meet the criteria, and Glen with not having - with having a disability, he actually couldn't get citizenship. So he actually wanted to become an Australian citizen, he didn't want to go back to New Zealand. He wanted to stay here where he felt safe and had a really good network of people.

10 CHAIR: So it was Glen's disability that was a major obstacle to obtaining citizenship?

15 MS ATHERTON: Yes. It was.

CHAIR: Thank you for that. The other question I had was you indicated that Glen had had a comprehensive health assessment in around about October 2019. Was that the first such comprehensive health assessment that Glen had?

20 MS ATHERTON: No. They had one - since he arrived here in Australia they actually had one every year. So it was an annual review, because some people obviously with disability, they can't talk, so that way with doing this, they can actually check. So it was blood pressure, heart, asthma, diabetes, podiatrist, so it was taking real good care of people to make sure they get everything that they need. And probably can't articulate what's wrong.

CHAIR: Right. And it was the 2019 assessment that picked up the heart condition?

30 MS ATHERTON: Yes. Yes, correct.

CHAIR: Thank you. I will ask Commissioner Atkinson if she has a question. Then I will ask Commissioner McEwin.

35 COMMISSIONER ATKINSON: No, thank you. I have no questions.

CHAIR: Thank you.

COMMISSIONER McEWIN: No, I don't.

40 CHAIR: Ms Atherton, thank you very much for giving evidence. I join with Ms Eastman in expressing our sympathy to you for the loss of your brother Glen, and I thank you very much for the assistance you provided and sharing his story and your story with us. Thank you very much.

45 MS ATHERTON: Thank you.

THE WITNESS WITHDREW

5 MS EASTMAN: Commissioners, our next witness is Joanna Mullins. We've scheduled a short break for 10 minutes.

CHAIR: Yes. We will take 10 minutes.

10 **ADJOURNED** [10.19 AM]

RESUMED [10.32 AM]

15 CHAIR: Ms Eastman, yes.

MS EASTMAN: Thank you, Commissioners. Our next witness is in Townsville. It's Joanna Grace Mullins, and I think, Commissioners, you can see Ms Mullins on
20 the screen now?

CHAIR: We can see you, Ms Mullins. Thank you very much for coming to give evidence. I will ask my associate to read the affirmation.

25 **MS JOANNA GRACE MULLINS, AFFIRMED**

CHAIR: Thank you, Ms Mullins. Ms Eastman will now ask you some questions.
30

EXAMINATION-IN-CHIEF BY MS EASTMAN

35 MS EASTMAN: You are Joanna Grace Mullins?

MS MULLINS: I am.

MS EASTMAN: I'm not quite catching your sound. I will just check that we're ---
40

CHAIR: Perhaps say something, Ms Mullins.

MS MULLINS: Yes, I am.

45 MS EASTMAN: That's better. You are an advocate and NDIS appeals support officer with Independent Advocacy North Queensland?

MS MULLINS: That's correct.

MS EASTMAN: You've prepared a statement dated 4 September this year. Is the statement true?

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MS MULLINS: Yes, it is.

MS EASTMAN: Commissioners, you will find the statement in Tender Bundle A behind Tab 19, and there are some annexures. At Tab 20 is a copy of Ms Mullins' CV. Ms Mullins's evidence is going to focus on one of her clients, and she is going to speak about her client with the consent of the client and the client's mother, and copies of the behaviour support plans in relation to the client who has a pseudonym ABK. ABK is the person who I described as Robin yesterday in opening. Those behaviour support plans should also be received into evidence and marked Exhibits 6.7.2, 6.7.3, 6.7.4, and the CV 6.7.1.

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EXHIBIT# 6.7- STATEMENT OF MS JOANNA GRACE MULLINS

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EXHIBIT# 6.7.1 - CV OF JOANNA GRACE MULLINS

EXHIBITS# 6.7.2 THROUGH TO 6.7.3 - ANNEXURES TO STATEMENT OF JOANNA GRACE MULLINS

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CHAIR: Yes. Thank you.

MS EASTMAN: Now, Ms Mullins, your statement is in four parts, setting out your professional background and experience and then your statement deals with regulatory overview and background. And then the third part is dealing with ABK, and then finally suggestions and reflexes on change and reform based on your experience. So I want to start with your professional background and then turn to the regulatory overview. I don't think we need to go into the full detail that's in the written statement, but it may assist in understanding what has occurred to ABK to understand the regulatory systems that operate in Queensland. Are you happy with that approach with your evidence?

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MS MULLINS: Yes, I am.

40

MS EASTMAN: All right. So let's start with you. You are an advocate and appeal support officer for people with disability, and you are an employee of Independent Advocacy North Queensland. What is Independent Advocacy North Queensland?

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MS MULLINS: We are, as the title suggests, an independent advocacy organisation. We receive funding from the Commonwealth and State Governments to advocate on

5 behalf of people with a disability in various settings. So advocacy is a bit of a singular job. We're not councillors, we're not advisers, we're not lawyers. Our job, in essence, is to be the voice of people with a disability who for whatever reason cannot speak up for themselves. So we help them explore what they want to achieve, what their options are for achieving it and we speak up for them and help them achieve their goals.

10 MS EASTMAN: You used something called a client advocacy action plan in the advocacy work that you do. You've described it in paragraph 10 of the statement, but can you tell the Royal Commission about how a client advocacy action plan works in practice? What do you do?

15 MS MULLINS: So when we first receive a referral, clients will come with a certain number of issues. We talk to the clients. We look at what their goals are in relation to those issues and then we have an agreement that says what I as an advocate will do and what they will do to help themselves. And because obviously our funding is not a magic pudding, once for a particular client all the items on the client advocacy plan have been completed, then we will close that file and a new client will be allocated.

20 MS EASTMAN: So you don't take on the advocacy role that you become the permanent advocate for the person. It's very much achieving the particular outcomes or goals by the client. That is the approach taken with Independent Advocacy NQ?

25 MS MULLINS: If a new issue that is related to existing issues come up during the course of advocating for a client, we can add that issue to the plan, with permission. But as I said, if we just became permanent advocates then we would have a permanent group of clients and no new advocacy or no new clients could get advocacy, so we do have to have influence.

30 MS EASTMAN: You are, we will reveal here, a lawyer by training. You are a qualified lawyer, and you've practiced as a lawyer over many years. But your role with the Independent Advocacy NQ is not as a lawyer; is that right?

35 MS MULLINS: That's correct. Certainly my legal skills come in handy, but I do not give legal advice to my clients at all. I'm not - I can't play any legal role. I can represent them in lower level tribunal hearings but I can't - I can't give legal advice.

40 MS EASTMAN: Well, one aspect of having some training as a lawyer is that your role as an advocate requires you to have a working knowledge of legislative frameworks as they operate for people with disability in Queensland and also the Commonwealth regulation. And I think, is it fair to say, stepping back from your statement, that understanding the relevant legislative frameworks are very complex?

45 MS MULLINS: Absolutely. I have a lot of experience in interpreting legislation, Commonwealth and legislation over 25 or more years and even I at first glance have to think hard and in order to understand the interactions between some of these pieces of legislation.

MS EASTMAN: Right. And ABK's case is an example of navigating back and forth between both the Queensland system and the Commonwealth system. So, to provide that background and context, can we walk through some of the regulatory
5 arrangements that operate in Queensland. So in Queensland there's two important pieces of legislation, the *Disability Services Act* of 2006 and the *Guardian and Administration Act* in Queensland. Is that right?

10 MS MULLINS: Yes. Absolutely.

MS EASTMAN: Now, those laws cover a wide range of issues but focusing for the purpose of this hearing on how the Queensland law defines and deals with restrictive practices, I want to ask you about what does the Queensland legislation say or do about that and where does chemical restraint, if at all, fit in for Queensland.

15 You've described this in your statement at paragraph 19 but can you tell the Royal Commission at a state level what are the classes of restrictive practices subject to regulation under the *Disability Services Act*?

20 MS MULLINS: So at the State level they divide them into three groups. The first group is containment, which is locking somebody into a particular area and not allow them - without allowing them to leave, if I can put it in layman's terms. No, that's seclusion. No, if they're by themselves it's seclusion. It's containment if you lock to not allow them to have access to their environment. Chemical restraint is giving
25 someone a drug for the purpose of controlling their behaviour, and that can be done either on a regular basis or on what they call a PRN basis, which is in response to a behaviour. The other classes there are physical, so using your body to restrain somebody and mechanical restraint, which is buckling people in, things like that.

30 The third class is very broad and called restricting access to objects, and that would include knives, any other sort of objects --- fridges, any objects, really.

MS EASTMAN: Now, the Queensland laws apply only to people over the age of 18; is that right?
35

MS MULLINS: Yes. That's correct. Not to all people over the age of 18 but certainly they don't apply at all to people under 18.

40 MS EASTMAN: And if a chemical restraint or frankly any other type of restrictive practices is to be authorised in Queensland, how does one go about getting authorisation? Where do you go and what do you need to satisfy?

MS MULLINS: The first thing that you are going to need to do is apply to the Department of Communities for a short-term approval. Do you want me to focus in
45 just on chemical? Yes ---

MS EASTMAN: If we just focus on chemical otherwise we might - this might take a

long time, so let's go on chemical only.

5 MS MULLINS: All right. So you would need to apply to the Department of Communities for a short-term approval of the chemical restraint. And a behaviour support plan will be required as part of this process. As well a qualification of the purpose of the medication from a doctor. Now, that - again, that does not apply to people in Queensland who only receive respite or community access services or community access.

10 MS EASTMAN: All right. Now, I want to come in a moment to some of the specific elements of that approval process and the role of family, service providers and medical practitioners in seeking approval. So that's for Queensland. Let's move focus to the Commonwealth scheme, and as you say in your statement, you're required to have knowledge of the NDIS framework but only to the extent that it
15 applies to your clients who are NDIS participants. Is that right?

MS MULLINS: Most of our clients, not surprisingly one way or another, are NDIS participants because we are an advocacy disability organisation but yes, that's correct.

20 MS EASTMAN: The NDIS commenced its rollout in Queensland on 1 January 2016 and was completed by 1 July last year, 2019. And the NDIS quality and safeguards commission began operating in Queensland on 1 July 2019. So there has been a state of transition and I think, as I understand the tenor of your statement, it has been a
25 little challenging for everybody who has got responsibilities both under Queensland law and the NDIS system to work out how do they fit together, but which of their patients or clients might be subject to the different regimes and when they're subject to both regimes.

30 CHAIR: Ms Mullins, I wonder if you wouldn't mind, instead of nodding, to say "yes" or whatever you want to say.

MS MULLINS: Yes.

35 CHAIR: Because we need to record it in the transcript. Thank you.

MS MULLINS: I'm sorry, Commissioner, yes, I will.

40 CHAIR: You can use your extensive legal experience to understand why we need to report this.

MS EASTMAN: So with the NDIS, there is something called the *National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules 2018*, and in terms of the NDIS behaviour support rules, what do they describe as regulated restrictive practices and do you want to comment on the difference
45 between regulated and unregulated restrictive practices for the purposes of the NDIS?

MS MULLINS: Well, they're classifications of regulated restrictive practices. Containment, seclusion, chemical restraint, physical restraint and what's called an environmentalist restraint which is very broad and basically means that is preventing somebody from accessing any part of their environment. So it's ---

MS EASTMAN: What does that mean in a practical - like, give us a practical example of what that would mean.

10 MS MULLINS: Stopping people from going - using a knife. Stopping people from accessing their fridge. Putting a guard in a car between the front and the back seats to prevent somebody who is being transported in the back from accessing the front. Locking the front gate so they cannot leave the property and go out into the environment. It's an extremely broad category and, in fact, a lot broader than the
15 Queensland category. And Queensland also has the exemption for what they call skills deficits. So in Queensland if we don't let you - if we lock the front gate because you don't know how to cross a road, then that's not considered a restrictive practice. At the Commonwealth level, there is no such exemption for skilled services so that would be considered a restrictive practice. The consequence of something not
20 being considered a restrictive practice for Commonwealth purposes is that it will only be regulated under the Queensland regime. There will be no oversight of that particular restrictive practice for the purposes of the NDIS Quality and Safeguards Commission. But really, the breadth of that environmental restraint probably means that in practice it's hard to think of things that wouldn't be covered by that, but would
25 be covered by the Queensland regime.

MS EASTMAN: And with respect to the NDIS definition of a chemical restraint, a distinction is made there between what is and what isn't a chemical restraint, and that's based on whether a medical practitioner prescribes a chemical substance for a particular purpose. Do you want to comment on the distinction in the Rules, and again from a practical perspective what does that mean?

MS MULLINS: So if it is - if a chemical, if a pharmaceutical is prescribed for a recognised medical condition, then it is not considered a chemical restraint. So, for
35 example, if somebody has been diagnosed with schizophrenia and they've been given anti-psychotic drugs, then they are being - the drug is being given for a prescribed medical condition. It becomes a chemical restraint if it's being prescribed for the purposes of behaviour, for controlling somebody's behaviour, rather than for the purposes of treating a prescribed medical - treating an identified medical condition.

40 MS EASTMAN: When you're talking about regulating behaviour, in your experience is there anything in the NDIS rules or anything in the NDIS framework that would tell you, well, what behaviours are in and what behaviours are out for the purpose of using medication as a chemical restraint? Is there anything about the
45 nature of the behaviours that you need to know about before it has that label "chemical restraint"?

MS MULLINS: In terms of - well, what's in the regulation is about what triggers a behaviour support plan. So it's more about behaviours that will harm themselves or harm other people.

5 MS EASTMAN: That could be anything, couldn't it?

MS MULLINS: Well, it could be, yes. Yes, it could. There is no hard ---

MS EASTMAN: Where is the definition?

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MS MULLINS: Not a definition, no. I mean, the definition - no, there's no further definition there that I'm aware of. I don't know whether in the documentation that's provided to behaviour support practitioners, I will say I've not read all of that. There may be something in that documentation but certainly not in the legislation that I am aware of.

15

MS EASTMAN: As you know, as lawyers, often we like to apply an objective test and we get nervous with subjective tests. Is there anything that gives you an objective test to understand what a challenging behaviour or behaviour of concern would be, or is the whole area really subjective? And if you want to talk about that difference, can I invite you to do so.

20

MS MULLINS: I think it probably is fairly subjective and often particularly when it comes to what I would describe as the lower level behaviours of concern, the ones where people aren't being physically hurt. Swearing, yelling, things like that. If people are being hurt or they're hurting other people, then that's important. But other sorts of behaviours, to start putting people on chemical restraints because they yell a bit when they're in public or they haven't been taught how to regulate their emotions, I think, is - and it is subjective in the eyes - sometimes the family, sometimes the service provider who just wants somebody to be quiet and they want an easy life.

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MS EASTMAN: What if the behaviour is it's actually embarrassing behaviour? Would that be challenging behaviour?

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MS MULLINS: Yes, yes. It certainly can if it might be like - like an example would be a sexualised behaviour, or people, there are people that sometimes like to get undressed in public, which isn't harming anybody except perhaps people's, their own sense of dignity and if other people don't want to see people naked. But, yes, there are certainly behaviours that are more about embarrassment for the people around the person who is engaging in the behaviour than it is about any potential harm to anyone.

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MS EASTMAN: So we're not going to find anywhere a checklist of behaviours that describe behaviours from category A to category Z or in alphabetical order, and that if a behaviour on a list occurs, therefore it might give rise to somebody being able to make an application for a chemical restraint? Will we find a list anywhere of what these behaviours are?

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MS MULLINS: Not that I'm aware of. There might be some scholarly article somewhere that somebody has written but certainly not within the legislative framework. And that's where it matters, I think. So nothing concrete.

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MS EASTMAN: Now, coming back to children and young people, if they are an NDIS participant then do the rules apply to them?

MS MULLINS: Yes. Yes. Certainly anybody who is receiving funding under the NDIS Act, the State rules don't apply but the Commonwealth rules, the NDIS Behaviour Support Rules absolutely apply.

MS EASTMAN: Okay. And in terms of what will be a chemical restraint for the purpose of the NDIS behaviour support rules, there's some key requirements that have to be taken into account in developing a behaviour support plan which is a critical gateway to go through for the purpose of the NDIS rules, treating something as regulated or unregulated; is that right?

MS MULLINS: Well, the chemical, in terms of once you've identified a chemical restraint?

MS EASTMAN: Yes, please.

MS MULLINS: Once you've identified that something is a chemical restraint, then there does need to be a positive behaviour support plan developed. The behaviour support plan needs to identify that the chemical restraint is the least restrictive practice that's possible. There is supposed to be a full behaviour and functional assessment of the person. An environmental assessment, because quite often it might be something in the person's environment that is setting them off, whether it's noise or a particular colour or water, or it could be anything. So you are meant to look at that first and for me, most importantly - obviously medication is going to be prescribed by a doctor, but the doctor should be - I'm getting a bit ahead of myself - the doctor should be looking at these alternatives and most importantly looking at whether the behaviour is being caused by pain. Because, really, all of these behaviours, bad as they are, they're a sign of distress. Whether the distress is "I want to do that, I don't want to do that", they're distressed because they can't communicate what it is they want to get across, and if you address the underlying distress first, then the need for chemical restraint will often not exist.

MS EASTMAN: Okay. Now, when we get to ABK we will flesh out a little bit about how the State and the Commonwealth legislation fit together, and what you've had to navigate in supporting him. So can I ask you to ---

CHAIR: Ms Eastman, I'm sorry to interrupt, but I wonder, before you leave this analysis of the legislation, if I ask Ms Mullins a question.

Ms Mullins, I'm looking at Rule 6(b) of the NDIS Rules which says that:

Chemical restraint - the restrictive practice is regulated if it involves

In this case:

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.... chemical restraint which is the use of medication or medical substance for the primary purpose of influencing a person's behaviour. It does not include the use of medication prescribed by a medical practitioner for the treatment of or to enable treatment of a diagnosed mental disorder, physical illness or a

10

physical condition.

That accords with what you've told us. But my question is, how does anybody know what the purpose of the use of the medication or chemical substance? By hypothesis, the medication must be prescribed by a medical practitioner. A medical practitioner

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has presumably two choices, either I am prescribing this in order to treat a condition which is as follows or I am prescribing this to control the person's behaviour. Is that what happens in practice?

MS MULLINS: Yes, Commissioner, that's exactly what happens in practice.

20

Because, as you rightly pointed out, nobody can get on these medications without them being prescribed, and there's a document called the Clarification of Purpose of Medication Form, which is pretty similar whether it's used for State or Commonwealth purposes. The doctor lists the name of the medication, what the dosage is, and then ticks a box to say whether it is for a diagnosed mental illness or condition, or whether it is for controlling behaviours. So in the end it is the doctor

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who makes that final decision and it's hard to influence that, can I say.

MS EASTMAN: This is one of the issues that you deal with in your statement and thank you, Commissioner, because I was just about to go to paragraph 37 where this issue is raised.

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CHAIR: I will treat that as a genuine thank you.

MS EASTMAN: This is where we are up to, so thank you.

35

So one of these issues is that the CPM form is an important form that can operate as a safeguard because it provides a written record that brings transparency to the prescribing practice. Is that right? But you identify in your statement three concerns in relation to the authorisation of chemical restraints, and this partly picks up on what the practice of completing the CPM form is. So can I ask you to have a look at your statement at paragraph 39.

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MS MULLINS: I have that.

45

MS EASTMAN: And one of the first issues is this, is that while the *Disability Services Act* in Queensland operates to regulate the use of restrictive practices including chemical restraints, you say medical practitioners aren't bound by that legisla

tion. So what does that mean in terms of a consequence of having a regulatory scheme to deal with restrictive practices including chemical restraint but as the Commissioner's question just raised, the medical practitioner is the gateway to the chemical restraint, but the legislation doesn't apply to the medical practitioner. So
5 what does that mean in terms of both an understanding of the system, but also is there a way of enforcing medical practitioners to complete their CPM forms?

MS MULLINS: Not that I'm aware of. It does and can become a huge issue, but there is really no way to force them to do it and, of course, because they're the
10 doctors, dare I say, there is no way to stop them from diagnosing perhaps dubious, dare I say it, medical conditions in order to justify a particular use of a chemical restraint, and say, "Oh no, this person has that condition, therefore that is not a chemical restraint."

15 They also, I think I said, they use a medical model. So the way they look at it is that the illness is the disability. The symptom of the illness is bad behaviour, and under a medical model, well, we give them the medicine and in their heads, that's not a chemical restraint, that's treating somebody. So it's hard sometimes to get GPs to get their head around that.

20 MS EASTMAN: You've said in your statement that some medical practitioners, you're not saying everyone, but some medical practitioners are not receptive to the term "chemical restraint", and just that language might steer a person to want to characterise the issue as a medical illness issue rather than a way of controlling
25 behaviour. Is that right?

MS MULLINS: Yeah, I agree. As a lawyer, we just see it as terminology and it's just a legal term. But as a doctor who doesn't have a great deal of interaction with the law when I think about it, it's a pretty full on term, "Chemical restraint". It does
30 sound bad which, of course, it is bad. So I can see why doctors don't like the idea that that - I don't know what terminology would be better but that terminology itself I think is part of the barrier.

MS EASTMAN: Then the final issue is this concern about the interaction between
35 the medical practitioner and the behaviour support specialists and you say that's an issue as well. But that leads you into a discussion in your statement about behaviour support and the development of behaviour support plans. And you identify a few concerns about, on the behaviour support side, how the plans are developed, the relevant expertise of the person preparing a plan, the way in which a plan takes into
40 account all of these relevant factors, and is it the case that when the behaviour support plans are developed, a chemical restraint might be only one small part, and that there might be a range of restraints being --- or restrictive practices being used together? So do you want to just say something briefly about the way in which the behaviour support plans are used and how they're developed, and then I'm keen to get
45 into the situation of ABK.

MS MULLINS: Okay. Part of the problem, particularly because there has been such

a huge expansion in the number of people requiring behaviour support plans, is that there are a limited number of people with real expertise in behaviour support and in writing behaviour support plans.

5 So you've got a lot of people with not very much expertise that are following precedents, effectively. And if you don't have experience in that behaviour support, going and meeting somebody with challenging behaviours can be a bit frightening. Not everybody reacts well to that. So trying to get them to take information from somebody other than the family who may have their own issues and may not have
10 ever had any training in how to deal with the client, so a lot of the information comes second-hand. And the emphasis is pretty well on what are the behaviours, how can we count the behaviours, how do we categorise the behaviours and how to limit the behaviours.

15 MS EASTMAN: And is there any differences between how Queensland requires behaviour support plans to be developed, and then are they regulated or is there an approval process for a plan or monitoring? And then for the NDIS, the same, is there a particular set of guidelines or rules that have to be followed and what about the monitoring or compliance issues? And what happens if both apply, both Queensland
20 and NDIS? What happens there?

MS MULLINS: There you go. If both apply, starting with that, then both apply, but to the extent of any inconsistency from a Constitutional point of view, the NDIA or
25 NDIS regulations will trump the State. The Quality and Safeguards Commission is a great idea, and the Regulations contain a lot of information about what should be in a plan or some information about what should be in a plan, but I don't think the Quality and Safeguards Commission have the resources to actually monitor whether the plans meet those requirements. So simply uploading the plan seems to be enough at the
30 moment unless you are one of the practitioners that they randomly monitor. In Queensland, so in Queensland it's a very different thing. You've to apply for a short-term approval, while to get your short-term approval through, there are hoops you need to pass through. You need the Clarification of Purpose of Medication Form. They usually expect some sort of behavioural support plan or some sort of structure in place. If they're not happy, you will have meetings with the Department
35 and they will talk to you about how things need to be improved, and if you can't meet what they think are the reasonable conditions, then it will be a condition of the short-term approval that you get these other ducks lined up. So if you haven't got your Clarification of Purpose of Medication Form, then the short-term approval will have, as a condition, you must get this by a certain date. Failing to get it by that date,
40 the short-term approval is gone and you can't, it suddenly becomes illegal to use those restrictive practices. So there's a lot more direct ---

MS EASTMAN: What happens if somebody uses an illegal restrictive practice? Is there a system for prosecuting somebody, any sanctions that occur?
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MS MULLINS: Under the Commonwealth legislation you need to - if you are a registered NDIS provider you need to report any use of either unauthorised you used

the term "illegal" so unauthorised restrictive practices have to be reported by the commission. Honestly, I don't know if there's any particular sanction. A lot of the time - there will be unauthorised restrictive practices occasionally. So the Commission doesn't jump on you just because you used a restrictive practice that
5 hasn't been authorised. But the way it works is that from the first time you use a restrictive practice, if it's clear that this is going to be an ongoing thing then that's what triggers having to have a behaviour support plan. So if I'm the support worker, for some reason I have to block or lock a door, I report it. We decide this might need to happen on an ongoing basis, then we have 30 days or a month to try and get an
10 interim behaviour support plan covering that in place. But there's nobody monitoring that. Like, the rules are there but I don't know that anybody is actually monitoring it or they have the resources to monitor it.

MS EASTMAN: Let's turn to ABK. And, as I said ---
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COMMISSIONER McEWIN: Ms Eastman, do you mind if I ask one question about what has just been discussed. Thank you.

Ms Mullins, when you were talking about your observation and experience of
20 doctors and the Clarification of Purposes of Medicine process, in your observation, in addition to the things that you've observed, that you've said, do you think there are any other factors at play in when doctors who --- balancing whether to prescribe the medicine, and you've observed some dubious --- you feel some dubious times against the known side effects?
25

We've heard from other witnesses about side effects of the medications such as increased stroke, et cetera; is there anything else that you think might be at play in terms of factors that might be influencing the doctor go down the path of a particular prescription?
30

MS MULLINS: I think a lot of the time, particularly when people are non-verbal or not able to speak up for themselves, that they are taken to the doctor either by a family member or by, if they live in a group home or supported independent living by a support worker, and I think that there is an interest sometimes on the part of the
35 family member or support worker that is being presented to the doctor. So, yeah, I think that family, not always family, but let's say particularly for people with older children with an intellectual disability, this whole idea of positive behaviour support plans and behaviour intervention was not around in the 50s. So you've these families with 40, 50-year old children where the parents are still looking after them who have never had any interventions. And it just works for everybody, the doctor does feel some empathy for the family who have to deal with this. Sadly, I think if the family knew that there were other options, then that is a possibility. But I've spoken to parents who have just said this person - "My child is a bad person, they've been a bad person all their life." And when I say they've never had training to understand what
40 an emotion is, how to control their emotions, how to understand their emotions ---
45

CHAIR: Ms Mullins, may I ask this. I take it that you haven't actually had firsthand

experience with what doctors do because you don't see what they do?

MS MULLINS: No. The closest I have come - I think Joyce-Lyn Smith is giving evidence after me and she has certainly been to the doctor with various clients.

5

CHAIR: Perhaps we might save this for her in due course. Thank you.

MS EASTMAN: All right. Can I come to ABK.

10 As I said earlier, you have the consent to share the story and there were some discussions about whether ABK and his mother might also come with you to give the evidence. It's their wish that you speak on their behalf; is that right?

15 MS MULLINS: Yes, that's right. ABK himself is not able to speak up for himself and would probably be pretty bored fairly quickly sitting through this. And his mother felt very comfortable with me giving this information rather than her giving it.

20 MS EASTMAN: Okay. And as you described earlier that often the advocacy is quite short-term, but you've continued to advocate for ABK for almost three years, and this length of time is reflecting the particular challenges that he has faced in receiving appropriate behaviour support. So when you were given the file, you had only shortly started in the role, and you met ABK for the first time in January 2018, and at that stage he was living with his mum and a younger sibling. And may I say,
25 you describe in quite graphic terms meeting him for the first time. Can you tell us what happened when you met him for the first time?

30 MS MULLINS: Yes. He was - he was locked in his room as he tended to be all the time. The only thing in his room was a mattress on the floor and some bottle caps. At that point, his only real - the thing that he did a lot was sitting there playing with bottle caps. So I was taken in, the door opened, he was sitting on the floor. He looked up, I smiled at him, thumbs up. He likes, he has always liked the thumbs up, said hello. He smiled back. And it was just a very quick meet and greet. He was happy but, yeah, that was it. To me, quite frankly, it was like he was living like he
35 was a caged animal, and I know that sounds emotive but that is how I felt.

40 MS EASTMAN: He was 15, he was just about to turn 16 in that January. He identifies as a First Nations person and he has a number of disabilities. You've described them in paragraph 60 of the statement. What can you tell us about his disabilities? Not just simply what the label or diagnosis is, but the nature of the disabilities have meant for his life. And I'm asking you that because as you've observed, he had very limited or indeed in some cases no childhood intervention or support, and so his life in terms of early childhood education, education generally and the support from allied health services has pretty much been non-existent in his
45 life. And from your experience, how do we describe or understand his disability against that background?

MS MULLINS: I should start by saying that now what happens to people like my client, like ABK, is that the NDIS, full steam ahead, they get early intervention, they would have access to speech therapists, occupational therapists, everything they need from a very young age. Unfortunately for my client he did not have any of that. He
5 has a severe intellectual disability which means that I know that the behaviour support plans say he has limited written skills. I can quite happily say he has no literacy whatsoever. He is largely non-verbal. When I first met him he was pretty much echolalic so he has never really been able to express himself properly, and he has never had the sort of supports that I talked about before, for OT and speech and
10 all these allied health interventions, that would help him learn how to regulate his behaviour. So without any of these interventions, he was basically wild for a while. When he was living in a remote location ABK would run around, do whatever he liked. When he was at school, there were cases of the teacher having to literally hold on to him, restrictive practices, but he was under 18, for anything up to an hour to
15 calm him down. When he became elevated, he would mash everything up. When he was upset, the whole house was in danger. And basically all of this has made is very hard for him to access any sort of health services. So he has had a number of health issues that have gone unlooked at for years. And when they are looked at, there's meant to be a follow-up and the follow-ups never occur.

20 In terms of his education, he had a brief period of education, if you could call it that. He had two several brief periods of attending school, never really received any education. When he was living in the Torres Strait it ended because of lack of funding. When he was in his current location it ended because of behaviours at
25 school. He was at the special school. So his whole life has been impacted. It's hard to think of an aspect of his life that hasn't been impacted by his ASD3 and his severe intellectual disability. We think he has Down syndrome but that has never been confirmed because the tests weren't done.

30 MS EASTMAN: And so the request to provide some advocacy support for him, and I assume his family, came through a service provider rather than from the family. Is that unusual?

35 MS MULLINS: No. Families don't always know about our services, so quite often it will be a service provider who is aware of IANQ that will refer this. This came from somebody who was not his regular service provider but somebody who was assigned by child safety because ABK's mother had tried to relinquish custody because the behaviours were just becoming too much for herself and her youngest
40 child.

MS EASTMAN: So you know the focus of this hearing is looking at the psychotropic medications as a form of chemical restraint, and also psychotropic
45 medications that may be used not as a restraint but to support people with disability. And your description of your advocacy of ABK over the last few years has covered a myriad of issues well beyond just questions of medication and restraint; is that right?

MS MULLINS: Yes, absolutely. It has been pretty much every aspect of his life.

Housing, health, accommodation. Yes, school, NDIS issues, guardianship, Public Trustee. It has been every aspect of his life, yes, pretty much.

5 MS EASTMAN: Without diminishing every aspect of his life, I want to ask you some questions to help the Royal Commission understand, in the context of the complexity of ABK's life and your hopes for him in the future, is how the disability and health systems have come together, and particularly in terms of diagnosis of conditions and circumstances that lead to the use of psychotropic medications.

10 So can we try to sort of focus on those issues. But I appreciate, and this is very clear reading your statement, that it's very hard to divorce the issue of the medications outside other issues, so let's try to sort of work through it.

15 So in early 2018 when you started the advocacy, having met ABK for the first time, did you have to have any interventions with ABK's health arrangements, and were you involved in meeting any of the medical practitioners providing support to him? And, if so, what occurred during this first part of your advocacy work with him?

20 MS MULLINS: Once we had established a regular stakeholder meeting, both a GP and eventually a paediatrician both came onboard. So my interactions in relation to the medication were at the stakeholder meetings. He had been put on Quetiapine in September by a visiting doctor, and that was around the time the child safety interventions were happening, so the State Government stepped up, a visiting doctor from the State Government service put him on Quetiapine before I was involved, and
25 then after that, the GP became involved and then tried to get State medical services involved locally, and having them refuse us, he eventually found a paediatrician. So it was a monthly stakeholder meeting that we all used to attend.

30 MS EASTMAN: You've subsequently become aware by obtaining some earlier medical records that ABK had been prescribed different medications throughout his childhood starting with - I can never say these words --- Dexamphetamine from the age of 5. Did you see anything in the records that explained those medications?

35 MS MULLINS: Yes, absolutely. I obtained his medical records from two different areas and the medical records show that he was put on Dexamphetamine at the age of 5, but there was nothing in the record that showed when he was taken off that, but at some stage he was. And there is nothing really to show why he was prescribed that except around his behaviours.

40 MS EASTMAN: And when he was 12, Risperidone was described but only used for two weeks because ABK's mother claimed that it made him more aggressive. Is that right?

45 MS MULLINS: Yes, I think --- that's correct, and she did confirm --- that was both in the medical records, and she certainly remembered him being on Risperidone --- when he was being put on it again, she remembered the first time.

MS EASTMAN: And just walking through what has happened since 2018 up to the present time, how has his health been managed and what is the current situation in terms of any particular medications being prescribed for him, and identification of the reason why? And if you want to touch on a particular meeting that you attended where a paediatrician I think said something and the room looked in shock, can I invite you to deal with that part of your evidence, please.

MS MULLINS: So there had been various different - there was a decision that Quetiapine was not right on a long-term basis because of the health implications, so he was moved to Risperidone by the paediatrician. At a stakeholder meeting ABK's respite providers reported that he was very, very sleepy all the time. And normally he was quite active and enjoyed hanging out with them and helping them with housework but all he wanted to do was sleep. So we kind of all looked at the paediatrician. She - I can't remember exactly what she said, but she did accept that it seemed like that he was over-medicated. He turned to ABK's mother and asked her whether it was all right if the medication was lowered. ABK's mother indicated some nervousness because she had been through a lot in the past. So she was not happy and basically said that she relied on the medication. So the paediatrician then said she would take his current dose in the mornings and halve it, so she would have the pharmacy halve the tablets, and he would be given the half tablet on a fixed dose in the morning and that ABK's mother would be provided a tablet or a bottle for the other half tablets for her to use just in case. She became concerned about his behaviour.

So I can remember - I think you will understand that sometimes it's difficult to question a doctor, particularly a specialist, which a paediatrician is. I remember the rest of us looking at each other, quite shocked, and I can remember afterwards us having a discussion that it looked like a casual PRN being given to ABK's mother but ---

CHAIR: Sorry, could you just explain PRN, please. We've heard that term. I'm not sure it has been explained.

MS MULLINS: Oh, the screen just broke up for a moment. You're back.

A PRN is a drug that is given when needed, as opposed to on a regular basis. So my client was on what we call a fixed dose every day, but sometimes drugs can be approved, "Oh, this person has become elevated, we can give them one of these tablets now to calm them down", because these anti-psychotic drugs do have quite a strong --- calming is one way to put it; turning somebody into a zombie is another way to put it.

MS EASTMAN: Okay. Can I turn now to the advocacy work that you've done in relation to the development of the behaviour support plans. You've included in your evidence a redacted form of three behaviour support plans that have been developed for ABK. What can you tell the Royal Commission about the process that you've observed around the development of these plans? Who had been involved, and from

your observation what expertise did they have in developing a plan for ABK?

MS MULLINS: I think I touched on this before and one of the problems at the moment is that there are so many - there is so much NDIS funding floating around
5 and so many people needing behaviour support plans that there aren't enough people who are experts in this field drawing them up. And that particularly in regional, remote areas, those people that are experts have a waiting list a mile long. So the first thing you're doing, you're often dealing with a behaviour support practitioner --- who is well-meaning, I'm not saying that they have bad intent, but they just don't
10 have the experience, and as I said before, if you're not used to dealing with challenging behaviours, you yourself can find them confronting and frightening, which makes it harder for you to actually step into the space and look at the person. They have a tendency to rely on reports from family, from support workers. So that part of the development of the plan, I think, rather than really looking at the person, relying just on second-hand accounts, I don't think is the best way to go there.
15

In terms of how the plan is developed, there is a requirement that relevant people are consulted. Again, there's the requirement - well, we liked the doctor, we hoped the doctor would sign a Clarification of Purpose of Medicine. That's really theoretically
20 necessary, but if they don't, you tend to rely on, like, take a precautionary approach and assume it is. That's in fact what happened with ABK, because after multiple attempts by all of us to get a CPM signed, it just wasn't coming, we received advice to say from the NDIS Quality and Safeguards Commission saying treat it like they are. And, of course, when it came around to the Queensland approval, she - the
25 person who approved it for Queensland looked at the drugs involved and said they are chemical restraints, it doesn't matter what the previous doctor said.

MS EASTMAN: All right. So pausing there.

30 MS MULLINS: Sorry.

MS EASTMAN: Up until January this year, ABK was only under the NDIS regulations and rules.

35 MS MULLINS: That's correct.

MS EASTMAN: When he turned 18 in January this year, that required the Queensland laws to kick in?

40 MS MULLINS: That's correct.

MS EASTMAN: And so there had to be the approval processes for any restrictive practices, that's not just the chemical restraints but every restrictive practices that were operating, there with were a number for ABK, the environmental restraints,
45 some of the containment restraints that you refer to. You say at paragraph 127 of your statement that because the plan that was developed that then had to be approved by the Office of the Public Guardian in Queensland included seclusion, a request for

approval was forwarded to OPG, and in February this year OPG advised that the approval was not granted for containment or seclusion, because there was insufficient evidence of the practice being necessary. And so you step in at that point in terms of advocacy. So I think you said earlier you had the discussion with OPG.

5 And then what happened? So bring us up to the sort of current time in terms of what is or is not presently authorised under Queensland law.

MS MULLINS: So after OPG said no to containment and seclusion, we did still need approval for chemical restraint, fixed dose and for a few physical blocking techniques. So that's where the short-term approval with Queensland came in. So we put a request for a short-term approval in. And that included the interim behaviour support plan as evidence of what we were doing. We were told by the Department of Communities that that was insufficient evidence. We provided insufficient evidence for them to make a decision. I then approached them once we have the comprehensive plan and said, "Well, here is the comprehensive plan, is this enough evidence for you to approve?" They said no. They agreed to have a phone hook-up during which we discussed they did not consider the positive behaviour support plan that was filed with the Quality and Safeguards Commission met the required Queensland standards. So they gave us a short-term approval, but one of the conditions was we had six months to do a new positive behaviour support plan. And I think we had like one month to get the chemical restraint clarification.

MS EASTMAN: So the short-term approval for both the physical and chemical restraint was granted by the department in June this year. So there's a process now of time to complete a new positive behaviour support plan. And I'm conscious of the time, Commissioners, so bear with me.

But, Ms Mullins, can I end by asking you about what are the current arrangements for ABK and as at the present time what is happening with him, and if you could just comment on his quality of life from when you first met him. And I know we've spent a lot of time navigating systems and regulations, but can we end actually by just telling us where is ABK now and what is happening with him?

MS MULLINS: Okay. Two and a half years later, I am really pleased to say that his life has changed completely. His mother and younger brother have moved into different housing but only five doors away. So they're still close by. So he has - he has turned 18, he has his own home. He has, I must say in his case, a very good NDIS plan with 24/7 supports. He goes out into the community. He is exercising his own choice and control over when he does things and what he does. He is showing the ability to do so many more things on his own. Previously it was thought that he didn't have the capacity to do, he is showing he can do it. So we're really pleased. We've put him in touch with a new GP and a new - and a psychiatrist. We're just navigating getting him there at the moment, which is proving to be the biggest issue. But really, his life, compared to when I started, has turned around a lot.

45 And frankly, if we can come back to the chemical restraints, there have been so many changes in his life that I think the next thing on the books is dealing with that.

5 Because I know, Commissioners, I know you've been shown photos of ABK and that you will see that the one of him by himself, he is considerably larger than in some of the others. We believe this is due to his Risperidone and that that is the - that one of the side effects is him putting on weight, and he really needs to - those issues need to be addressed urgently but he is getting help.

10 MS EASTMAN: Ms Mullins, I know you've also included some very helpful suggestions in your statement from paragraph 160 and following for change, and the Commissioners have read that part of your statement, but I might conclude your evidence here and thank you very much for telling us about the journey ABK has taken over the past few years.

And, Commissioners, that concludes the evidence.

15 CHAIR: Thank you. I will ask Commissioner Atkinson if she has any questions.

COMMISSIONER ATKINSON: No, thank you.

20 COMMISSIONER McEWIN: No further questions. Thank you.

CHAIR: Can I ask you, Ms Mullins, you've referred to the improvement in the quality of ABK's life. In your assessment, have changes in the extent to which chemical restraints have been applied or indeed that has been administered psychotropic drugs, has that played a part in the improvement?

25 MS MULLINS: There hasn't been - the last change that was made to his drugs was when they - when he was being reported as too drowsy. So no, I think it was well over a year ago. So, no, there have been no changes to the chemical restraints. It has been more about just him being given more choice. But I do believe that he - I'm not a doctor ---

30 CHAIR: That's all right. I don't want you to go beyond your expertise. I thought you might have had a view about it over your experience in the last year or so, but if that hasn't changed, that's fine, thank you.

35 MS MULLINS: Sadly it hasn't, and that is one of the things that needs to happen and needs to change soon.

40 CHAIR: Thank you for giving evidence and thank you for your very detailed statement of 46 pages which we have read. It has been very helpful. We appreciate your evidence.

45 **THE WITNESS WITHDREW**

MS EASTMAN: Thank you, Commissioners, a little bit of slippage and I apologise

for that. Can we have 15 minutes and come back at 11.55?

CHAIR: Certainly.

5

ADJOURNED

[11.42 AM]

10

RESUMED

[11.59 AM]

CHAIR: Yes. I think we have Brisbane on the screen. So we shall proceed straight to Brisbane, if we may.

15 MS ZERNER: Thank you, Commissioner. The next witness we call today is Ms Joyce-Lyn Smith.

CHAIR: Ms Smith, thank you very much for coming to give your evidence. If you would be good enough to follow the instructions of my associate, she will administer the affirmation to you. Thank you.

20

MS JOYCE-LYN SMITH, AFFIRMED

25

EXAMINATION-IN-CHIEF BY MS ZERNER

CHAIR: Yes, please. Thank you.

30

MS ZERNER: Thank you. Ms Smith, it's correct, isn't it --- oh, can you tell the Commission your full name, please?

MS SMITH: I am Joyce-Lyn Smith.

35

MS ZERNER: Thank you. And it's true, isn't it, that you provided a detailed statement to the Commission which is dated 14 September 2020?

MS SMITH: That's correct.

40

MS ZERNER: And that statement you've had a chance to review recently?

MS SMITH: Yes, I have.

45 MS ZERNER: And it's true and correct to the best of your knowledge?

MS SMITH: It is indeed.

MS ZERNER: Commissioners, you will find Ms Smith's statement at Tender Bundle A, Tab 24. There are some annexures to her statement at tabs 25 through to 29.

5

Commissioners, I seek leave to tender those documents and mark them as Exhibits 6.8.1 through to 6.8.5.

CHAIR: Thanks, Ms Zerner, we will mark them in that way. Thank you.

10

EXHIBIT# 6.8 - STATEMENT OF MS JOYCE-LYN SMITH

15 **EXHIBITS# 6.8.1 THROUGH TO 6.8.5- ANNEXURES TO STATEMENT OF JOYCE-LYN SMITH**

MS ZERNER: Thank you, Commissioner.

20

I want to commence with a little bit of an introduction about you.

As I understand, you are the Clinical Director of Professional Disability Development Supports and Services. That's correct?

25

MS SMITH: Correct.

MS ZERNER: And it's shortened to be called PoDDSS; is that right?

30

MS SMITH: That's right.

MS ZERNER: You set that business up in July 2017?

MS SMITH: That's correct.

35

MS ZERNER: And your organisation consists of a number of people there, but there are certain services you provide in the organisation. That's correct?

MS SMITH: That's right.

40

MS ZERNER: It ranges from support coordination, positive behaviour support planning, training and skills development of disability support workers and psychology and counselling services?

45

MS SMITH: That's correct.

MS ZERNER: Today part of the focus is going to be on behaviour support plans and

we will take you to that shortly. But you've got experience in disability that spans over 22 years. That's correct?

5 MS SMITH: That's right, yes.

MS ZERNER: In January of 2007 you commenced working with the Queensland Department of Communities, Child Safety and Disability Services, as it was known then?

10 MS SMITH: That's correct.

MS ZERNER: And in your time at the Department, it's the case, isn't it, that you worked in the Intensive Behaviour Support team?

15 MS SMITH: That's right.

MS ZERNER: And is it the case that that came out of the Carter Inquiry in Queensland in relation to services being provided to the intellectual disabled people?

20 MS SMITH: That's correct.

MS ZERNER: And in regards to your role in the intensive behaviour support team, you were responsible for writing and reviewing positive behaviour support plans, weren't you?

25 MS SMITH: That's right.

MS ZERNER: Now, not all of those plans had chemical restraint?

30 MS SMITH: No, they didn't.

MS ZERNER: Some did and some contained other restraints?

35 MS SMITH: That's right.

MS ZERNER: In 2007 to 2008, around the time you started in the Department, it's true, isn't it, that you completed a six-month training course on behaviour support with the Institute of Applied Behaviour Analysis?

40 MS SMITH: That's correct, yes.

MS ZERNER: That organisation is based in America, in Los Angeles?

45 MS SMITH: That's right.

MS ZERNER: As you explain it in your statement, you say you were involved in intensive training and working through the various stages of a positive behaviour

support plan?

MS SMITH: Yes.

5 MS ZERNER: When you say intensive training, what did they put you through?

MS SMITH: It's a six-month program where you write a positive behaviour support plan with somebody and it's overseen by Professor Gary La Vigna. He supports very robust discussion around the development of those plans, what they should look like and how they should be constructed.

10 MS ZERNER: Okay. And you were able to apply those skills and that training you've had and you've been doing that work ever since, really?

15 MS SMITH: That's right.

MS ZERNER: In May 2016 you had perhaps a unique opportunity to work in the National Disability Insurance Agency?

20 MS SMITH: Yes, that's right, on secondment as the Department of Communities was winding down.

MS ZERNER: Okay. And that was for six months, was that right?

25 MS SMITH: That's right.

MS ZERNER: And what did that give you an insight into when you had that opportunity?

30 MS SMITH: It gave me an insight into how the NDIS system works, and how things needed to be presented to them to assist with getting the best outcomes for people.

MS ZERNER: And then in 2017 it's the case, isn't it, that your position at the Department had become redundant?

35

MS SMITH: That's correct.

MS ZERNER: And part of that was in relation to the rolling out of the NDIS; is that correct?

40

MS SMITH: That's right.

MS ZERNER: All right. Now, you provided the Commission a very detailed statement. It's 32 pages long. We're not going to have the opportunity to go through all of your statement today, but there's two topics I would like to take you to specifically.

45

We're going to look at behaviour support, and then challenges in relation to the regulation. Now, some of the astute people that are watching on or are in court will notice that you've the same backdrop as Ms Mullins; that's correct?

5 MS MULLINS: That's correct.

MS ZERNER: And you've had the opportunity to listen to Ms Mullins's evidence?

MS SMITH: I have.

10

MS ZERNER: You would have observed there were a number of questions asked, and I hope we can answer those questions throughout your evidence today.

MS SMITH: Yes.

15

MS ZERNER: In regards to behaviour support, we've heard a recurring theme, and that theme is that the gateway to chemical restraint is through the medical profession.

MS SMITH: Correct.

20

MS ZERNER: We've also heard another theme, and that is the difficulty in differentiating between perhaps challenging behaviours and mental illness?

MS SMITH: Correct.

25

MS ZERNER: And that you would see in practice a fair bit, don't you?

MS SMITH: I do, yes.

30

MS ZERNER: And in Queensland, the service provider is required by the Department to use a Clarification of Purpose of Medication Form.

MS SMITH: That's correct.

35

MS ZERNER: And you would have heard Ms Mullins refer to that, and the importance of that in relation to restrictive practices?

MS SMITH: That's right.

40

MS ZERNER: Can I please ask that a copy of the Department's Clarification of Purpose of Medication Form be brought up.

Commissioners, this document is within the Tender Bundle, at Tender Bundle C behind Tab 44, and it's one of the annexures to the statement of Donna Lockyer.

45

I just wanted to go through that with you. You will recall that Commissioner Sackville referred to the NDIS Restrictive Practices Behaviour Support Rules, and he

referred to the definition in regards to chemical restraint. Do you recall that?

MS SMITH: Yes, indeed. Yes.

5 MS ZERNER: And that definition was that chemical restraint which is the use of a
chemical substance for the primary purpose of influencing a person's behaviour, but
does not include the use of medication prescribed by a medical practitioner for the
treatment of, or to enable treatment of a diagnosed mental disorder, a physical
illness, or a physical condition.

10

MS SMITH: Correct.

MS ZERNER: Now, on this particular form we can see the definition under the
Queensland legislation, the *Disability Services Act* 2006, and we can see there's a
15 difference in the definition, isn't there?

MS SMITH: Yes, there is a slight difference.

MS ZERNER: And that slight difference is that in Queensland, it refers to the
20 primary purpose of controlling the adult's behaviour in response to the adult's
behaviour that causes harm to the adult or others. So there is a difference between
the definitions in relation to chemical restraint. That's correct?

MS SMITH: That's right.

25

MS ZERNER: All right. Now, in regards to this form it obviously sets out the
definitions. At the top of the form it refers to that term that we just referred to before
of "PRN", so as required, or a fixed dose. And then if perhaps we can go over the
page and this is the section that is required to be filled out by medical practitioners.
30 That's correct?

MS SMITH: That's right.

MS ZERNER: And we can see there, there's lots of information that needs to be
35 recorded but the three columns with the check boxes are the critical boxes, are they
not?

MS SMITH: That's right.

40 MS ZERNER: And so it's up to a medical practitioner to assess the patient and try
and fit what information they've been provided into one of these boxes?

MS SMITH: Correct.

45 MS ZERNER: And it's the case, isn't it, depending on which box they tick, it will
lead the patient to a different pathway?

MS SMITH: That's correct, yes. So one pathway would be that it is treated as a medication for therapeutic purposes where there's no regulation or oversight. That's right?

5 MS SMITH: Yes.

MS ZERNER: And the other being that if it is deemed as being chemical restraint, the regulation or the regulatory frameworks come into effect. That's right?

10 MS SMITH: Yes. Yes.

MS ZERNER: All right. Now, we will come back to that particular form and how the challenges that you have had with that in regards to service providers as we go on in your evidence. So I just wanted to understand. So really, the trigger is going to be
15 that you get this form, the form has indicated - the doctor has indicated that the primary purpose is controlling a person's behaviour, it therefore becomes a chemical restraint.

Now, under the regulatory framework ---
20

CHAIR: I'm sorry to interrupt. I would just like to clarify something which is at present unclear in my mind.

MS ZERNER: Yes, Commissioner.
25

CHAIR: Ms Smith, at paragraph 43(a) of your statement you say that:

One issue is that because medical practitioners are not regulated by the [State Disability Purposes Act], they are not required to complete a Clarification of Purpose of Medication Form
30

I'm a bit uncertain as to where the requirement to complete such a form actually comes from. Is it because of the requirement that is imposed on an NDIS service provider to get approval and that's one of the conditions of approval or is it
35 something else?

MS SMITH: Well, when the medication is prescribed as for the primary purpose of controlling the person's behaviour, then that usually or even if there's a question about it, usually people will seek advice from a behaviour support practitioner if they
40 can or from a doctor to clarify the purpose of medication.

CHAIR: Yes. But why does the doctor have to fill it out?

MS SMITH: Well, it's part of the legislation. We can't assume why the doctor has
45 prescribed the medication.

CHAIR: I understand that.

MS SMITH: We ask if they will complete it.

5 CHAIR: I'm not sure where it's found in the Act or the Rules, but no doubt we will be able to find that in due course.

MS SMITH: I don't know that it's actually in the Act or the Rules but it's part of the procedure that actually occurs to confirm ---

10 CHAIR: That's why I asked the question, Ms Smith.

MS SMITH: Yes.

15 CHAIR: Carry on.

MS ZERNER: Ms Smith, just picking up on that, is it your understanding that it's a requirement of the department in Queensland that one of these forms is completed when a person is deemed to be receiving chemical restraint?

20 MS SMITH: That's correct.

MS ZERNER: All right. Now, I wanted to then lead on to behaviour support plans. Now, we've heard this morning of some examples of perhaps ineffective or not particularly of a high standard of behaviour support plans. With all your extensive
25 experience and the training that you've had, I would like to focus on what is an effective behaviour support plan.

30 You talk about a behaviour support plan being person-centred and really that's about meeting with the person, meeting with the people around them and getting a good sense of that particular person that you're actually preparing the plan for. That's right?

MS SMITH: That's right, including doing some observations and spending some time with the person.
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MS ZERNER: And when you're spending time with the person, what does that involve?

40 MS SMITH: That depends on the individual concerned, but can be things like just going on activities with them when they go, I try to observe them in different situations, both at home and out in the community.

MS ZERNER: And do you feel that it's important that you're spending different times or different periods with a person to get a true sense of their behaviours?
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MS SMITH: And also a true sense of what their day looks like because often one of the things that happens with behaviours are that people are bored, or they're not being

stimulated, or they're in pain. Then behaviours can occur. So that's some of the things we're getting a sense of.

5 MS ZERNER: All right. Now, in paragraph 80 of your statement, I don't need to take you there, you refer to the model at the Centre of Excellence that perhaps wasn't as person-centred as perhaps what your practice is. Is that right?

MS SMITH: That's correct.

10 MS ZERNER: Now, the Centre of Excellence was set up again out of the Carter Inquiry; that is correct?

MS SMITH: That is correct.

15 MS ZERNER: It was set up for research development, training and to help people with disability?

MS SMITH: That's right.

20 MS ZERNER: There are different schools of thought in relation to the practice of behaviour support plans?

MS SMITH: I guess from my point of view the IABA model would be what I would consider the gold standard. And I think that previously some of the problems that
25 may have occurred were that some practitioners were overly verbose when they came to completing the plans and things - the documents got a little bit unwieldy in terms of size. So I think it's important - I acknowledge the reason why the shorter document was developed, but I think it became too short and missed important aspects of the person.

30 MS ZERNER: All right. Thank you. Just moving on to the next element of an effective behaviour support of what you say in your statement, you say that it involves initial and frequent ongoing consultation with all stakeholders involved, families, doctors, allied health. When you say "initial", that would be part of the
35 person-centred aspect, is that correct?

MS SMITH: That's right.

40 MS ZERNER: In relation to the ongoing and follow-up, can you just explain how that works?

MS SMITH: With the work we do, often through stakeholder meetings, regular team meetings with the support workers themselves, all of those things we catch up around the changes that are happening for the person, but also the data collection feeds into
45 how that person's travelling. And so all of that, what should happen is that the more the positive behaviour support plan is implemented, you see a reduction in the behaviour of concern.

MS ZERNER: Okay.

5 CHAIR: Ms Smith, can we just go back a step again so I can understand it. Others may well understand it already.

How do you come into this process? What's the start of getting a support plan that you formulate? How are you asked to do that?

10 MS SMITH: So that usually comes through the NDIA or in terms of somebody doing a self-referral, or a family member doing a referral, or a service provider doing a referral.

15 CHAIR: Why would a service provider do a referral?

MS SMITH: Because something may have changed for the person where they are aware that, for example, they may have been prescribed chemical restraint at their last visit to the doctor, and so then the service provider may request some assistance.

20 CHAIR: But how could they administer a chemical restraint prescribed by a doctor as a chemical restraint without a support plan being in place in the first place?

25 MS SMITH: Well, often the referral to the doctor is what starts that process off, so usually it's not identified that it's chemical restraint until the person starts on the medication, and then you've timeframes to meet in terms of interim plans, et cetera.

CHAIR: Yes. Thank you.

30 MS ZERNER: Just picking up on that, Ms Smith. Is that in relation to those short-term orders that Ms Mullins was talking about earlier?

MS SMITH: That's correct.

35 MS ZERNER: So there is an interim order put in place that the medication has started and is a chemical restraint?

MS SMITH: That is correct.

40 MS ZERNER: So in developing this plan, I just wanted to refer to proactive and reactive strategies to attempt to prevent behaviours of concerns. Can you briefly give us examples of the sorts of strategies that you would put in place?

45 MS SMITH: Well, you document things that would give a support worker some clear idea about how to work with a person. For example, don't use the word "no". Because sometimes people don't like the use of that word, they've heard it a lot, they don't want to hear it any more, so a support worker in that situation shouldn't use that word. And there may be a way that to get them --- to do something to prevent

behaviour, you may ask them to do a non-preferred activity and then a follow-up with, "And then we're going to go to do a preferred activity", whatever that might be for that person.

5 So it's really around the person and what works and doesn't work for them that you give support workers stat gist so that they try to prevent getting in a situation where there is behaviour of concern.

10 MS ZERNER: Once you've identified those proactive and reactive strategies and they're incorporated into that behaviour support plan, is it your role then to assist in the implementation of that plan?

MS SMITH: Yes, it is.

15 MS ZERNER: So how does that work?

20 MS SMITH: So we will have identified through the data that we've collected from the service provider different skills and things that people need to learn so they don't need to display behaviour of concern to get their needs met appropriately. But also it's about a look at quality of life. So we look at somebody's quality of life and what could improve that quality of life so that they have a more fulfilled role in the community and outside for them. So they don't need to display those behaviours.

25 MS ZERNER: And in regards to the implementation of the plan, the people working with the person with the disability become critical, don't they?

MS SMITH: They do indeed. Very important to have them being consistent.

30 MS ZERNER: And it may be family, but when you say consistency, I assume you're talking about support workers?

35 MS SMITH: I'm talking about everybody, family as well as support workers, anybody who interacts on a consistent basis with the person needs to understand how they need to interact with the person appropriately.

MS ZERNER: Part of that is you would provide training to, for example, support workers in regards to those strategies?

40 MS SMITH: Absolutely, yes.

MS ZERNER: Now, I want to come back to the data collection because you said that data is critical, that's --- the bent I got on your evidence is that it's a critical element of this process?

45 MS SMITH: That's right.

MS ZERNER: And when you're talking about data, it's the case, isn't it, that you're

looking at incidents that occur over a period of time?

MS SMITH: That's correct.

5 MS ZERNER: And it's the case that you are asking those support workers to monitor the effectiveness, so to speak, of the strategies you've put in place by identifying the reactions, for example, if there's an incident or there's an adverse behaviour, et cetera?

10 MS SMITH: That's correct.

MS ZERNER: So when you've got that process in place, what happens when you get that data?

15 MS SMITH: So you input the data and depending on how often the stakeholders are meeting or the service providers are meeting, you update that data and give it to the service provider so that they have a clear indication of how things are travelling. And you can also provide that information to the doctors and GPs because that can help them inform any medication changes that they may make.

20

MS ZERNER: All right.

MS SMITH: You because you can see the changes in the behaviour whether there's less or more behaviour when medication changes.

25

MS ZERNER: Now, can you give the Commissioners an example of that in practice, in the sense of a time where you've collected data --- I may go to your case studies later but I'm thinking of a quick example in regards to data collected, feeding that information back to support workers and a change in behaviour.

30

MS SMITH: So we had a situation where over two years we gathered data for a particular person, and we could tell the service provider that on Wednesdays - and sorry I can't remember the percentage - but on Wednesdays it was pretty significant around the 3 o'clock mark there would be a behaviour of concern. So that was when that led us to believe that those particular support workers who regularly did those shifts together potentially may be having a conversation about the person that they could overhear. I mean, that's because one of the things that often happens for people with various disabilities is they often have higher hearing ability so they can hear conversations at a distance and I'm talking at considerable distance from where those conversations can be heard, despite numbers of walls and things. So, in terms of their ability to overhear conversations that are negative. So he was overhearing those conversations. We had a conversation with the service provider and suggested that they needed to make the support workers aware that he was not responding well to those conversations they were having.

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MS ZERNER: And the impact of changing that strategy?

MS SMITH: Well, Wednesdays at 3 o'clock isn't such a bad day any more.

5 MS ZERNER: All right. Thank you. In your statement, I don't need to take you to it, but you make a reference that under the NDIS Behaviour Support Rules, and I will annotate that to that term, that a positive behaviour support plan is to be reviewed every 12 months. And you have a view that that's perhaps too soon because there's needing time to implement the plan. Can you just explain what you mean by that process and perhaps what you see as being an alternative or a solution?

10 MS SMITH: Well, I see that, you know, in terms of being a person-centred approach you can't have a whole lot of strategies that you lump on top of a person with a disability, and expect them to be able to take it all onboard at once. And so, needing a sufficient amount of time to successfully implement a plan, in my opinion, needs to be included in that. I'm of the opinion that maybe a plan should be done
15 approximately every two years rather than every year, and so that throughout that time you should be able to demonstrate the implementation of the plan, how that's progressing, and also how the behaviours are going in relation to the implementation.

20 MS ZERNER: I just want to pick up on something you said there, and that was in relation to the demonstration of the implementation of the plan, be it successful or unsuccessful. Currently, is there any requirement to show that we've put this plan in place and that it has been effective or not?

25 MS SMITH: Well, you can do that within the reports but there's no - maybe this is the statistician in me, there is no actual evidence of the success of that necessarily provided, depending on the person doing the plan or the practitioner.

30 MS ZERNER: In relation to preparation of these plans, they can be expensive to prepare a plan; that's correct?

MS SMITH: Yes, very.

MS ZERNER: And figures of \$12,000 to \$20,000 wouldn't be unusual?

35 MS SMITH: No, not at all.

MS ZERNER: Can be higher?

40 MS SMITH: Yes.

MS ZERNER: And an element of that funding is to go towards the training as well as the development of the plan. That's correct?

45 MS SMITH: That's correct.

MS ZERNER: But once that plan is in place, there's nothing else in relation to any tied funding or anything like that in regards to the implementation and the

effectiveness of that plan?

MS SMITH: That's correct.

5 MS ZERNER: So we could come back 12 months later and required to undergo that same process again. That's right?

MS SMITH: That's correct.

10 MS ZERNER: Now, in regards to behaviour support plans, you've been doing these for a long time, since 2007, 2008. What do you see, and perhaps you can give some examples, of the effectiveness of a good behaviour support plan when it has all of those elements we talked about? So it's person-centred, it involves all of the team, so we've got stakeholders; it's got the proactive and reactive strategies; it's implemented
15 by a team that is trained to be able to put it into place; and there is data collected to see if it's working, if it's effective. Can you give us examples of when it has worked and what those outcomes have been?

MS SMITH: I worked, it was actually the very first case I did under the IBIA, where
20 I completed the first part of the report and presented that to the support team. We noted that the gentleman had had 13 serious incidences and it just happened that I was presenting that information on 16 March, so mid-month pretty much.

25 After I presented them this gentleman's history and explained some of the things that had happened to him, for the rest of the month there was one incident. So even presenting information to the support staff to understand the person, and why he was doing some of the things he did, made a significant impact on the behaviour.

30 In terms of other incidences, in terms of the full implementation of a plan, I have a gentleman who was initially identified, he was at the notice of the courts and was on a suspended sentence for aggressive assaultive behaviour, and his work turns up all the through having a positive behaviour support plan implemented, to the point now where we've done an anger management program with him which was part of the positive behaviour support plan. He can now identify his emotions, and in terms of
35 his anger, we've measured pre and post testing, and his anger management is now within the normal range for somebody of his age.

40 This gentleman who had previously been in the receipt of quite a lot of trauma during his childhood, and that is frequently something that affects people's behaviour as they get older. He is now addressing some of that trauma through EMDR therapies, and very pleasingly is now playing hide and seek with his support staff and recently used his skills that he had learnt to calm down an anxious support worker, which just goes to show exactly how far this man had come when he had a 98 per cent receptive communication difficulty.

45 So he didn't understand much previously of what people were saying to him. As he has worked his way through the process, he now has a far better receptive

communication ability and obviously he is in the best place he has ever been in his life.

5 MS ZERNER: Thank you. You say in your statement that there has been instances, and that may be an example of there is no further interaction with the justice system because of putting in those behaviour support plans and strategies that you talked about?

10 MS SMITH: Yes.

MS ZERNER: I guess the big question ---

15 COMMISSIONER McEWIN: Ms Zerner, sorry to interrupt. Could I just ask, you mentioned EMDR therapies, is that my understanding of the acronym, and what does it mean?

20 MS SMITH: It is Eye Desensitisation Movement, and I can't remember what the R stands for, I do apologise. But it's a type of therapy that has really good effect with people with disabilities who have been subject to abuse or trauma of some kind to help them process what has occurred.

COMMISSIONER McEWIN: Thank you.

25 MS ZERNER: Ms Smith, I guess the really big question for this hearing is from your experience implementing an effective behaviour support plan, does that reduce the need for chemical restraint or reduced chemical restraint in these people?

MS SMITH: Yes indeed.

30 MS ZERNER: Again, can you give me a brief example of a person that you've worked with that there has been a significant decrease or a ceasing of the chemical restraint?

35 MS SMITH: So along similar lines, there was a young lady, this is not in any of the evidence I've given previously, but a young lady was subject to chemical restraint and the doctor really used his behaviour support practitioner to best effect, to monitor reductions in medication as he slowly withdrew her from medications she had previously been on. So that was implementing the plan, then giving him the data and the information so he could see what was happening as he slowly reduced the
40 medication.

MS ZERNER: Thank you. Just on that particular point, and it's something that has occurred to me from your earlier evidence, when we went to that medication form, the Clarification of Purpose Medication Form, that can be any doctor, it can be a GP
45 that has never worked with people with intellectual disability before, isn't it?

MS SMITH: That's correct.

MS ZERNER: All right, I wanted to clarify that point. I want to move on, if I can, please. At paragraph 21 of your statement ---

5 COMMISSIONER ATKINSON: Can I ask a question.

MS ZERNER: Yes, Commissioner.

10 COMMISSIONER ATKINSON: I wish to interrupt to ask a question. You mentioned someone being subject to, I think a suspended sentence - sorry, I'm not looking at you because I'm looking at you on the screen.

MS SMITH: That's okay!

15 COMMISSIONER ATKINSON: It's very disconcerting. How often are people who have these behaviours of concern, as we've referred to them as, how often do they come in contact with the police and the criminal justice system?

20 MS SMITH: Frequently. And if I can be frank, you will find that most jails and - sorry, I can't remember the name for the detention ---

COMMISSIONER ATKINSON: Detention centres.

25 MS SMITH: Detention centres often have people with disabilities in those settings.

COMMISSIONER ATKINSON: So an alternative way of dealing with them might be these positive behaviour support plans rather than chemical restraint and being put in criminal justice institutions such as jails and youth detention centres?

30 MS SMITH: Well, it has been my experience that usually people with disabilities have been missing large pieces of information to know what is and is not appropriate in particular situations. Can I give you an example?

35 COMMISSIONER ATKINSON: Yes, please.

MS SMITH: So a gentleman that I know, I asked him, he got a really good communication system that he hadn't previously had. And I asked him why he was targeting his mother, and he told me that, "My mum hurt me". And I asked him what he meant by your mum hurt me. He said "When I was little, Mum made me do
40 exercises." I asked him if he was referring to the fact that he had had to undergo a lot of therapy and be put in standing frames, et cetera, and he advised me that he was. I had a big conversation with him around the fact what a mother's love entails and the fact that his mum would never have liked him doing that stuff, but she knew if he didn't do that he wouldn't be walking. So I said, "While you think your mum was
45 punishing you, she was actually doing the best thing a mother could possibly do to help you."

COMMISSIONER ATKINSON: Okay. So one of the advantages of the positive behaviour support plans is not only for the rights of the person but actually to improve their relationships with other people whom they might otherwise physically harm?

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MS SMITH: Exactly. Because they've misunderstood what has been going on for them. Yes.

COMMISSIONER ATKINSON: Thank you very much. Thank you.

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MS ZERNER: Ms Smith, this picks up on a question that Commissioner Sackville asked you in relation to how you're engaged. At paragraph 21 of your statement you refer to that you're engaged when the funding is allocate for support coordination as a person's NDIS, so that support coordination. Then you say that:

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.... I am often engaged after families have made several attempts to locate appropriate service providers to provide support for the person concerned.

Can you just give some insight into what the issue is?

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MS SMITH: So in terms of - programs I will use ABK's example from Joanne Mullins earlier.

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So I became involved because they couldn't find a service provider who could work effectively with him. And that service provider didn't have the necessary skills, and were pretty keen on having some pretty full-on restrictive practices involved, not understanding that they didn't have the skill set or they needed the training to be able to have the skill set to work with that person. And in his case he had actually been through two service providers when I became involved because they didn't know how to manage behaviours of concern. So there are some organisations who specialise and in managing people with behaviours of concern and there are some who have no clue how to go about it.

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MS ZERNER: Can I ask you a question then in relation to behaviour support plans. Have you come across the scenario where a behaviour support plan has been developed by someone perhaps who is not as experienced as you, and you've had to redo the plan?

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MS SMITH: Yes. That's correct. The difficulty often, and I actually don't have a degree, but obviously have training and experience. And often some of the people who are involved in this do have degrees but have never worked hands-on with somebody with complex and challenging behaviour. So the mismatch and the understanding of how somebody is portrayed and discussed, but also understanding some of the things that may affect somebody's behaviour, that you don't necessarily learn at a university makes it very challenging for them to be able to understand what's happening for somebody. So I'm referring to, for example, sensory processing and movement disorder, where people's bodies behave in different ways and

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sometimes that's mistaken as challenging behaviour but it's actually a movement disorder or a sensory processing difficulty.

5 MS ZERNER: And it's the case, isn't it, that you have also been called in perhaps by a service provider after a behaviour support plan has been written and given to the service provider to train the staff and to implement that plan?

MS SMITH: Yes. Because they didn't think the practitioner was able to do that.

10 MS ZERNER: And that is even when the funding is linked to training and implementation of such a plan?

MS SMITH: That's correct.

15 MS ZERNER: Leading on to this, and it's another question that came out of earlier evidence today about quality control of the behaviour support plans. At paragraph 91 of your statement you say, in your experience, one in five plans that you have uploaded to the portal for the NDIS Quality Safeguards Commission is checked for quality control. That's your understanding?

20 MS SMITH: That's what I understand.

MS ZERNER: Now, in regards to economic of strategies, and you said that's a concern in relation to checking the strategies are appropriate, and that they, restrictive practices, are used as a last resort, I'm interested in prior to the NDIS, what happened in Queensland in relation to quality control?

MS SMITH: Well, obviously in terms of the Department, depending on the person, some of that stuff would be checked through the Public Guardian, and that was really ticking their boxes in terms of the Act and making sure that particular items were included within that. And obviously apart from that, obviously your manager or the senior practitioner would be checking those.

MS ZERNER: So just to clarify on that, is that if a person is under a guardianship order for restrictive purposes, the Public Guardian will actually review that plan and give their approval or not. So you they are reviewing that plan in detail?

MS SMITH: When there was containment or seclusion, that was the level, that it went to them. When it became chemical or physical restraint or restricting access to objects, it would depend on who was appointed for the decision-maker for those things. Sometimes that was the Public Guardian, sometimes that would be a family member.

MS ZERNER: All right. Thank you. You said a manager. So it's the case that there was a lot of behaviour support plans prepared within the department?

MS SMITH: That's right.

MS ZERNER: And it's the case that some of that is still happening if they are not NDIS-funded, is that correct?

5 MS SMITH: Not to my knowledge, but I understand a lot of it is done in kind.

MS ZERNER: All right. We can clarify that. Okay.

10 Now, what I would like to do is just move on to the next topic which is regulation and the challenges you faced.

15 Now, Ms Mullins has covered a number of these gaps, I think you call them in your statement in relation to the regulation. There's two I just want to look at briefly. One is the invisible group, and I'm going to take you to something in a moment. And the second is in relation to the doctors and we've been talking about the regulatory framework and doctors as well.

20 Now, if I can please ask for Ms Smith's statement at paragraph 49 to be brought up on the screen, please. I found that that was a really helpful table to really understand the interplay between the regulatory frameworks. So what you're saying there is that for children under 18, obviously the Queensland framework doesn't apply, and if they're non-NDIS it doesn't apply and I will come back to that shortly. But there's a number of gaps and the gaps for the adults is in relation to no disability services and non-NDIS participants. So in those situations, is it your understanding that there are
25 people on chemical restraint that don't fit into any of those categories?

MS SMITH: Potentially, yes.

30 MS ZERNER: And do you know for sure or is it just something that you understand?

MS SMITH: Something I understand.

35 MS ZERNER: Okay. Now, in regards to those particular people, is it the majority of people in Queensland, when the NDIS funding came, in that were under the regulatory framework in Queensland became under the regulatory framework of the NDIS?

40 MS SMITH: Correct.

MS ZERNER: And that in itself presented some challenges in regards to the differences in the frameworks, is that right?

45 MS SMITH: That's right, yes.

MS ZERNER: And can you just very briefly give us a couple of examples of those challenges for you?

MS SMITH: Some of the definitions are slightly different. It would be really quite good for us if the legislations were the same for both Federal and State legislation. And obviously terms of their application, so when it didn't apply to children under the age of 18 for the Queensland framework but does apply under NDIS, that was a little more complex as well.

MS ZERNER: All right. Just in regards to the regulatory framework and not applying to doctors, it has been canvassed so far today already, and we've heard something yesterday in regard to that, can you give us some practical examples in regards to the challenges you've had in regards to your liaison with medical officers in regards to chemical restraint and the regulatory frameworks?

MS SMITH: I have seen situations where medical professionals have what I will describe as adding a diagnosis to somebody rather than have noted his managing behaviour to avoid that aspect. And obviously that really deeply concerns me. I've seen situations where a GP has refused - sorry, not a GP, it was actually a senior medical practitioner, refused to sign a chemical restraint medication even though we showed them evidence that it was chemical restraint under the NDIA for Risperidone, and even --- that person even described it as to manage their behaviour, but absolutely refused to put it down on a Clarification For Purpose of Medication Form. So that's the different scenarios.

Other doctors are wonderful and are happy to complete it and then take an active interest in what's actually happening for the person, seeking information on a regular basis.

MS ZERNER: And in regards, are you attending these consultations? Do you have the opportunity to attend them?

MS SMITH: Yes, I do.

MS ZERNER: I'm wondering, in regards to the knowledge of different practitioners and experience of working with intellectually disabled persons?

MS SMITH: That's very ad hoc, can I say, and there are certainly some doctors who specialise in working with people with disabilities and there are some who are not as open to that kind of work, so that makes it quite difficult in itself. And there are some who are outstanding as far as that goes.

But the other thing they often don't recognise is the importance of CHAP --- because I know you're going to ask, Comprehensive Health Assessment Program --- and that is one of the starting points from my point of view for all positive behaviour support plans. Part of that is being a good detective and making sure that pain is not part of the problem for the person and why they're displaying the behaviour that they are.

MS ZERNER: That is something that I was going to pick up. We've talked a lot

about behaviour strategies and the person exhibiting the behaviour, but the starting point has to be that assessment to work out what is causing the behaviour?

MS SMITH: Yes.

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MS ZERNER: And is part of that person-centred approach, and the liaison with the stakeholders to work out what is the cause of these behaviours?

MS SMITH: Part of it is data analysis and part of it is being a good detective, having a look at their environment, having a look at the service providers and their ethos and the way they go about business and how person-centred they are, but also looking at the pain-related stuff in quite a bit of depth.

MS ZERNER: And for that to happen it's the case, isn't it, that there has to be a collaboration between the medical profession and, for example, a behaviour support practitioner to work out what's the cause and how can we try and fix the cause, if that's the right way, or put strategies in place to manage the cause?

MS SMITH: Absolutely.

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MS ZERNER: All right. Now, I'm conscious of the time. I just want to go to the scenario where we looked at in that table and the invisible persons. And in Queensland prior to the NDIS there was no regulation in relation to chemical restraint. That's correct?

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MS SMITH: Well, there was for that but not for children under the age of 18.

MS ZERNER: Thank you. So those children under the age of 18, from your experience were any of them undergoing chemical restraint?

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MS SMITH: Yes. That's certainly become very clear with NDIA and doing positive behaviour support plans that have been funded by NDIA when we have worked in the child safety space in particular, where we've struck a number of children who are on chemical restraint and then obviously that's fraught with its own challenges.

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MS ZERNER: All right. I will come to that in a moment. But just in regards to not having that regulatory framework around chemical restraint, and you go to some detail in regards to the challenges you've had with pediatricians in Queensland in this particular area. Can you just very briefly explain what the challenge has been in relation to pediatricians?

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MS SMITH: Well, I think previously the department actually did quite a lot of training with psychiatrists, et cetera, to help them understand the medication and the clarification of purpose of medication and why they were asking for it. But I don't believe any of that information ever trickled down to pediatricians who support people under the age of 18 for that reason. That they were under the age of 18 and weren't subject to the regulation. The pediatricians don't have the requisite

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knowledge or understanding of the process.

5 MS ZERNER: All right. You mentioned that you have worked with children who are in care of the Department. And I just wanted to understand the difference between pre-NDIS and post-NDIS for those children that may be on restrictive practices, particularly chemical restraint I should say?

10 MS SMITH: Well, obviously, previously because they didn't come under the legislation, they were never identified. We knew the cohort existed but we didn't have access to do work with them around restrictive practices. And obviously post-NDIA because NDIA's funding wasn't for support plans for children with challenging behaviour, that's when that has become more evident.

15 MS ZERNER: And what is the process? So now that the NDIS Quality Safeguards Commission has oversight and there's the regulatory framework for a child under the age of 18 who is receiving chemical restraint, what is the process that you undergo as a behaviour support practitioner?

20 MS SMITH: We are contacted by the support co-ordinator and asked if we can complete a positive behaviour support plan and/or the guardian. And obviously we go about it in a similar way. If there is funding for it, we go forward. But what has happened with the child safety cohort is that child safety don't acknowledge the use of restrictive practices and so we've been in a situation where we're identifying restrictive practices are happening but they're not acknowledged by the Department
25 of Child Safety and they won't sign those off.

MS ZERNER: Okay. So is it the case you've received funding to undertake a plan, you do all of those things that you said in relation to the effective gathering of material, you put all of that, you upload the plan to the NDIS portal and NDIS has
30 got it but the Department hasn't signed off on it. Is that right?

MS SMITH: That's correct.

35 MS ZERNER: So what happens then, do you know?

MS SMITH: Well, we carry on and do our implementation and we will let NDIA and the Department sort that out between State and Federal Governments. I'm sure that's an ongoing conversation.

40 MS ZERNER: Sure. Thank you.

COMMISSIONER ATKINSON: Now, the children that we're talking about will be in the school system?

45 MS SMITH: Yes, they are.

COMMISSIONER ATKINSON: And are you involved in training teachers and

principals, et cetera, educators in the implementation of the plans?

5 MS SMITH: In a lot of situations they won't actually let us come into the school to do that. They consider that they have the necessary background for that. But some schools are actually getting us in to take training to help them understand things like sensory processing.

COMMISSIONER ATKINSON: Thank you.

10 CHAIR: Ms Smith, can I ask this. As far as service providers are concerned, how do they get their information as to the rules and regulations that apply to chemical restraints or indeed the administration of psychotropic drugs?

15 MS SMITH: From the same places that I get it from in terms of the NDIS Commission and previously the State Government would provide information to service providers.

CHAIR: What sort of information?

20 MS SMITH: Often written, so that it's left up to interpretation depending. For example, the interpretation around physical restraint can be quite interesting depending on who is involved in that discussion.

25 CHAIR: So this documentation provides in simpler language the way the legislation or rules operate, is that what it - -

MS SMITH: Yes.

30 CHAIR: To which my response would be it's not an easy task.

MS SMITH: No, it's not.

35 CHAIR: I've been trying to find my way through the interaction of the NDIS rules, the State legislation and various other provisions and it is complex to say the least?

MS SMITH: That's correct.

CHAIR: Do you think you understand it?

40 MS SMITH: I think I've probably got a better handle on it than most.

CHAIR: Which suggests that most don't have a good handle on it?

45 MS SMITH: Yes, I agree.

CHAIR: Yes. Can I ask another question. Is it your understanding that a behaviour support plan is not really about changing the behaviour of the person with disability

but rather understanding why that behaviour occurs and then focusing upon the factors that caused the behaviour. Is that a fair description?

5 MS SMITH: That's a fair description. Our thing is that you need to change often the behaviour of the people around them.

CHAIR: Rather than the person with the disability?

10 MS SMITH: Yep. And teach them the skills that they need to know.

CHAIR: Which in a couple of sentences are?

15 MS SMITH: Often improving communication systems, improving quality of life and teaching things like managing emotions.

CHAIR: Yes. Thank you. Commissioner McEwin. I think Commissioner McEwin has a question.

20 COMMISSIONER McEWIN: Thank you. Ms Smith, when you were talking about behaviour support plans and it was your view that not many of these plans, not many are person-centred and you stated that it was your view that plan should be reviewed every two years rather than the standard one year as it appears to be. What is your rationale for why you believe there should be a longer period between reviewing plans?

25 MS SMITH: Because you have to move at the pace of the person that you've written the plan for. You can't just wholesale go in and change a whole lot of things and teach someone a whole lot of things all at once. It has to be think big, start small, move slowly, grow program.

30 COMMISSIONER McEWIN: All right. I might just ask you then hypothetically if behaviour in six months changes dramatically and it's clear perhaps to you that something is not working, then are you suggesting you would wait for two years to review that or is there some mechanism where you can implement other things in between?

35 MS SMITH: Certainly a behaviour practitioner would use their data to have a look and see and if things are not happening, then you would make adjustments and what I will describe as tweaks that are appropriate to try and get things on track. Because 40 maybe there has been a misjudgment in the way the person learns or any other possible scenarios. So you make those tweaks as you go along and then incorporate in the bigger document later on.

45 COMMISSIONER McEWIN: Thank you.

COMMISSIONER ATKINSON: Can I ask - -

CHAIR: Yes, Commissioner Atkinson.

5 COMMISSIONER ATKINSON: Thank you. You were talking about you have to affect the behaviour of the people around the person with a disability and a number of other things about the environment. But in the end is the success of the positive behaviour plan assessed by reducing the behaviours of concern without the need for chemical restraints?

10 MS SMITH: Exactly. Or with a master plan of the person having a drug reduction program so that all of the things are in place that they don't need to display the behaviour and then drug reduction program so that the chemical restraint is removed completely.

15 COMMISSIONER ATKINSON: Thank you.

MS ZERNER: Ms Smith, I'm just about finished. The last thing I wanted to just touch on, you've got concerns in regards to training that's happening with behaviour support plan practitioners and also with support workers. That's correct?

20 MS SMITH: That's correct.

MS ZERNER: Now, the Commissioners obviously have the benefit of your very extensive statement. You've certainly challenged us today and prompted a number of questions and thoughts about this area. I just want to finish on in regards to behaviour support plans. It's the case, isn't it, that you are looking at strategies to be able to assist this person to have a better quality of life?

MS SMITH: Absolutely.

30 MS ZERNER: To try and reduce restrictive practices?

MS SMITH: Absolutely.

35 MS ZERNER: And it's not about the person being at fault but it's about putting systems in place to support those people?

MS SMITH: Exactly.

40 MS ZERNER: Commissioners, that concludes Ms Smith's evidence.

CHAIR: Thanks you, Ms Zerner. Thank you, Ms Smith, for your detailed statement and giving evidence today. It has been very helpful. Thank you very much.

45 MS SMITH: Thank you.

THE WITNESS WITHDREW

CHAIR: Ms Eastman, is there anything we need to do?

5 MS EASTMAN: No, Commissioner. If we could just adjourn and start again at 2 pm.

CHAIR: Yes. Let us start again at 2.02 pm.

10

ADJOURNED [1.02 PM]

15 **RESUMED**

[2.02 pm]

CHAIR: Yes, Ms Eastman.

20 MS EASTMAN: Thank you, Commissioners. The next evidence is a pre-recorded evidence that was prepared by Dianne Toohey and Kathy Kendell. They are from SUFY, the advocacy group Speaking Up For You. The prerecord video takes about 20 minutes and, Commissioners, could I ask you to receive the recorded video as part of the evidence. It's behind Tender Bundle A. It will be placed in Tab 31, and if it can be marked 6.9.1.

25

Commissioners, you will hear during the video reference being made to a submission that SUFY has provided, and at this stage I won't tender the submission and I will come back to that tender in due course if the Commissioners please.

30 CHAIR: Yes. Thank you. Shall we move to the recording. Thank you.

EXHIBIT# 6.9 - STATEMENT OF MS DIANNE TOOHEY AND MS KATHY KENDELL

35

PRE-RECORDED EVIDENCE OF MS DIANNE TOOHEY AND MS KATHY KENDELL COMMENCED

40 MS EASTMAN: Our next witnesses for the Royal Commission are Dianne Toohey and Kathy Kendell. They are both advocates with a long involvement with SUFY, which is Speaking Up For You.

45 **MS DIANNE TOOHEY**

EXAMINATION IN-CHIEF BY MS EASTMAN

5 MS EASTMAN: Dianne Toohey, can I start with you. Your name is Dianne Toohey?

MS TOOHEY: That's correct.

10 MS EASTMAN: And the evidence that you will give to the Royal Commission today is based on a submission that you prepared with Ms Kendall, is that right?

MS TOOHEY: That's right.

15 MS EASTMAN: Do you promise to tell the truth in the evidence you give today?

MS TOOHEY: Yes, I do.

20 MS EASTMAN: Now, Ms Toohey, you've been involved in a voluntary personal and a professional advocacy role for over 30 years?

MS TOOHEY: That's correct.

25 MS EASTMAN: And you've advocated for your son to be included in mainstream schooling from preschool to his high school graduation?

MS TOOHEY: That's right.

MS EASTMAN: You've been the manager of SUFY for 26 years?

30 MS TOOHEY: Yes.

MS EASTMAN: Your role as manager means that you are responsible for the overall management and the day-to-day operation of SUFY as an efficient, effective and accountable social advocacy organisation?

35

MS TOOHEY: That's correct.

MS KATHY KENDALL

40

EXAMINATION IN-CHIEF BY MS EASTMAN

45 MS EASTMAN: Can I next turn to Kathy Kendall sitting who is next to you. You are Kathy Kendall?

MS KENDELL: That is right.

MS EASTMAN: Your evidence is based on the submissions you prepared with Ms Toohey, is that right?

5

MS KENDELL: That's right.

MS EASTMAN: Do you promise that the evidence you will give to the Royal Commission will be the truth?

10

MS KENDELL: Yes.

MS EASTMAN: You have a Bachelor's degree in Health Science and you have completed some full-time coursework in a Master of Public Health and Hospital Administration, is that right?

15

MS KENDELL: Yes.

MS EASTMAN: You've sat on a number of health practitioner boards, and you founded and managed the Health Consumers Network?

20

MS KENDELL: Yes.

MS EASTMAN: And in 2008 you joined SUFY and you've worked as a disability advocate ever since?

25

MS KENDELL: Yes.

MS EASTMAN: So can I ask you both now about SUFY.

30

Ms Toohey, SUFY provides individual advocacy on behalf of vulnerable people with disability whose human rights may [audio distorted] with actors and individuals such as family members, practitioners, and independent allied health practitioners. Is that right?

35

MS TOOHEY: That's correct.

MS EASTMAN: And can I ask you, what is the approach that you take to the advocacy work at SUFY?

40

MS TOOHEY: Are you --- sorry, is that directed to me or Kathy?

MS EASTMAN: Either of you.

45 MS TOOHEY: Well, we first get to know the person well. We spend time investigating the issue that they might come to us with about, and then we talk to people that may know them, know the person well as and what's going on with that

person. Then we develop an advocacy plan with a vision and strategies of how we're going to work with that person. We involve the person as much as possible in all the meetings and all the actions we take, we talk about with the person first. Our advocacy used to be quite lengthy, long-term and, yeah, we work with an array of different people with different types of disabilities in different situations.

MS EASTMAN: In your submission, Ms Kendell, you've said at page 5 that there are challenges in advocating for a person who is subjected to chemical restraint and you say there that it's not easy or comfortable work. Why is that?

MS KENDELL: I think we come from an entirely different perspective that many people do, particularly service providers, and those who might be in senior positions trying to administer a hospital or different areas of government. We come from a perspective that respects a human rights framework and often while there is lip service paid to those principles and legislation, often we find that we're up against a standing culture that sometimes reacts very differently.

MS EASTMAN: And, Ms Toohey, in the submission at pages 6 and 7, you identify three key challenges. The first is getting access to the person that you're advocating for. Secondly, getting access to incident reports. And, thirdly, obtaining information about your client's medications. Can I ask you to briefly comment on each of those three challenges.

MS TOOHEY: Many of the people that we work with live in isolated and congregated living situations, so in group homes or in locked facilities, so the physical environment is not easy to just go and knock on the door and say, here. Most of those people are under guardianship, and in some cases we have to get authority from the guardian to actually advocate for the person, and that's not always easy. And I think that there's a culture of closedness within some of those group homes, and I think there's a level of apprehension that somebody is coming in to see what's happening. So, yeah, there's often lots of barriers put up as to why we can't actually meet and see people.

MS EASTMAN: What about getting access to incident reports?

MS TOOHEY: A lot of services regard incident reports as internal documents, and don't give us access to them. So we can sometimes go to a QCAT hearing and not even be aware there's been any incidents happening, and all of a sudden there was an incident is that a service would ring up and argue as to whether the person has to remain under restrictive practices, and we haven't even been given access to those incident reports to know what has been happening.

Incident reports are written by service providers and they are very one-sided. And I don't think they tell the story of what's really happening in the house. And that's how

MS EASTMAN: Sorry, go ahead.

MS KENDELL: The person involved in the challenging behaviour that the incident report is about would rarely get an opportunity to be able to have a look at the incident report or give their own perspective.

5

MS EASTMAN: In your submission you talk about chemical restraint and behaviours that concern, and you look at it and explain from different perspectives, from the person with a disability, family members, service providers, doctors and pharmacists. Based on your very long experience and advocacy in the area, what are the key concerns that you have identified about chemical restraint of people with behaviours of concern?

10

MS KENDELL: Well, from my perspective a decision to use chemical restraint should be a highly transparent process, but we - we don't find that that's the case. It should be a well-planned process where the service provider has already spoken to the family about it, about the need for restrictive practice and chemical restraint.

15

The service providers should seek an expert advice who can weigh up whether the benefits or the disadvantages, you know, which way it should go, and they really should give a written statement to the family in a prescribed - there's actually a form to explain why there is a need for chemical restraint. But often we find that service providers can approach medical practitioners directly and request a chemical restraint to help them in caring for the person. Often, the doctors are all too willing to go along with whatever the service provider wants. They want to help the service provider, and so a psychotropic could be prescribed. If there is definitely no mental illness, we have doctors who are prepared to put down a diagnosis of depression or something where the service provider can avoid the use of appropriate legislated guide safeguards. If a doctor does that, there will be no follow-up often from that prescription. There's no way of monitoring it, there's no way of knowing how much PRN a person is given. There's no incident reports to try and minimise the future use of that medication. Often families don't understand these sorts of important, you know, requirements around the use of chemical restraint, so we're relying on doctors to really educate patients' families and that often doesn't happen. Everybody's busy. And we find that the person who is prescribed the chemical restraint ends up falling through all kinds of safety nets that are supposed to be there as a result of the legislation. Yeah.

20

25

30

35

MS EASTMAN: One thing you've said in your submission is the importance of communication and behaviour support. This is page 16 of your statement. And you've said there:

40

When a person has a cognitive disability, including autism or intellectual disability, they often require additional support in receiving and processing information. They may require specialised approaches with communication techniques.

45

In this part of your submission, you also talk about positive behaviour support plans,

and did you want to make a comment about what you've seen in the course of your advocacy about positive behaviour support plans?

5 MS KENDELL: Well, I find, and you have to remember that SUFY gets - we get the problems. So we get the ones that aren't working well, and from our own personal observations we would feel that there's not a whole lot of expert skill out there by people who are writing these positive behaviour support plans. They're often over-prescribing strategies that focus on the challenging behaviours rather than a proactive approach where the environment is being looked at and redesigned to help ensure that there's no need for restrictive practices to be used. But we have support plans that aren't usually followed because there's poorly skilled staff, they're not trained, they don't stay very long and so people have different ideas about how to handle certain situations. So even if the plan had a chance of being written well, often they're not implemented well, and they're not reviewed and monitored well to see if they can be improved. And this can only happen if there are well done incident reports where the incident reports can analyse how the strategies worked or what sort of strategies would work better in the future. Because positive behaviour support plans are supposed to be fluid, you know, in a sense that they can be updated regularly. You know, every three months is a good way of doing that. We don't see that happening. Usually these plans sit on the back shelf of a staff office in the house perhaps, or employees can't really even get access to it often.

25 So, all of the safeguards that the legislation was intended to create, we just don't really believe that the safeguards function very well. And when - because chemical restraint has legislation behind it, you know, it's sort of normalises the use. It makes it socially normative to use chemical restraint. It's often used as a first rather than a last resort. Especially if a person is - whose behaviours are quite threatening, people, out of fear, just go directly to the use of the chemical restraint.

30 We don't believe that the medication use is monitored very well. We have observed situations where we have seen even chemists using old prescriptions which means that the amount of chemical restraint can be doubled and tripled without anyone having knowledge of that happening. You know.

35 MS EASTMAN: You've shared with the Royal Commission in your submission a couple of case studies and can I ask you about one of those case studies. This is on page 20 of your submission. One of your clients is now 30 years old and he is a man with disability and from the age of 19 he was living in a locked facility following his challenging behaviours. And you say that the man has a traumatic history having suffered criminal abuse, neglect and assault including sexual assault when he resided within children's respite care.

45 And you've said that he has a long history of being over-medicated with psychotropic medications to address challenging behaviours. And while he's been a client of your service he was on, you say, a large cocktail of sedative, psychotropic and anti-depressant medications along with blood pressure medication. So pausing there, what has been your role in advocating for him in the use of these medications in his

life?

MS KENDELL: Well, I have, firstly, been very concerned about how isolated this man was when I first met him. He did not communicate very well at all. I was told
5 by most people I came into contact with, through the Department, that he was quite high risk, could be very dangerous with me. So that part, it made it difficult for me to do what I could, but I have raised several times in QCAT my concern about the high levels of medication, and polypharmaceuticals that this man was on. In fact the TGA had a warning with one of the medications he was on, that it offered no benefit,
10 that over 150 milligrams of a particular drug, if it was used to treat generalised anxiety disorder. This man didn't even have general anxiety disorder. This man just had episodic periods where he would become so frustrated because he was not being given any community access for up to two years or longer.

15 MS EASTMAN: Can I finish by asking about that part of your submission. It's right at the end around page 25, of some of your suggestions about a better way forward. Do you want to comment on a few of those matters?

20 The first is, you say, a medical model is to fix people, and you don't believe the social model of disability has been adopted. So you would like to see the barriers being removed to ensure further equality and offer people with disability more independence, choice of control, and this relates to your advocacy for supported decision making rather than substituted decision-making. Is that right?

25 MS TOOHEY: That's correct.

MS EASTMAN: And you also want to see a change from chemical restraint being used as a first option, and see it to become a last-resort option. Is that right? If at
30 all?

MS TOOHEY: That's correct. Too often it is the first option and issues such as environmental issues of where the person's living and who they're living with and what - how their service is responding and so forth aren't addressed, and are never addressed, really. Yeah, the medication is a way of assisting service providers to be
35 able to work with people without too much of a backlash from the people who live in that house.

MS EASTMAN: And you also say in your submission, this is page 28, that:

40 *A whole of governance approach is urgently required to initiate a framework of very early intervention and safety around children and young adults, not just older adults with intellectual disabilities.*

45 And that's a particular concern?

MS KENDELL: Because most of the behaviours that we're seeing in adults is actually stemming from bad practices as children. They're often very entrenched,

these behaviours, and become more difficult to disentangle, you know, than from the person's habits of behaviour.

5 MS EASTMAN: May I thank you both very much for your submission to the Royal Commission and the time that you've spent with us today to share some of the experience of your advocacy work. Thank you.

MS KENDELL: You're welcome.

10 MS TOOHEY: Thank you.

PRE-RECORDED EVIDENCE OF MS DIANNE TOOHEY AND MS KATHY KENDELL CONCLUDED

15

CHAIR: Dr Bennett.

20 DR BENNETT: Commissioners, the next witness is Dr Jane Law and she will give her evidence here in person in Sydney.

CHAIR: Thank you, Dr Law, for coming today to give evidence. If you will follow the instructions from my associate, who will tell you about the affirmation.

25

DR JANE LAW, AFFIRMED

30 CHAIR: Thank you, Dr Law. Just so you're clear, I am sitting with Commissioner McEwin who is in the same room, and Commissioner Atkinson who you can see on the screen is in Brisbane joining us from there. And Dr Bennett is now going to ask you some questions. Hopefully the whole system will work.

35 **EXAMINATION-IN-CHIEF BY DR BENNETT**

DR BENNETT: Doctor, can you please tell the Commission your full name.

40 DR LAW: Jane Sarah Law.

DR BENNETT: You are a general practitioner consultant, is that right?

DR LAW: Yes.

45

DR BENNETT: You've provided a statement to the Royal Commission, and that is dated 10 September 2020. Have you read that statement?

DR LAW: Yes.

DR BENNETT: Is the statement true and correct to your knowledge?

5

DR LAW: Yes.

DR BENNETT: Commissioners, that statement can be found add Tender Bundle A, Tab 33. The statement will be marked as Exhibit 6.10 and there's an annexure CV, and that is at Tab 34, and is to be marked as Exhibit 6.10.1.

10

CHAIR: Yes. Thank you.

DR BENNETT: I tender that.

15

CHAIR: That will be marked accordingly.

EXHIBIT# 6.10 - STATEMENT OF DR JANE SARAH LAW

20

EXHIBITS #6.10.1 - ANNEXURE TO STATEMENT OF JANE SARAH LAW

DR BENNETT: Thank you.

25

Now, Dr Law, do you have a copy of your statement with you?

DR LAW: I do.

30

DR BENNETT: At the beginning of the statement from paragraph 4, you've set out your background. You are a general practitioner and you've got over 30 years of general experience. Can you please tell the Commissioners something of that clinical experience leading up to your current position today?

35

DR LAW: I initially worked as a GP for nearly 20 years in general practice, and then during that time I started working at the Developmental Disability Health Unit seeing adults with intellectual disability, doing comprehensive assessments. And ultimately I gave up my general practice and have just continued to see people with intellectual disability.

40

DR BENNETT: Thank you. You've just mentioned the Developmental Disability Health Unit that you currently work in. Can you please tell the Commission something about the background of that unit and where it exists today?

45

DR LAW: It started in 1999 by Dr Helen Beange and it operates a clinic at the Outpatient Department of the Royal Rehab Centre in Ryde, and the structure of the

DDU has changed over time. And we have special funding for the clinic which has been provided by NSW Health. It's run independently from the New South Wales Department of Health under the auspices of the Centre of Disability Studies, which is affiliated with the Faculty of Medicine and Health at the University of Sydney.

5

I joined in 2001 and along with one other doctor, and there are three GPs working at this clinic forming comprehensive medical assessments, and there is one rehab physician who is a professor of rehab and ageing dementia, who comes at times. I work two days a week at the clinic, and the other doctors work between half a day or one day, a week or month. Limited services are available from a special needs dentist, a social worker and a psychologist.

DR BENNETT: At paragraph 17 you refer to various components of the assessment you carry out at that unit. Can you tell the Commissioners something about the assessment process itself?

15

DR LAW: At the clinic, for a first consultation we usually allow up to two hours. Just prior to the initial consultation, we have a look at a pre-filled questionnaire that has been done that was sent to the primary carers to complete, and the visits include a comprehensive history taken from those present, the patient, the accompanying carers, support workers, allied health workers, and we make contact with the key carer by phone if they are unable to attend at that time or a later time. We attempt to do a thorough physical examination and we have a hoist which allows us to get people who can't transfer on to the bed who are in wheelchairs. Following that, we order any laboratory tests, x-rays as needed, and we make referrals to medical specialists or allied health as required. If we see a patient who is displaying ongoing behaviours of concern, we will usually refer to a psychiatrist if there isn't, and recommend a psychologist or behavioural team.

20

25

DR BENNETT: Well, on that issue of any ongoing behaviours of concern, in terms of the initial referral when somebody comes to see you, a person with intellectual disability, have you a sense of what percentage of these people have behaviours of concern?

30

DR LAW: That's a very difficult one because even mild behaviours which might have a negative impact, I think, are of concern and need addressing. But not necessarily serious in that a simple conversation can deal with that, I don't know, maybe 50 per cent. Certainly the more - I see a lot of people with moderate to severe intellectual disability and the severer the intellectual disability, probably more commonly behaviours that they increasingly, perhaps severe or difficult to understand and manage.

35

40

DR BENNETT: Right. So in terms of those observations of yours, what is the trigger for you to make the decision as to whether to refer on or include in the assessment process an assessment by a psychiatrist or a psychologist?

45

DR LAW: Well, the assessment really includes the full details about the patient,

professionals, agencies, devise a problem list. We have a look at all the medications, have a look at all their current history, both in terms of detailed physical and mental health and behaviours of concern. We look at the systems, sleeping, swallowing, and have a look at the family, birth development and social history so we get some idea
5 of the longitudinal issues and functional abilities, do a physical examination.

And in order to make recommendations, if there are serious behaviours of concern, if they haven't got a psychiatrist and they're on psychotropic medications, it's usually the case that they should be seeing somebody to oversee this. It doesn't take much to
10 refer.

DR BENNETT: No, that's right.

CHAIR: Dr Law, how do patients come to you in the first place?
15

DR LAW: Either self-referred by families who found us by various means, and often an internet search which is pretty good because it's quite difficult to find us on the internet.

20 CHAIR: No referrals are required by ---

DR LAW: No, we do ask for a referral from a GP just really that so we can communicate with them and to let them know what we're doing, and so we can send a copy of our report to them. And we will also try and contact all the other
25 specialists they may be seeing in order to get that information.

CHAIR: Thank you.

DR BENNETT: So you are a consultancy service, so they get referred to you and ultimately you will do your assessment process and you will have no further ongoing
30 role in their care and management later on?

DR LAW: No, that's not true. We see them a few months later to review our initial consultation and see where we're going from there and we will see them annually,
35 second yearly, depending on the need and their wants. I think with the advent of digital health it will be very much easier to have a quick conversation more often. But they are coming from a long way away, many of the patients.

DR BENNETT: Right. At paragraph 19 of your statement, Dr, you've set out what goes into one of your comprehensive reports, so you've done your assessment
40 process and you fit your findings within a report. Can you please take the Commission through the various aspects of the issues that you address?

DR LAW: Well, obviously the list which I've discussed, and really the report just
45 concludes with our assessment and management recommendations. So we have standard recommendations of how often they need to get an eye examination, hearing, dental care, immunisations, but we will also look at the very specific issues

with that person and try and address those problems, try and come to a diagnosis if we can. If not, continue it as a problem and keep on working at that. And we usually find that there's a good few, three, four, five new issues that come up for new consultation.

5

DR BENNETT: Right. And if you are seeing people annually over time, would you do this complete process each time?

10 DR LAW: The second bit is the only one that I don't tend do a full examination unless there is something else to attend to, so --- yes, I think one of the big things is doing a physical examination. I'm a great believer in seeing the whole skin, touching them, listening to their hearts. You will miss things if you don't have a look. Do a breast examination, feeling the tummy. It's not always easy for people. Sometimes they prefer to be examined standing or seated, so it's not necessarily done in a typical way, depending on their anxiety.

15

CHAIR: Do you have particular training or experience in dealing with people with cognitive disability, to address things like their sensitivity to being touched, perhaps?

20 DR LAW: Nothing at all. Just from working in this area for 20 years now, and as a teenager doing some voluntary work with people with intellectual disability.

CHAIR: Should there be training?

25 DR LAW: 100 per cent, yes.

CHAIR: Who would do it? You?

30 DR LAW: It's a very good question. Yes. I mean, there are people at the Centre for Disability Studies and other organisations, academic units who could do this training. Doctors can be embedded within the health system.

CHAIR: You've referred in paragraph 20 to people with linguistically diverse backgrounds. How do you deal with language issues?

35

DR LAW: It's not easy sometimes. I've had a deaf interpreter and a language interpreter in one room with a few other people with somebody. It's incredibly challenging. Often they'll come with just a family member. I know it's ideal to get interpreters, but sometimes they don't turn up, or just the organisation is difficult. And it adds another person into the room and professional interpreters are, I guess, ideal. We just keep on trying. I've used some of the Google Translate, much to the delight of some of the patients. It makes it quite easy to just get some key ideas across.

40

45 CHAIR: Filtering out ---

DR LAW: A lot of my patients are bilingual. They understand English sometimes

better than their parents.

COMMISSIONER McEWIN: If I could just ask Dr Law a question also relating to training, if you can reflect on the time you went through Medical School and the
5 training adopted now, what would be your observation about the level of training or the level of awareness for people about people with intellectual disability?

DR LAW: Well, I'm aware that some of the universities have a two --- perhaps lecture series and they might have somebody with a disability coming along to talk.
10 The problem is it's much better in practice when you're actually seeing a person in a clinical setting that's going to really embed your good practice if you've got somebody to do that. So really they should be sending medical students along to the different clinics. Even going to a group home for one day, it's not much, but rolling up your sleeves and just joining in would be helpful for everybody. And trying to
15 walk in their shoes.

COMMISSIONER McEWIN: Thank you.

DR BENNETT: Thank you. Dr Law, from paragraph 25 you refer to patients with
20 behaviours of concern and you said there that:

Many patients that are seen at the unit have behaviours of concern which vary greatly in terms of their negative effect on the individual. Behaviours of concern are various, the following

25 And you are describing some of the most common occurring that are observed in my patients. In the next paragraph you describe some of those. So I'm going to ask you to take the Commissioners to some of those behaviours but also tell the Commissioners what it is that those behaviours tell you.

30 DR LAW: Well, the first thing is behaviours are really just an expression of your mental state as far as I see it. And if you are anxious or uncertain then behaviours can occur and if attention is difficult for them, impulse control, emotional regulation, that can all be very difficult. So the sort of behaviours we see are physical
35 aggression, and that can be to the self with self-injury, such as hitting, picking at their body, finding objects to hitting themselves with and at worst they will find sharp edges and really, really go for it. And this is pretty distressing. And then there's physical aggression to others. Carers, other residents, members of the public, their families. And it can be directed, so absolutely deliberate or it could just be
40 collateral damage because they are throwing out their arms because they are anxious and you happen to be in the way.

Verbal aggression, invasion of other people's spaces, refusals to move both within their home and outside the home. The sit-down strikes are very difficult to deal with,
45 to give them the middle of the road. And other behaviours like overeating, food seeking, food refusals, other oppositional behaviours, it can be a change to the sleeping pattern. A low mood, loss of interest, withdrawal, inappropriate toileting,

deliberate soiling, stripping of clothes.

5 So those are the types of behaviours. I'm sure they've all been discussed before. And care needs to be really taken to interpret these behaviours because of all our bias. So carers and parents will come in, and I will ask them about the behaviours and they will tell me why it's happening. I'm interested about their theories, but I want to actually find out what the behaviours are. Because we need to really try and understand, and they occur often out of frustration and communication. We need to be non-judgmental regarding these behaviours and try and assess what is the
10 meaning behind them. Is it a mental illness? Is it the environment? Is it both? Is it the drugs? Are the drugs helping other drugs making it worse? And there are so many factors in the patients that are very complex. And it's really important to try and tease out these areas.

15 DR BENNETT: Thank you.

CHAIR: Is that a medical issue or would you describe it in some other way, what you've described as working out what is behind the ---

20 DR LAW: It's everything. It's both medical, and I think from the medical perspective and with drugs and experience with patients, we can tease it out, particularly those with experience, but it could also be with a behavioural team.

25 CHAIR: And your centre uses - involves non-medical practitioners?

DR LAW: We have very little funding and very little input, so now with the NDIS, I like to - and the other thing is people are coming from a long way away so I like to embed all the allied health near where they live.

30 I think it's pretty useless, people coming from a long way away, trying to do things from afar. They need to be there, they need to be on site.

DR BENNETT: At paragraph 27 you said:

35 *Bearing in mind that the rates of mental illness among people with intellectual disability is about two and a half times in the general population many patients we see are often on one or more psychotropic medications when we first see them.*

40 And then you say the challenges to avoid excessive or unnecessary use of the medications and polypharmacy. How is it that you respond to that challenge?

45 DR LAW: To really monitor the side effects and behaviour management, it's optimal for the patient, and it just does require a full history, conducting a physical examination, making sure there's no physical cause, making investigations and compiling a problem list, noting the multiple comorbidities that they may have which are common in people with intellectual disability. And we need to collect

information from all carers, people involved as well as obviously the person themselves. And observation. It becomes obvious if there's totally inappropriate use of medicine, but we have to bear in mind a lot of medicines have perhaps been used for a long time and haven't necessarily had that full review, or when young people
5 are living at home with their families and the behaviours are very challenging indeed for the person and the families and having a huge impact on their life, that these medicines may be required, and I regard them as treatment more than chemical restraints. And I think they are absolutely essential in order to help them. But it goes without saying really that all the other things need to be put into place and that is our
10 biggest challenge I think in this society.

DR BENNETT: And so in those circumstances if you do have concerns about the medications specifically in relation to psychotropic medication, is that an instance where you would refer on to a psychiatrist?

15 DR LAW: If they don't have a psychiatrist I would generally refer on to the psychiatrist. I might start to wean them off, with agreement from all present, to see what happens. Everything is a trial. I don't say it's an absolute because it's very scary for parents or carers to suddenly have a change in the medications. And if
20 we've got all the behavioural supports in place and we can just start taking one drug off at a time, then perhaps one can see the results, and it gives people more confidence. And it's important to look at the time that you're doing it. Never change drugs just before Christmas. People get very unsettled around that time. Or important events. So the important thing is really to work well with the parents.
25 And, yes, it's ideal for them to eventually get to psychiatrists but that can take time.

DR BENNETT: And when you say "take time", how long can that take?

30 DR LAW: Waiting list is six months. So it's really problematic. And the majority of psychiatrists that people see are in the private sector because of the way our system is set up.

DR BENNETT: They are the current networks you mostly rely on, are they?

35 DR LAW: There are some people in the public sector but the public network of community mental health don't really have capacity to see patients, and sometimes regrettably they refuse to see our patients saying that they have an intellectual disability, that's the cause of their behaviours" and not understanding the complexities in mental health issues that can occur. But they would be in the ideal
40 space to see them because they can do home visits, and they work in a very good team with nurses and psychologists. So if they had capacity and they had the ability to speak to specialist psychiatrists to work with them in terms of drug management, I think it would be ideal.

45 DR BENNETT: Right. So in your view the structure is there but in terms of the content of knowing, understanding how to work with people ---

DR LAW: Potentially there.

DR BENNETT: --- with intellectual disabilities is missing currently.

5 CHAIR: Can you prescribe psychotropic medication yourself?

DR LAW: Absolutely. Do I do it very often? No.

CHAIR: How do you address the question of the consent of the patient?

10

DR LAW: That's with the complex ones. So the majority of people that I've prescribed psychotropic medications, antidepressants would be the area that I'm most comfortable with, and for somebody with an acute sort of depression where it's obvious that they're telling me they're depressed, you can talk to the patient and so talking to the patient and explaining what it is and talking to the family members. Often it's the family gives consent, and then it gets more complicated with guardianship, and that's when I think a psychiatrist probably should be involved.

15

Other medications, when there's an acute crisis and nobody is coping and nobody is coming to help the families and the parents are being assaulted and my patient is incredibly unhappy and agitated, something needs doing. So it's a short-term solution until the behavioural teams come in and they can see a psychiatrist.

20

CHAIR: And that sort of situation is the short-term solution anti-depressant or anti-psychotic?

25

DR LAW: It could be an anti-psychotic. And that's a very low dose, and just with regular phone follow-up with the family. Often they are quite far away and ultimately I usually manage to get them into psychiatrists very quickly. But it's very hard.

30

CHAIR: I'm not minimising the difficulties, but in order to prescribe something like an anti-psychotic, do you have to make a particular diagnosis?

35

DR LAW: Sometimes I can make a diagnosis. Where somebody has a severe intellectual disability it's very difficult to make a very accurate diagnosis, particularly on only one or two visits. It might take a long - if you look at it longitudinally, it will become obvious when somebody --- there is an aha moment, you think definitely it's a mania or hypermania. But you might do it for - all my patients are very agitated and anxious and worried and they look miserable. And if I can assess as much of their health problems as possible, and ---

40

CHAIR: So sometimes this is, in effect, an emergency response?

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DR LAW: It's an emergency response.

CHAIR: Thank you.

DR BENNETT: Doctor, from paragraph 29 you've set out some evidence in relation to psychotropic medications and the various side effects and then down at paragraph 31 you've said:

5

I understand that historically, psychotropic medication, in particular anti-psychotic medications which were used in part for their sedative effect, have been relied on in responding to behaviours of concern or "problem behaviours".

10

And then you said:

From my clinical experience, this is sometimes the case.

15

And then you go on to say:

A change is gradually occurring

20

So can you tell the Commissioners, in terms of your view currently, do you recognise this and what are your views about current practice?

25

DR LAW: The current practice I would say very few people that I see that come through, that I would regard it as the behaviours and the treatment is due to - really given as a chemical restraint. It's just perhaps that the mix has not been reviewed well enough and it could be done better. And also usually all the environmental behavioural management is just not in place. And the poor person is in chaos really.

30

DR BENNETT: Right. You were asked a question earlier about the referral process. Is there any sort of consistency about triggers, the events in the lives of people with intellectual disabilities that triggers a referral to come and see you?

35

DR LAW: Often from group homes, they know us and so we end up seeing a lot of people from the same organisations, and it has been word of mouth, parents who have had a problem and if we've helped their child then they will send an adult child. A lot of people come through the door that way. But it's important to remember that access is really difficult, particularly to psychiatrists with a special interest in intellectual disability. There are not enough of them. There is no special training for them. Hopefully this is being addressed. And there are some very strong-minded psychiatrists who do have a special interest and have worked for years in this area who are trying to change this. And within the medical world, a lot of GPs are doing a great job with their patients and I don't feel I have much to add when they come and see me. But there are a lot of people who are quite frightened of examining my patients, they haven't had a physical examination, and they haven't really been looked at in detail and they go from doctor to doctor at these multi-centre clinics.

45

DR BENNETT: When you say access, you are referring to specialists or specialist units that work as a team?

DR LAW: Yes.

5 DR BENNETT: Now, from paragraph 34 you set out some identified examples and what I'm going to do is ask you to describe them. I will start from paragraph 35 there, you've referred to Patients 1 and 2, and you've said that you determined that the cause of the behaviour of concern was physical. So can you just explain to the Commissioners what that is and perhaps illustrate it from those examples?

10 DR LAW: Well, I've had a number of patients, but these two are a very stark example. It's two people who have walked in my room with their carers and it has been obvious as they walked in, to me, that they are blind. But because they have coped so well and have developed coping strategies, that it was not obvious to the carers and had been missed by anybody seeing them. They both had cataracts, dense
15 cataracts. And the tripping became obvious, and the fact that they were in foreign surroundings they had to be led to the bed but the carers had got so used to doing that. And management with the cataract extraction and lens, they both had terrible behaviours, terrible self-injurious behaviours. Everybody was very worried about what this would do to the operated eye. We had everything in place with one-to-one
20 care for a number of days and nights, but that wasn't needed. And as soon as they could see, it was a huge difference. It didn't take away the behaviours, but it was sensational. The reactions were sensational.

CHAIR: Are these long-term carers?

25

DR LAW: Yes. Lots of people had seen them ---

CHAIR: And they did not know that the people they were caring for were blind?

30 DR LAW: No. But I've seen somebody who is living at home, who has managed so well, was clearly blind but his parents --- beautiful people --- hadn't really noticed because he was refusing to go out of the house. And just walking around the house and managing incredibly well. Get to the bathroom and throw his towel over the rail. So

35

COMMISSIONER McEWIN: Dr Law, on that note of the more broader note of having patients come to you with their family members or support workers, et cetera, if you feel you need time with that patient alone, do you ask for it or what is your experience with that?

40

DR LAW: When I'm going to examine a patient, that is the perfect moment to send people out of the room, but people are very uncertain so I give them the option. I really like to get people who are verbal on their own if I can, but if they're uncomfortable I will often say, let me know and we will bring them into the room, or
45 when we come to examine personal things they can turn around.

A lot of people really don't care, they're not shy, but --- so we sort of try and maintain

modesty when it's needed. But, yes, there are certain people that do want to spend time alone with me and, yes, I will certainly give that to them.

5 COMMISSIONER McEWIN: And do you often have that respected by the family members or support workers?

DR LAW: Definitely. I make sure that it's respected.

10 COMMISSIONER McEWIN: Thank you.

COMMISSIONER ATKINSON: Sorry, my question was, going back to the two people who were blind, why did they come to see you? Was it because of the behaviours?

15 DR LAW: Because of the behaviours.

COMMISSIONER ATKINSON: And were the behaviours related to the fact that they were blind and that no one had realised it?

20 DR LAW: They had had a long history, a life-long history of that, challenging behaviours and self-harm, but things had escalated.

25 COMMISSIONER ATKINSON: And what were the particular behaviours that brought them to you?

DR LAW: Self-injury. Hitting their heads on objects, bruising --- multiple bruising, in fact.

30 COMMISSIONER ATKINSON: And did the operations which solved the blindness make a change to the behaviours?

DR LAW: Yes. It reduced the behaviours and helped with the management, yes, definitely.

35 COMMISSIONER ATKINSON: Thank you.

40 DR LAW: And the other physical problem which is quite common, and Dr Helen Beange noticed this earlier on, gastroesophageal reflux is really painful. If it's occurring and some people have a lot of self-injury, if you treat it, they can melt away. They are very dramatic examples but it's quite satisfying when that happens, to sort that one out.

45 DR BENNETT: You give an example of iatrogenic cause or issues. Can you explain to the Commissioners what an iatrogenic cause is?

DR LAW: It's caused by the medications you give, so obviously there is the side effects, but they can cause behaviours --- and I believe everybody has been through

the problems that psychotropic drugs can cause, but in short the patient that I saw had a history of depression, was treated for that, had a history of reflux disease, was treated for that. And then I didn't see him for some years and everything was quiet, but the patient went to live in a regional part of New South Wales near his family, and I recently caught up with them during COVID through a video consultation, and they explained that he had had shingles, was put on an opiate because of pain, and they didn't seem to be able take him off the opiate, because every time they did, he displayed terrible behaviours, but he was clearly very constipated.

10 So I ordered an X-ray. He was very backed up, cleared his bowels out, gradually started reducing the opiates on a measured thing, and worked with a GP who had not encountered many people with disability, who was fantastic at organising everything straightaway, and as far as I know --- I haven't spoken to them recently --- things are going much better, and he is back to his happier self.

15

COMMISSIONER ATKINSON: Has the teleconsult made a difference to the availability to people with disability from your service?

20 DR LAW: From my service, gosh, it's a yes and no one. GPs are allowed to - they've changed the funding, so we are allowed to do teleconferences if we've seen the patient within the last year. If you are not a GP and as a specialist, that won't be reimbursed. It doesn't mean it to see that people in the clinic aren't doing the consults. It's fantastic for those who are at a big distance and particularly for catch-up and for reviewing medications, I think it's a very good thing. It's very good for the psychiatrists because so many patients won't get out of the van or the car and even come into the room, that they can actually see them in their home surroundings. And I've had people taking me around their house with a phone and iPad. It's good to see them in their home setting.

30 COMMISSIONER ATKINSON: Thank you.

DR BENNETT: Dr Law, you also give an example of environmental behaviours as a cause of concern. Can you explain what you mean by environmental cause?

35 DR LAW: Again, I've given dramatic examples. Frequently there's a lack of consistency in routines or the clashes between residents in the group home, or a resident and a carer which can have significant negative impacts with restrictions placed on them by living in a group home.

40 So the example that I give was of a young man with severe intellectual disability, autism, congenital blindness and severe behavioural concerns when he was young, described as peripubertal mood dysregulation.

45 And he was on a fair number of medications and transition from a paediatric to an adult psychiatrist hadn't occurred. I don't know why that had failed, but it just hadn't occurred. And so when he came to see me, the first thing that I did, and he was in a group home, was to organise a psychiatrist who has a special interest in people with

intellectual disability and behavioural management was put in place with varying success.

5 And then the family came to see me in late 2018 and he had an appointment but the carers didn't bring him. And we had confirmed the appointment two days before, but they just didn't turn up. And the family at this time expressed concerns about the communication with the group home, saying that they felt that they just didn't have access to what was going on, that the manager was quite obstructive. So I contacted the regional manager and had a talk about the concerns. We organised another
10 appointment early the following year and we still didn't really know what was going on. He was very unsettled and he went back to see the psychiatrist. Later, mid that year, it was discovered and reported, I think by carers, that he was being verbally and physically abused by two of the staff members. This is with the police, as far as I understand, but recovery was a really long process for this poor young man because
15 we don't know how long it had been going on probably for a couple of years. And it was very severe, his self-injury, he had to attend - even when they had a new house manager and a lot of behavioural management going on within the home, he managed to break a glass window and sat on the floor trying to eat the glass, and had to be seen in casualty to be sutured.

20 But I spoke to the mother recently and after one year he is in a very much happier place, almost back to his pre-trauma stage. And there is a very good relationship now between the group home and the family. But I don't think anybody could have anticipated that.

25 And the other example I've given is of a patient who had multiple changes of accommodation over the years, all in respite care because the mother had to relinquish care because she couldn't organise a group home with a proper transition into a group home. They just weren't available. And she did display some
30 behaviours but they just got much worse, and none of the group homes seemed to be able to cope with this. She would often go to casualty. She would hit, punch out at people. She was miserable, and when she got very, very anxious - sorry, would start to regress to the point that she would lose her toileting skills, not want to go out, stop eating. At one stage she was admitted to hospital. Basically the people who were
35 looking after her, she had been in that group home for two years, I don't know whether it was a respite, it might have been a true group home but they couldn't cope and they relinquished care to the hospital, and she was there three months, during which time I was contacted me, they asked me what I think should happen. A psychiatrist came to see her, I also took the opportunity to make sure there's nothing
40 physical --- and because examination was difficult, they did examination under anaesthetic, they did everything. They did CT scans, they did endoscopy, they took blood tests. Everything was normal.

45 Then she ultimately was discharged again into respite or temporary accommodation, and apparently they were - it was to have been set up with a full behaviour management team augmenting and teaching and training the carers. That just didn't happen. Her behaviours kept on happening, and it took quite a while for that all to

settle down. And she did really well. She had a short period of having to move back to her mum's home because of the bushfires. She did very, very well for a while, and then COVID hit. There was a change of carers in the group home. There was a lot of uncertainty. The behaviours started right up, her aggression increased. She pulled out some hair of the carer, hit them. They dropped her off at hospital - no, they didn't drop her off at hospital, they phoned the mother up and said they are dropping her off at the hospital or you take her home immediately. So the mother had her return for a month or so. She now, I believe, has got permanent placement with one-to-one care. I think this could have all been avoided way earlier.

10

DR BENNETT: That is what you referred to in your statement as being a mismanagement?

DR LAW: Totally. And very difficult to get anybody particularly in the NDIS, you really need, I mean who can you talk to to say "This person who really needs a home"?

15

DR BENNETT: And that is the need for a stable accommodation.

DR LAW: Stable accommodation with an established behavioural team who is working continually with the person, not a huge behavioural management plan that they can't fathom where to begin and where to end, and that really needs to happen.

20

DR BENNETT: Thank you. Now, towards the end of your statement you've referred to "Areas of concern to me and my suggestions for change." They are at paragraph 59. You say:

25

Managing behaviours of concern including reducing or eliminating the use of psychotropic medication, requires full examination into the cause(s) of the behaviours. Thus a coordinated, well-funded and robust system is required

30

What vision do you have there, Dr Law, in terms of that structure?

DR LAW: Well, first of all the care team and doctors need to communicate. Yes, we as doctors can do better, but if psychiatrists were embedded in behavioural teams and management, I think within community health teams or differently, they could go into the houses and sort things out at an early stage. The suggestion or the idea of restlessness, that is the time to go in, not when the horse has bolted and there is a disaster happening. Ensuring the environment is correct for everybody and adapting that. Making sure --- and holistic care really requires adequate training and specialisation of all those caring for people, particularly people with behaviours of concern where it's known. Most of the carers have had absolutely no training, and I really admire them for what they do. They are quite remarkable, so many of them are quite remarkable. And very patient, but they do need help. They do need training. They do need support. And it needs to be ongoing and regular, and they need to be able to pick up the phone and say, "This has happened, how do I deal with this?"

40

45

And that's impossible. People don't get back to them. Those services with in-house management, behaviour management, there are not many of them that I know of, it can work really well.

5

DR BENNETT: And so that's training at all levels?

DR LAW: Training at all levels from the carers, psychiatrists, doctors, and that was talked about yesterday I believe.

10

DR BENNETT: Thank you, Dr Law. That completes Dr Law's evidence, Commissioners.

CHAIR: Commissioner Atkinson, do you have any further questions?

15

COMMISSIONER McEWIN: No, I don't, thank you.

CHAIR: Dr Law, your evidence has been very interesting and enlightening. Thank you for coming today. Thank you.

20

THE WITNESS WITHDREW

25 MS EASTMAN: Commissioners, there is one final witness today whose evidence is also pre-recorded. It takes 36 minutes. Could I ask the Commissioners if we have a short adjournment, say, of five to seven minutes, something less than ten, something more than five, then we will be able to complete the evidence today with Dr Branford's evidence.

30

CHAIR: We shall adjourn for seven-and-a-half minutes.

ADJOURNED

[3.13 PM]

35

RESUMED

[3.30 PM]

40 CHAIR: Yes, Ms Eastman. What shall we do now?

MS EASTMAN: Thank you, Commissioners. You will recall from Paula McGowan's evidence yesterday her discussion about STOMP, and the final part of the evidence today is based on a submission prepared by Dr David Branford and Professor Giles Glover, both of whom have been involved with STOMP and some developments in the United Kingdom.

45

Dr David Branford kindly gave us some of his time last week and I conducted a pre-recorded interview in relation to his evidence. We will play that in a moment. But, Commissioners, could you receive into evidence the submission which you will find at tab 7, and that will be marked Exhibit 6-11, and then the pre-recorded video marked as Exhibit 6-11.1. If the Commissioners please.

CHAIR: Yes. Thank you.

10 **EXHIBIT# 6-11 - JOINT SUBMISSION OF DR DAVID BRANFORD AND PROFESSOR GYLES GLOVER**

15 **EXHIBIT# 6-11.1 - VIDEO OF DR DAVID BRANFORD**

PRE-RECORDED EVIDENCE OF DR DAVID BRANFORD COMMENCED

20 MS EASTMAN: The Royal Commission will next hear from Dr David Branford who joins the Royal Commission by providing some pre-recorded evidence, and Dr Branford is based in the UK. So I will start by asking Dr Branford to confirm his full name.

25 DR BRANFORD: Hello. My name is David Michael Lofts Branford.

MS EASTMAN: Dr Branford, do you affirm that the evidence you will give to the Royal Commission will be the truth, the whole truth and nothing but the truth?

30 DR BRANFORD: I do.

DR DAVID BRANFORD, AFFIRMED

35 MS EASTMAN: Thank you. Now, you've provided a submission with Professor Gyles Glover to the Royal Commission, and the Commissioners have a copy of that submission. And our evidence today is going to address some aspects of that submission. So can I first confirm that you've a copy of the submission with you?

40

DR BRANFORD: I do.

MS EASTMAN: And are the contents of that submission true and correct to the best of your knowledge and belief?

45

DR BRANFORD: They are.

MS EASTMAN: Dr Branford, can I start by asking you to tell the Royal Commission a little bit about your professional experience and background.

5 DR BRANFORD: I'm a pharmacist. I qualified in 1971 so I've been a pharmacist for nearly 50 years now. For much of my career I worked as a Mental Health Chief Pharmacist and a joint academic. I did my PhD in intellectual disabilities, leading a large review program of the anti-psychotic drug use of people with intellectual disability living in Leicestershire. Since then I've been involved with a variety of roles in mental health and in intellectual disabilities. Since the Winterbourne scandal
10 I have been involved with this STOMP Program.

MS EASTMAN: Can I just pause there. In the Royal Commission we have heard about the Winterbourne scandal, but perhaps if I can just ask you to explain to people who may not be familiar with the scandal that broke in the UK in 2011. What
15 occurred then?

DR BRANFORD: The Winterbourne Assessment Centre was a very expensive, high-quality private facility in Bristol which catered for people with autism and with intellectual disabilities who had severe behavioural problems. There was a
20 Panorama exposé of severe mistreatment of the people who were living there. One of the findings, which is really where I come in, was that there seemed to be an overuse of medication and in particular anti-psychotic drugs which would normally be used for people with schizophrenia and anti-depressant drugs which would normally be used for people with depression.
25

MS EASTMAN: And so following the Winterbourne scandal, what did that mean for you and your work? Did you have a role in conducting any investigations?

DR BRANFORD: Following the Winterbourne scandal we had a real problem
30 around the medication in that since the closure of the institutions, the facilities and the arrangements for people who used to live in institutions had become widely scattered, and people mostly lived in smallish facilities and they were dealt with by all sorts of agencies and organisations. And we had no real understanding of what medication was being used across the country. So we were called together, and both
35 Gyles Glover and I were involved in the early investigations to really try to find out, initially, what was going on. We had - we had heard rumours of overuse of all kinds of psychotropic drugs within both intellectual disabilities and within autism care, but we had no evidence to support this.

40 And just at that time, the Chief Pharmacist for England had begun to work with an organisation called CPRD, the Clinical Practice Research Datalink, and he organised for us to work with them to begin to look at what was going on across the whole of England.

45 In addition, we were invited by the *Mental Health Act*. Under the UK *Mental Health Act*, at the three-month point of a detention, a second opinion doctor is invited in to agree that the drug treatment that the person receives is necessary and must continue.

And they record at that time what the drug treatment was and why they authorised this treatment. And so they had records of all the people with an intellectual disability who were detained under the *Mental Health Act*, so we had a second piece of work that we could look at some data there.

5

And then finally, they commissioned six health boards or trusts to undertake a review program with no particular remit, just to investigate how they might improve medication use within their trust for people with intellectual disabilities.

10 And that took quite a while because the data is quite hard to get at, and Gyles and I really took quite a while to investigate that. But the findings were, as indicated on the document, that really the use of medication in both people with learning
15 disabilities - sorry, we call it "learning disabilities" in the UK --- and intellectual disabilities in the UK, the prescribing was really very much higher than we would have expected. We had always been told once the institutions closed, we should expect that the use of medication would reduce substantially, but here we were, 20 or 30 years after the closure of the institutions, and, if anything, we seem to be witnessing a very large use of medication.

20 And on the only - originally the original studies from USA had always focused on drugs used for schizophrenia called the anti-psychotic jobs. But what we found that was almost every group of psychotropic drugs, or any group of drugs that had an impact on the brain, was being used in far greater extent than we would have expected, and they were often being used together as well.

25

MS EASTMAN: So having undertaken this research and those findings being released, what occurred in the UK following those findings?

30 DR BRANFORD: Well, what happened after that was the Government or the Department of Health brought together a very large meeting of all the stakeholders, and Gyles and I and others presented what our findings were, and everyone was really quite alarmed to find such an excessive use of medication going on here. And so, five years prior to this program, there had been a similar issue over the use of
35 anti-psychotic drugs in dementia, and a real desire to reduce the use of drugs in dementia for the management of behaviour difficulties during dementia. And that program was a sort of a pulling together of all the organisations involved with Alzheimer care or dementia care called a Dementia Alliance. So all the organisations came together, and they set up a new methodology at that time called a
40 "call to action" which was based on a number of American pieces of work.

40

Fundamentally, what a call to action does, it's completely unscripted and you basically explain the issue to people and then get them to commit to do something about it. And it's not controlled in any way. You just take all the organisations to undertake some kind of role.

45

The main difference between what we were doing here and what the Dementia Alliance program was, was in addition to the call to action, there was significant

financial assistance also to trusts to employ pharmacists to undertake medication reviews in care homes. So one of the things that we always complained about in the STOMP Program was that we did it on a shoestring. We didn't really have any substantial funding or any legal or other levers to make sure that this happened. So

5 organisations would come to a conference. I always worked jointly with a person with learning disabilities, called Carl, and we would present findings and what the call to action was all about, and then people would commit to undertaking pieces of work.

10 And we would give them ideas as to what to do, but we were not prescriptive. And so what happened over the following years was really a massive interest in the area. Over 500 organisations committed to undertaking some kind of activity in relation to STOMP.

15 MS EASTMAN: Right, so can I pause you there.

DR BRANFORD: That was how we got there.

MS EASTMAN: Just backtracking a little bit. First of all, what is STOMP?

20 DR BRANFORD: Stopping the overuse of medication in what you call intellectual disabilities, we call learning disabilities, and autism. Don't forget the autism bit because the people who were in Winterbourne were jointly autism and intellectual disabilities. So the STOMP Program was this call to action, and where there was a

25 small group of us who were employed by NHS England, which is the major health commissioning organisation, to encourage and provide assistance to organisations to undertake all kinds of initiatives relating to medication.

MS EASTMAN: In the submission, you identify three aims of STOMP. The first, to

30 encourage people to have regular check-ups about their medications. Secondly, to make sure doctors and other health professionals involve people, families and support staff in decisions about medications. And, thirdly, to inform everyone about non-medication therapies and practical ways of supporting people so they are less likely to need medication, if any. So those are the three aims of STOMP, is that

35 right?

DR BRANFORD: Yes.

MS EASTMAN: You also want to make it clear what STOMP is not, so what can

40 you tell us about what STOMP is not, and you set this out again in the submission?

DR BRANFORD: Well, in many ways it's a fine balancing act because as soon as you try to start this, you immediately come up against a number of organisations which are incredibly anti-medication. And so trying to explain to people that this is

45 not an anti-medication program - I'm a pharmacist and I've been involved in this field for much of my career, and many people benefit from psychotropic medication, and so the last thing we wanted was people insisting that everyone was taken off these

medications and that they were bad things.

5 So, trying to keep that middle line between "Hey guys, these are really useful and helpful medications, but maybe you're overusing them a bit and maybe once you've got over the initial problem you need to stop them", what appears to be happening is that once people are on these medications, it's very, very difficult to get them off. People are reluctant to take them off because they are afraid sometimes that the original problem will re-emerge or that they have no help or facilities to cope with the problem if it re-emerges. So I suppose what we were doing with the program
10 was trying to provide organisations with information and support to encourage them to try alternative ways of managing the problem rather than just using medication.

15 And there's a huge amount of literature developed both by ourselves and by other partners in this to try and increase people's support for this.

The second part is that you - everybody thinks the medication is somebody else's issue. So one of the reasons why we developed programs with almost every health professional group was that everybody blamed everybody else. So one of the first things I had to do in the program was really stop the GPs blaming the psychiatrists
20 and the psychiatrists blaming the GPs. And then the GPs would blame the carers and the carers would blame the support workers, and it just went on and on and on. And what you found was the more you got involved with people like advocates and social workers and all these other non-organisations, you would find that they would all say, "Oh, well, what do you do about the medication?" And they would say, "I don't do medication, I don't do anything about medication, no, it's too complicated, I can't do it".
25

30 So, one of the reasons why STOMP was so broad in really trying to involve every kind of avenue was so that they would all feel like it was something to do with them. So, for example, support workers often didn't know what people were on even, let alone whether the medication would be having any side effects. So a number of the social care organisations set about training all their staff about medication to understand, to recognise side effects, to, when they went to see a GP, perhaps reproduce a document which they would complete before they went to the general practitioner to tell them all about the medication. So lots and lots of supports for a
35 wide variety of people who are involved with intellectual disabilities. Because since the closure of the institutions, it's a massively diverse area. People are being cared for in all kind of different settings involving all kinds of different people. And unless you involve them all, it was going nowhere.
40

The second issue with all of this is who would undertake a review. So if you are on a psychotropic drug, whose job is it to take you off it?

45 GPs would say "Oh, this is too difficult, this is far too complicated, I can't possibly do this, this is a job for a specialist." Well, the role of the specialist in the UK has changed to being much more of a crisis approach where they only become involved if there's a crisis. So if you wanted - say you had someone on an anti-psychotic drug

for the last 15 years and you thought maybe they didn't need it any more, it's really difficult to know how you went about doing it. The GPs would say, "Well, we can't do it" and the specialist would say, "Well, no, we can't do it, we haven't got any time because we're dealing with crisis work."

5

So you kind of realise that unless you could create pressure within the system for this to happen, it wasn't going to happen --- and that, I think, is probably one of the failings of STOMP is that although we hugely raised information and interest in medication across the whole field, what we also needed to do was to have some serious money in there to fund proper review programs, and to assist and ensure that there was as much effort being put into taking people off these medications as there was putting them on.

MS EASTMAN: What do you think has been the impact of STOMP in the UK? Has it made a difference in terms of prescribing practices? Has there been any change at all?

DR BRANFORD: Well, Gyles and I were asked to undertake a follow-up study to the CRPD study. STOMP had only been going two years at this stage, and part of the problem is that data is always about a year behind. So we probably are only now in a position to begin to see whether or not there has been an impact. I think what everyone expected was there would be, following the STOMP Program, there would be a dramatic and sustained reduction in every group of psychotropic drugs, and that hasn't happened. In a number of areas there was a steady increase in the use of these drugs across the field, and at the moment it appears that there has been a levelling off of that. But we unfortunately didn't really - we weren't really able to get a good idea of what was going on in children, and we're hoping to do some follow-up work looking at children, and we could really only get a feel for what was happening in intellectual disabilities. Our work with autism, I think, is really still very - we're not quite sure about. So we do - we've done a number of surveys looking at people's knowledge and understanding of the medication, and I think across the whole field there's a much wider understanding of the role of medication. There's a very wide acceptance of the fact that we need to be doing something about reviewing people more effectively and finding some way of reducing the medication, and really we're waiting for a phase now, what I call "Phase 2" in the document, which has been kind of put on hold because of the COVID issue.

But within the 10-year plan for NHS, there is the expectation to train up a cohort of specialist pharmacists to assist with medication reviews and there is also a program to establish de-prescribing clinics, they're going to be called, which is where complex cases like this can be referred to, the de-prescribing clinic, and then a sustained program of trying to take people off them. So that's kind of what we've done so far, we've called it "Phase 1", which is awareness raising, which has been very successful. But really I think now we need to see the money and we need to see the incentives.

There isn't any expectations of a legislative program at the moment, but actually that

would be fantastic.

MS EASTMAN: Well, your submission sets out some lessons, perhaps, for Australia, and I think the submission identifies nine lessons. So I won't ask you to address you all of them, but can I take you to a few in particular.

DR BRANFORD: Okay.

MS EASTMAN: The first one is, you say, don't expect GPs to do this on their own, and you refer to some recent work from the Netherlands looking at medication reviews and GP attitudes to reducing psychotropic medication, and that's a relevant consideration. What have your colleagues in the Netherlands been doing that suggests that a lesson for Australia is "Don't expect GPs to do this on their own"?

DR BRANFORD: Well, the approach in the Netherlands has been slightly different in that they have been focusing very much on the adverse effect of medication and they've also been largely working with older people with intellectual disabilities. The work is by a person called Zaal and they developed a ratings system for assessing how many problems there were being caused by the medication and then trying to take them off.

But mostly the studies identified lots and lots of problems associated with medication and lots of prescribing of medication but a huge difficulty in getting anybody to take them off. So that's the work by Zaal and then the work that I think I reference here, which is De Kupijer, then did a follow-up study where they looked at what were the issues that were stopping the general practitioners from undertaking the reviews. I think they have a slightly different system in the Netherlands in that they have very few specialists. So I think a lot of the expectation falls on general practitioners who are commissioned to oversee and care for people in a variety of homes or so on.

And the general finding was that these general practitioners were very reluctant to reduce the psychotropic medication of people with intellectual disability or autism unless they had someone holding their hand really. And that work has really informed and helped the STOMP Program in formulating its ideas about what to do next. And that's really where the idea of training up 200 pharmacists to undertake review programs comes in.

We also have the Sunderland STOMP Clinic which is again something people might be very interested in, which is where a prescribing pharmacist working with a behavioural support team has been over the last three or four years systematically taking people off their psychotropic drugs and when they hit problems, the behavioural support team are brought in and they manage it behaviourally. They've managed to take more or less everybody off their anti-psychotic drugs that has been referred to it. So that has been a huge success of that program.

So that's really the lessons from Holland is that GPs in the UK, their time is very controlled. They only have seven minutes for a consultation and so undertaking

something which is going to require up to a year of gradual reductions and so on, really requires a very sustained effort over a long period of time and that really doesn't fit very well with the role of the general practitioner.

5 MS EASTMAN: So I think in your submission you deal in some detail about the lessons that could be learnt in establishing specialist intellectual disability de-prescribing clinics. So that's touching on the example that you've given of the Sunderland STOMP Clinic; is that right?

10 DR BRANFORD: Yes.

MS EASTMAN: And the next one is that you say there needs to be an agreement on a national method of reporting and making the results public. And you appreciate in Australia we have a Federal system with a number of different jurisdictions with
15 different laws and procedures. So this may be of interest to the Royal Commission. What lessons do you say there are for Australia about the importance of a national method of reporting and then also making the results public?

DR BRANFORD: Okay. Maybe I should have used the word "Federal". My
20 apologies, I had forgotten you didn't do that. But obviously in the UK now we have a separate system for Wales and Scotland and so all of our work is England. The only reason why I mention the word "national" in that context is that many of the databases are based on GP data systems and the different countries, so Wales and Scotland and England use the same GP --- have access to the same GP systems that
25 England has.

So you're able to compare just by the fact that they're all using the same system. But, no, I probably should have used the word "Federal" for you there. One of the --- we struggle with data. We still at the moment really don't have a good understanding of
30 full electronic prescribing systems. And the extent to which the GP data is encompassing what we want to look at is quite difficult. We are hoping at the end of the year to begin to see some more data looking at particular aspects. But data --- data is still very much in its infancy.

35 So if you have a system within the Australian Federal --- your states that can collect the data in the same way, that again would be really helpful because you can compare New South Wales with Victoria and so on. Interestingly, Scotland and Wales are much more interested in our data than seems to be the case in England. So it's very, very different. Gyles is the data man. He is a public health specialist and
40 really I rely very much on him with the data. So trying to set up --- if you're going to look to try to set up some kind of system that enables an overview of what is going on, Gyles is your man.

The second point is that we have many areas in the UK where practices can compare
45 themselves to other similar practices, but they're really poorly developed within this area. So, for example, all the practices in the UK can compare their stats on use or their, you know, how they're doing with some new medication or whatever but really

this area is quite --- and that's why we didn't know what was going because actually getting hold of data is really difficult. So this is a recommendation from Gyles and if you want to do something, I would really encourage you. Because if your practice is using wildly more psychotropic drugs than an equivalent practice which isn't, really that helps people to begin then to ask the question of well, why is your practice using all these medications and others aren't.

MS EASTMAN: All right. So the final one I wanted to ask you about, and the Royal Commission will read all of the suggestions, is somewhat provocatively you say no more guidelines and in the submission you say the usual response to a problem is to establish a high level authoritative guideline and you say, well, we already have the guidelines and now the issue is the implementation of the guidelines. So can I just ask you about guidelines and the development of guidelines. And the guidelines that presently exist, the Royal Commission may be interested in understanding the relevance of those guidelines to the Australian context. Do you want to comment on that? And that's the final matter that I want to ask you about.

DR BRANFORD: Okay. Fine. If you look at the history of all of this, the first point at which you really begin to get the establishment of guidelines is following these very expensive legal challenges in the USA. The side effects of the anti-psychotic, older anti-psychotic drugs were quite severe, and various people took institutions to court and won very large financial settlements because of the side effects. So in the USA, there was a massive movement towards creating guidelines, and then giving these guidelines to the various State institutions to implement. And so during the 1980s, up until the '90s, you saw a really large scale development of guidelines in the USA, and that went on until about 2000.

Following the closure of the institutions, I don't know what really happened in the USA because it all goes very quiet. There was no legal requirement, once a State institution was closed, to have such guidelines. So I don't really know what's happened, it's all gone very quiet.

And then, internationally, there's an international intellectual disability organisation, and they had a series of guidelines which were led by one of our professors, Professor Deb, so there is also international guidelines.

And then following on the Winterbourne scandal in the USA - in the UK we've had a whole series of guidelines by our organisation NICE, National Institute For Clinical Health and Excellence, which includes the management of behaviour disorder, mental health in intellectual disabilities and so on. And then in addition to that, of course, we've had a flourishing of guidelines from people like the Royal College of Psychiatrists, we've had all the STOMP guidelines. So we have absolutely tonnes and tonnes of guidelines, and it's really finding ways of implementing these guidelines which I think is the key to it all.

I mean, I'm sure you will want to develop your own guideline, simply so as to give it

authority in Australia, but what I'm saying is that, you know, there are lots of guidelines out there already. Yeah.

MS EASTMAN: All right.

5

Dr Branford, thank you very much for your time today to pre-record this evidence and your enormous assistance to the Royal Commission. Thank you very much.

DR BRANFORD: Thank you. Bye.

10

THE WITNESS WITHDREW

15 **PRE-RECORDED EVIDENCE OF DR DAVID BRANFORD CONCLUDED**

CHAIR: Ms Eastman, it is perfectly clear that you cannot possibly be accused of interfering unduly with the flow of the witness's evidence.

20

MS EASTMAN: Thank you.

Commissioners, that concludes the evidence for today, so if we can resume at 9.30 tomorrow morning, and just to finish with the International Sign Language today.

25

CHAIR: Very good. Thank you. Yes, we will adjourn until tomorrow at 9.30.

30 **ADJOURNED AT 4.08 PM UNTIL THURSDAY, 24 SEPTEMBER 2020 AT 9.30 AM**

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