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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, THURSDAY, 24 SEPTEMBER 2020

DAY 3

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

CHAIR: Good morning, everybody. We commence, as is customary, by acknowledging and paying our respects to the traditional custodians of the lands on which this public hearing is being conducted. We pay respects to elders past, present and emerging and all First Nations people who are following this public hearing.

5 Thank you.

Yes, Ms Eastman.

10 MS EASTMAN: Good morning, Commissioners, and everybody following the Royal Commission proceedings. Today will be a long day for evidence and we're going to commence at 9.30 and we're likely to sit close to 4.30 this afternoon, so there will be a number of breaks during the course of the day.

15 Before I deal with our first witness, can I just remind, for people following the work of the Royal Commission, some provisions of the *Royal Commissions Act* which I refer to in opening. Section 6M of the Act provides as follows:

20 *Any person who uses, causes or inflicts, any violence, punishment, damage, loss, or disadvantage to any person on account of:*
(a) the person having appeared as a witness before the Royal Commission; or
(b) given evidence before the Royal Commission; or
(c) produc[ing] document[s] [to the Royal Commission]
commits an indictable offence.

25 That is a serious offence and a serious matter and the maximum penalty for committing such an offence is a term of imprisonment.

30 The Royal Commission has mentioned on a number of occasions the importance that witnesses who appear at the Royal Commission are not subjected to any loss, disadvantage, punishment or otherwise. So may I just provide that as a friendly reminder in relation to any attempts to mistreat any of the witnesses who have appeared at this hearing.

35 CHAIR: May I add my endorsement to the comments of Senior Counsel. All witnesses who give evidence at this hearing are entitled to feel safe and respected.

40 MS EASTMAN: Thank you, Commissioners. The first witness this morning is Dariane McLean, and she is represented. I will ask her lawyer to announce his appearance.

MR LEWIN: May it please the Commission. I am Adrian Lewin appearing for Ms McLean.

45 CHAIR: Thank you very much.

Ms McLean, thank you very much for coming to give evidence, and if you wouldn't mind following the instructions of my associate who will administer the affirmation

to you.

MS DARIANE MCLEAN, AFFIRMED

5

CHAIR: Thank you. Now Ms Eastman will ask you some questions.

10 **EXAMINATION-IN-CHIEF BY MS EASTMAN**

MS EASTMAN: Good morning. You are Dariane Lee McLean?

15 MS McLEAN: Yes.

MS EASTMAN: And youyouyou are an advocate and a counsellor?

20 MS McLEAN: Yes.

MS EASTMAN: You have provided a statement to the Royal Commission dated 9 September 2020?

25 MS McLEAN: Yes, that's correct.

MS EASTMAN: Are the contents of the statement true?

MS McLEAN: Yes, they are.

30 MS EASTMAN: Sorry, I'm getting head of myself. Commissioners, you will find a copy of the statement in Tender Bundle part A. The statement is found at Tab 35 and I will ask you to mark the statement as Exhibit 6.12, and then there are three attachments at Tabs 36 to 38, and they should be marked Exhibits 6.12.1 through to 6.12.3.

35

CHAIR: Yes, thank you. They will be marked in that way, thank you.

EXHIBIT# 6-13 STATEMENT OF MS DARIANE LEE McLEAN

40

EXHIBITS# 6-13.1 THROUGH TO 6-13.3 ANNEXURES TO STATEMENT OF DARIANE LEE McLEAN

45

MS EASTMAN: I'll slow myself down. Ms McLean, I want to start with you, and while your evidence has a focus on the experience of your son, I wanted the Royal

Commission to know a little bit about the work that you do and how you came to the role that you presently have.

5 You've told the Royal Commission in your statement that you're currently an advocate at the Victorian Advocacy League for Individuals with Disability known as VALID, and that's a role that you've held for 14 years.

MS McLEAN: Yes, that's correct.

10 MS EASTMAN: And youyouyou came across VALID when you came to a conference and you heard somebody from VALID speaking about issues arising in relation to restrictions on people who lived in group homes, and I think you say in your statement that was a little bit of a moment for you in understanding the nature of restrictive practices to describe what has been happening to your son, is that right?

15 MS McLEAN: Yes, that was a session that VALID ran at their conference by the Office of Senior Practitioner, but in fact I first met Kevin Stone, the CEO, when the organisation who was running my son's supported accommodation set up a parent group and they had him come along and talk about advocacy, and how to improve our advocacy as a parent for our son or daughter.

MS EASTMAN: That led you to take on some further education and training, and you now work as an advocate and you specialise in complex needs clients, especially those that have histories of concerns and you say in your statement that cases often run long term because of the complexity of the clients that you work with, and you might at any one time have between five and ten clients, and what you seek to do is to become involved in their lives to provide support systems when those systems are otherwise breaking down for the individual.

25 30 So some of the work that you do at VALID you've described in your statement as strengthening family advocacy and also providing that peer support.

Now, the Royal Commission has heard from Mr Stone who gave some evidence at the Public Hearing 3 in Melbourne last year, but could you tell the Royal Commission a little bit about your role as an advocate and perhaps your experience in working with clients with complex needs and the work that you do in providing peer support and family advocacy?

MS McLEAN: Thank you. Well, certainly my role as an individual advocate usually entails me receiving a referral through VALID's intake and generally speaking there is a family actively involved in the person's life because there are certainly, and this is an important distinction because there are certainly, I would say, hundreds of people within the support system with very complex support needs who have no family involvement and VALID certainly does work in that regard. But my role is predominantly working with families and their family member. My role is to be an advocate for their family member, not them. And most of the time the families are doing a great job at trying to get a better outcome for their family member, so

often I will get that referral and then start sort of making contact with the family or with a support coordinator or in the old days it was a case manager, and just gathering some data. Sometimes I would meet the individual. There certainly are occasions where I don't actually meet the individual because in some cases
5 introducing a new person into their space initially can be quite challenging for them as well.

So I will gather people around the table, really, to talk, and to try and figure out, you know, why the system around this person is falling down, you know, is there an
10 effective behaviour support plan involved, are there professionals involved? Are the family being listened to and, you know, given their voice as well? More often than not the key question that nobody sort of raises is, has anybody asked the person what they want? What is, you know, what's bothering them? And inevitably people will
15 sort of be surprised at in a question because the person's presentation is so complex that there's an assumption that they don't have a view on what they want.

MS EASTMAN: What's been your experience, when that question's asked, what happens when a person has an opportunity to be heard and express their view?

20 MS McLEAN: There's a lot of learning that can occur, even for family members and, you know, in support of family members, it's pretty challenging, you know. Most of these families have placed their family member in care because at some point they were in crisis and were not able to continue to care for their family member at home. And it's very intense - I relate to this personally - it's very intense,
25 you desperately want to help your family member who, in some cases, is harming themselves, is doing significant property damage, is harming others, and in most cases these families have not had great support through the years from professionals so they don't have a really clear understanding as to why their family member is doing what they're doing, and how might they best support them so that they're less
30 stressed.

So it can be a bit of a revelation and, you know, my role is to keep that central throughout the discussions because often families, or the support providers, will have very firm views on what's best for the person when they clearly have not consulted
35 the individual in a way - and sometimes that information needs to be gathered in a very creative way, depending on how the individual presents.

MS EASTMAN: And you've had firsthand experience in seeing what's happened to your son and your family over a number of years. Can we turn to those matters now.
40

MS McLEAN: Sure.

MS EASTMAN: You've said in your statement that you once were a stay-at-home mum, that's your words, for most of your seven children's younger years, and at the
45 age of 45, when your second eldest son was put into care, that's when you started the studies that then led to the work that you now do as an advocate and counsellor, and the qualifications that you now hold in psychology and also disability studies.

You've got your own counselling practice as well as the work that you do with VALID.

MS McLEAN: That's right.

5

MS EASTMAN: Now, your second eldest son, he's now 42 years old and you describe him as generally very respectful, very gentle, very generous, he's creative and artistic, and I think a little bit later on he's given you some drawings that you would like to share with the Royal Commission, but we'll come to that. But let's start with what it was like for him and your family as a young person.

10

He was diagnosed with severe autism and a suspected mild intellectual disability when he was 2 years old.

15 MS McLEAN: Correct.

MS EASTMAN: You've said to the Royal Commission that diagnosis hasn't changed, but in your professional view he now displays symptoms of post-traumatic stress disorder.

20

MS McLEAN: Correct.

MS EASTMAN: And the PTSD diagnosis is as a result of his accommodation and the impact on his life after he went into care, is that right?

25

MS McLEAN: That's right.

MS EASTMAN: And you've said in the statement at paragraph 14 that when your son was approximately 8 years old, he started physically harming himself and you went to see a specialist to get some advice about what to do. So what happened when you went to see the specialist at this sort of first point in time when you're looking for external help or intervention? What happened?

30

MS McLEAN: Well, we were just basically told that there is no medication or treatment per se, you know, that we can't give him a pill and he will be all better. And that, you know, he has very severe presentation with his autism. We were, yeah, not given many - what's the word - certainly knowing what I know now, we were given very few resources on how we might best support our son. Nobody talked to us about occupational therapy and its role, its very key role around sensory issues for people on the autism spectrum. We weren't referred to a speech pathologist at that point, either, and in fact, the only advice we were given was very much aversive-based, so when a particular behaviour occurs you respond in a particular way.

35

40

45 There was just no understanding of why he was behaving the way he was.

MS EASTMAN: Was in that stage in anybody's thought or contemplation that the

behaviours might be a form of communication, and signalling to you what was going on, or at that stage was it, "Well, why is the behaviour occurring and how can we stop the behaviour?" You understand that - you very well understand the distinction now and you talk about this in the statement, but just taking yourself back to when he was 8, I mean what was the thinking and advice that you received about understanding the nature of the behaviours as a form of communication?

MS McLEAN: There was none. There was no understanding of that offered at all.

10 MS EASTMAN: Right. And in your statement you say that he's been prescribed a plethora of medication over the years and because he also has a diagnosis of epilepsy, the medication was used to control seizures starting from when he was about 8 years old. So he's been on a range of medications, is that right?

15 MS McLEAN: That's right.

MS EASTMAN: And then when he was in his teens he began seeing a psychiatrist through the public health system and he was prescribed psychotropic medications for the purpose of what you say here, of stabilising behaviours of concern. We haven't seen that expression before. We've had "managing", "treating", "dealing with" behaviours of concern but you've used this expression "stabilising behaviours of concern". Can you explain to the Royal Commission why you've used that expression and does or did this medication have the effect of stabilising behaviours of concern?

25 MS McLEAN: Yeah, it's a good question. I'm not sure why I used that word. But certainly for me as a mum, it has been, you know, trying to find the solutions that will help him to stabilise his mood. It's very obvious that well, at that stage it appeared to be very mood-based, so high levels of anxiety. So, trying to seek ways of stabilising that was certainly central to my motivation. And, you know, if you are aware of the behaviours that families have to deal with and you know what their family member has to live through, as well. There's not time here today to describe those, but they're pretty horrific. They're certainly not for the fainthearted. And as a parent, if you're living that day in and day out, your absolute motivation is somehow bring some stability back to your family member's life.

MS EASTMAN: And your son, as he grew and became a teenager, that the behaviours became more challenging but this also coincided with him developing gastrointestinal issues and his inability to sleep, which in turn caused you, and I assume other family members, to also have sleep deprivation. He was diagnosed with ulcers and oesophagitis. It took a while to get these diagnosed because he doesn't communicate pain well. So at this stage when he was a teenager, were you going in this cycle of trying to work out what the underlying health conditions were, what the behavioural issues were telling you by way of the underlying concerns and trying to work out what was happening?

MS McLEAN: Absolutely, yeah, absolutely. You know, when you see your family

member so distressed, and he certainly got to the point where he started to try to communicate that he was feeling sick, that he had a sore tummy, the reality is that a lot of people on the autism spectrum have a very high pain threshold, so when they indicate pain, it's usually at an extremely severe level. So it would explain why we see some of the behaviours that we do that are categorised as behaviours of concern, that that appear to some to be behaviourally-based and sometimes, you know, they're accused of being manipulative due to their behaviours, when, in fact, they're just, you know, the only way they can letting us know that they are really suffering.

10 MS EASTMAN: So in the 1990s you were considered considering as a family, some form of supported accommodation options for your son, and you wanted to find some options that will give your son independence so that he would be able to develop independence, not be dependent on you and the family to deal with the day-to-day life or the crisis, and you accepted an offer of accommodation at a group home and he moved to his first group home in February 1998, and he had moved from a very large family with an older sibling and younger siblings. How was that transition for him and what transitional arrangements were made for him when he first moved out of home?

20 MS McLEAN: That experience for him was absolutely horrific. He wasn't given an opportunity ---

CHAIR: Please take your time, and if, Ms McLean, you need a break, please let us know.

25 MS McLEAN: No, I'll be fine, thank you. I'll just stabilise.

CHAIR: Are you sure?

30 MS McLEAN: Yes, thank you.

So he was given no opportunity to choose to leave home. He was not given an opportunity to choose where he lives or who he lives with. In fact, we were advised at the time, and, you know, let me say that my knowledge of advocacy, of disability support at that point was very different to what it is now. But at the time we were advised that to help him adjust that we should move him into this home and not have contact with him for a month while he adjusts.

40 MS EASTMAN: And when he moved into that home and you had no contact with him for a month, he moved into a home that had other residents with complex behaviour support needs. He moved into a home where the doors and windows were locked, he moved into a home where the cupboards in the kitchen were locked. He moved into a home where the TV and stereo were locked behind screens and he moved into a home that had a concrete space as a yard, very high fences, and that was the only place to go for fresh air. So he moved into a home where he wasn't permitted to go outside and you describe, when you did go to visit him, that it was like him being in a large, caged area.

MS McLEAN: That's right.

MS EASTMAN: Now for your son, this was, as you say in your statement,
5 devastating and absolutely, utterly traumatising and his reaction was to destroy his
bedroom in every way possible. So he smashed the walls, broke windows, ripped
wardrobe doors off. And looking back on that, you say he was experiencing distress
and sensory overload, and so he was engaged in an absolute flight response, and one
10 of the consequences was then some behaviours which have been described as
behaviours of concern, but what were they, and you could tell the Royal Commission
about the 170 missing persons reports that were filed in relation to him in the six
years he lived at this group home between 1998 and 2004. What did he do?

MS McLEAN: I guess if I'm speaking for him, after him initially adjusting, I don't
15 even feel that's an accurate word either. After he'd been there for a period of time, it
was clear that he devised a plan of how he would gain his freedom or, on some
occasions, how he would escape the very threatening environment that he lived in.
Some of his co-residents, through their presentation, certainly engaged in predatory
behaviour, aggressive behaviour. So within his living environment, it's fair to say
20 that he was hypervigilant for most of the time. So I guess he developed a plan of
how he would escape that and that's exactly what he did, and he used an incredible
amount of intellect and pragmatic thinking to be able to escape that environment
because it was very highly locked and he got out.

25 At the time there wasn't enough funding, there wasn't enough funding that he
attracted that allowed for anybody at this service provider to send somebody to
follow him and support him whilst he was out in the community. So each time he
escaped, he was out there on his own basically.

30 MS EASTMAN: When you say he's out there on his own, he would walk?

MS McLEAN: Absolutely.

MS EASTMAN: He would walk and he would walk, in some cases over 100
35 kilometres and just walk?

MS McLEAN: Yes.

MS EASTMAN: Often barefoot?

40

MS McLEAN: Yes, pretty much always barefoot at that stage, and they were often
known locations as well for him. Like he had a plan.

MS EASTMAN: And so --- you said there wasn't funding, so what did this mean?
45 That there was no one who would follow him or track him down?

MS McLEAN: No.

MS EASTMAN: So the response was to report him as a missing person to the police which, in turn, led to a call to you and your husband and you would often be part of the search party to find him, is that right?

5

MS McLEAN: That's right, yeah.

MS EASTMAN: After six years of living at this group home, you say you resolved to say this isn't working, and we can't focus on containment, and you say in your statement you were frustrated by the lack of progress for your son and a decision was made to relocate him to some new accommodation, that was in 2005.

10

So the move was to -

CHAIR: Sorry, just before we move onto the next phase, may I ask you a question, Ms McLean, about this period? Were you aware during this period of the medication that was being given to your son during this six-year period?

15

MS McLEAN: Most of the time, but there were certainly a couple of occasions where medication was given and I wasn't 100% aware of that. Certainly within this environment he was administered medication twice and became very unwell because of that.

20

CHAIR: During this six-year period. Thank you.

25

MS EASTMAN: The second group home was, as you say, a terrible match and he was only there for a short period of time, but he wasn't locked up in the way he was in the first group home. And so you made a decision to move him again, later in that year, and then he moved to what you describe as a cluster facility. Can you tell the Royal Commission, when you use that expression "cluster facility" in relation to accommodation in Victoria in the mid-2000s, what does that mean?

30

MS McLEAN: That means that it is a cluster of homes and small units that are all located in the one spot, and the only people who live there are people with disability.

35

MS EASTMAN: And he found living in that environment triggering because there were so many other people in his space, and so, again, he kept leaving and, again, there were reports made to the police, and I think for the period that he was there, which was just under a year, is that right, there were 80 missing persons reports?

40

MS McLEAN: That's correct. Yes. So if he left the facility and did not return within an hour, they would report him missing.

MS EASTMAN: As far as you know, any strategy used other than management reporting to the police each time he left the facility?

45

MS McLEAN: No, not really. Over the years there's been attempts, and some really

good documentation produced by the behavioural intervention team that DHS had at the time and on the face of it, and reading the document, you know, there were some really positive elements there. The challenge always is, and still remains, is that that information doesn't flow through to what is being offered in the form of support to that individual every day in a considered way.

MS EASTMAN: So a decision was made in the sense that you were given advice that based on the Department having a duty of care to your son, that he would need to be housed in a more restrictive environment. Can I ask you this: do you recall any discussion at the time about asking why he wanted to escape, as you call it, but to just go for a walk, be on his own, perhaps, and addressing that issue? Because the response, as you say in your statement, seems to be well he needs more restrictions. So it sounded to me, reading your statement, that what the response was is how do we prevent him leaving rather than why was he leaving. What's your recollection of the way in which that decision was made, that he move into an even more restrictive home environment?

MS McLEAN: The main driver of that decision would have been not my son's welfare, in a creative way. Some, at the time making the decision would have argued that, but they had not effectively measured risk, so they felt there was a risk to him and to the public if he continued to access the community. But nobody talked about the risk to him of being locked down for the rest of his life.

MS EASTMAN: If he was just walking, what was the risk to him and the community?

MS McLEAN: Look, he can sometimes cross the road in a less than - would certainly be observed as an unsafe way. But I guess the way I looked at it was that nobody in the community behaves in a 100% risk-free way when they're accessing the community. Choice, having choice in our lives involves risk, but the alternative they were offering us was forcing him into what they thought was 100% risk-free. But, really, the motivation would have been that the police were probably putting pressure on them because they were getting called all the time, and there were people within that organisation that, yeah, could sleep at night thinking that it was okay to lock my son up without any - and certainly at the time I said to them "So what is the plan? You're saying that because X happened yesterday, he must be locked up again tomorrow." And I asked them "What was the plan?" At the time we were told "Look, just for three months, until we figure out a better way. "

MS EASTMAN: How effective was that plan?

MS McLEAN: It was absolutely useless.

MS EASTMAN: What happened?

MS McLEAN: Well, he remained in the house and at the time one of the managers, it was reported to me, that the support workers were told not to even let him out in

the backyard because he will climb over the fence and basically his response was to jail and really to contain him in the house. The other residents within this home were placed there for the safety of other people. Because there was this focus on containment, of course he ends up in environments where, you know, there's very complex individuals that are housed there, and he was bitten and --- goodness knows what he's endured. He's not able to tell us that. We are certainly picking up in his art that he has suffered trauma at a very significant level and because he's not able to tell us in detail, we're not able to support him in the way that anybody else who has had a traumatic experience where they're able to talk about it and get some validation.

10

MS EASTMAN: You say in your statement that at this point in time you felt your son was becoming suicidal.

MS McLEAN: Yeah, that was pretty obvious. It was at that stage that he started a particular behaviour that has led to now, he requires us to lock up knives and scissors. He would mimic cutting his throat, he would certainly get the knife and have it sitting on his wrist, and if you didn't know, you would swear he was about to slice his wrist but he would sort of, like, just mimic the act of it without actually breaking the skin.

20

He then would begin to use - he likes to use a knitting machine to create cord, and he still does that to this day, but he was using those cords to make a noose.

MS EASTMAN: At this crisis point, you decided that he had to move again and by this stage he's almost 30 years old and he moves to a different environment, this time a three-bedroom unit and this was another place that he hated living, and when you took him out for the day or he went back to your home, he would beg you not to go back. And he kept leaving and going for a walk. But you say that there was a concerned citizen who saw him out walking about and who assisted him to return to the unit, and then that person made an application to the Victorian Civil and Administrative Tribunal for an independent guardian to be appointed because that person believed that your son should not be able to independently access the community and your informal decision-making arrangement should be challenged. What can you tell us about this step? What happened?

35

MS McLEAN: Yes. Well, thankfully by that stage I was a lot more confident in my advocacy. I was actively working in the sector and I was also aware of the role of the Senior Practitioner, and he had - that Office, and the Senior Practitioner himself had supported the move from the locked facility to the unlocked. So we approached them and were able to get some, you know, terrific support from them, but our view is that this concerned citizen indeed wasn't as "non-connected" as they might make out. They certainly weren't a random citizen. It was a person who worked in another region supporting people who was part of the State Government support arrangement, what they call DAS or Disability Accommodation Services, and this concerned citizen clearly, there had been a complaint behind the scenes to use the application for guardianship as a way of locking our son up again, and certainly it wasn't just some random concerned citizen.

45

MS EASTMAN: So a guardianship application was not successful and ---

MS McLEAN: No.

5

MS EASTMAN: --- and you and your husband continue to have the informal guardianship arrangements, is that right?

MS McLEAN: That's correct.

10

MS EASTMAN: And you get to 2011 and by this stage, as you say in your statement, you've just had enough and you made a decision to apply for an exit funding package, and that then enabled you to find some rental accommodation for your son and you moved him out. So what did this mean? That he was being moved out of the care of the Department or service providers and you took over the day-to-day supports for him?

15

MS McLEAN: Yes. Well, one of the challenges that one of the previous witnesses alluded to was how the system worked then and would now as well, is that when you're requiring accommodation for a family member, you approach the Department of Human Services, they would go onto a register and then you would have to wait until a bed became available, and that then means you're in the system. So they can't throw you out of that system. The only way that you would leave that system would be to exit voluntarily, and at that stage they provided a small package that would go with the person to pay for the support, that is the support workers, that would support that individual as they established themselves independent of government-funded accommodation.

20

25

It was a very small package and this was a huge leap of faith, but I just knew that my son could not continue to live within these environments that he was placed in.

30

MS EASTMAN: So effectively, what, you've taken him out of a system, is that right?

35

MS McLEAN: That's right.

MS EASTMAN: Right. I'm going to ask you in a moment what his life is now, but before I do that, in your statement you reflect on those 13 years and the Chair has asked you a question about your son's medication, if any, while he was in the first group home and in your statement, at paragraph 33, you tell the Royal Commission that you remained involved with your son's medical care and treatment as much as you possibly could, and you describe the process of consent and your involvement in consent to medication. But it's the case, isn't it, that you say in the statement that you're not entirely sure if medication was used while he was in the various forms of accommodation over that 13-year period. Is that right?

40

45

MS McLEAN: I'm certainly aware that he was using medication. I guess the

main - the main thing I can speak to in relation to the use of psychotropic medication is that there was more than one occasion where the - those running this service had a locum doctor come in and prescribe a psychotropic medication to control my son's behaviour, and on at least a couple of occasions we were not informed of that until
5 after it had happened.

MS EASTMAN: And during this period of the 13 years of reflection, were you aware as to whether any behaviour support plan or a program of that nature was developed?
10

MS McLEAN: Absolutely. That was, you know, one of the things I continually try to advocate for, and I still have the copies of some of those plans. The reality is that there remains - often remains a disconnect between a behaviour support plan and what is actually happening, what their lived experience is from day to day.
15

MS EASTMAN: Can I ask you this question, and the Royal Commission heard a little bit of this evidence yesterday: is your experience of the behaviour support plan, a plan that was seeking to change your son's behaviour, or a support plan that identified what might be the environmental causes and triggers for his behaviour
20 around him? And I just want to - given your experience with advocacy, I want to come back and ask you about this in terms of your own role as an advocate, but just looking at this period from 1998 to 2011, what can you say about what the purpose of the behaviour support plans were and was there focus on changing behaviour or identifying causes or triggers of behaviour?
25

MS McLEAN: They were heavily loaded with the changing behaviour approach at that period of time, very much so. But, you know, sometimes there would be some reference to how the support workers should approach him and communicate with him, but it was very much about "When he does this you need to respond this way."
30 No insight for anybody around why might he be behaving that way, what might be the contributing factors, and there were certainly no references in those behaviour support plan to his sensory needs.

MS EASTMAN: And in your experience of the behaviour support plans over that
35 period, what was the extent of the consultation with your son and asking him what he wanted to achieve from such a plan?

MS McLEAN: Zero.

MS EASTMAN: Okay. So what is his life like now? And you described this in the
40 statement but can I ask you to tell the Royal Commission have there been positive changes, have there been ongoing challenges, and what's the current circumstances for your son?

MS McLEAN: Certainly in the early part of his - where he currently lives now, there were challenges because there wasn't enough funding. It appeared to us that after a period of time - so he moved into this home, I didn't have - there wasn't enough

funding to have all hours of the day where he has support. There was a period of time where there was no funded support. But he certainly showed us on a few occasions he was quite capable to stay at home by himself and wait for support workers to come in.

5

But after a period of time, we realised that the full impact - because he'd gotten out of the stressful environments where he was hypervigilant and he moved to his own rental home, that that was all removed and after a period of time we started to see some of the trauma emerge, the impact of the trauma of those previous environments. So there's certainly emergence of mental health issues, in my view, has been our number one challenge since he's been living in his rental property.

10

I had difficulty getting support providers to come in and provide the support because ultimately it often came to that point where he might have been in the community engaged in a particular behaviour and there was a panic response, or a very risk-averse response, and the provider was very much driven by their obligation to their support workers and not to my son. And that's, you know, I think, systemically, that is a huge issue that needs to be addressed, around the management of risk, and where - because my experience with my son and as an advocate is that when it comes to the pointy end, it's OH&S or duty of care that will trump everything, in terms of what decisions are made about the person's life. It's very difficult for people to keep that person central if there are behaviours that appear to put him or others at risk.

20

So eventually, I worked with two providers but that eventually led to, on both cases, them leaving and saying it was too hard. So then I started to develop a self-managed approach where - which has led to what we have now where he has his own support provider organisation, he's the central - the centre of everything that happens in that, and the outcomes have been significantly positive.

25

MS EASTMAN: Okay. Could I just ask you, before we go to some of the outcomes. In terms of health support, and any integration of health support into your son's life and the current supports and arrangements around him, what have you done differently in terms of using medical supports? Does he have a GP? Does he have a specialist psychiatrist? Is he receiving particular treatment in relation to the trauma that you've described? What's the health situation?

35

MS McLEAN: Yes. What we have now is what I've dreamed of for many years. So he has a multi-disciplinary team involved which includes an OT, a speech pathologist, a behavioural specialist, somebody we call a practice coach who has been trained in a similar way to one of the witnesses from yesterday. And more recently as part of that team we've brought in what we call an art mentor, and this is an individual who personally relates with how my son experiences the world, and she's an artist as well and this has been a hugely positive addition.

40

We also meet - and that team meets every month to six weeks. We also have regular medical care team meetings with his GP, his psychologist, his psychiatrist and myself and one of his - the person from his support team.

45

MS EASTMAN: Do you have someone called a practice coach, what's the role of the practice coach as part of the multi-disciplinary team?

5 MS McLEAN: So when somebody is supporting my son and he might be presenting as not coping well and quite distressed, they have the ability to ring a phone number and speak to a live person who is the practice coach, who has already established a trusting relationship with our son. He knows who she is, he knows why she's there, he feels completely safe with her. So they're able to ring her, give her a little bit of
10 context around what's happening. She will either coach them, you know, say this, do this, whatever, or sometimes she'll instruct them to put her on speaker and she will have a conversation with our son and she will be able to coach both our son and his support in these intense moments so that he's able to eventually calm down and not engage in the behaviour of concern.

15 MS EASTMAN: And you say in the statement that if there's one good thing that's come from COVID-19 for your son, is that he's now able to have videoconference sessions with a psychiatrist and a GP when required and that's, you say, been life-changing in terms of access to medical help. Is that right?

20 MS McLEAN: Oh, absolutely. And I will definitely be advocating systemically that telehealth remain part of the life of these individuals. To get - sometimes to get my son to a medical procedure, we have to put a huge amount of work into informing him in a way that he understands of why he's going, what will occur, when he has a
25 terrible fear of blood tests and things like that, and we'll often have to give him some sort of sedation just so that we can get him to walk in the door of wherever like an X-ray clinic or whatever.

30 Telehealth means that certainly to have a consultation with their GP or their psychiatrist, that's no longer required and he's in his safe home environment and able to connect in a way that's never happened before.

MS EASTMAN: All right. So your son has always wanted a job, and he's told you that often, and he's now a recognised and practising artist, and you - he's provided
35 you with some of his drawings and you've selected a drawing that you wanted to share with the Royal Commission. So we'll just put that up now.

Why have you selected this particular drawing?

40 MS McLEAN: We've certainly - it's not the one I thought it was, but that's okay.

MS EASTMAN: We've got the others.

MS McLEAN: No, that's okay. So a lot of his drawings, and I wish I had his art
45 mentor present because she interprets his drawings beautifully. But his drawings often will always have people in them and this one obviously, it appears that people are in bed, and by the expression on their face they're feeling safe. There's no - if

you have - he's very good at drawing expressions and feeling comfortable and safe and I think that, for me, that tells me that's always been his hope, you know, the way he would want to feel. It was clearly the way he felt when he was living at home with us. You know, he's expressed that in this drawing.

5

MS EASTMAN: There's a lot of other matters that you've covered and discussed in your statement that I'm not going to have time, unfortunately, to deal with this morning, but the Royal Commissioners have read the statement and others following the hearing will also be able to read, including some very helpful and thoughtful suggestions for change and improvement that require us to look at life as an integrated process, not just accommodation or medical treatment or behaviour support.

10

So can I thank you for those suggestions that the Royal Commission will take on board, and thank you very much for your time this morning to share your evidence with us.

15

Commissioners, I'm just going to ask to come up on the screen some telephone numbers, that if anybody has felt distressed by hearing the evidence this morning or it's raised any concerns with them, we'll just put up some of the telephone numbers.

20

Blue Knot contact details and information about Blue Knot are also available on the Royal Commission's website.

Commissioners, thank you.

25

CHAIR: Thank you. Commissioner Atkinson, do you have any questions?

COMMISSIONER ATKINSON: No, thank you.

30

CHAIR: Commissioner McEwin?

COMMISSIONER McEWIN: Thank you, Chair.

Ms McLean, can I ask you to clarify when you were discussing the move into the current arrangement for your son, you mentioned self-management. I assume that's in the context of the National Disability Insurance Scheme. Can you just clarify by what you mean by self-management, thank you?

35

MS McLEAN: Sure. So that is one of the offerings of how funding might be applied. It can be self-managed, which, in our case, allows a lot of flexibility to be able to meet our son's support needs. He currently requires two support workers during the day and one overnight, because we're working very intensively to try and, I guess, mitigate some of the behaviours that have developed, that is driven by the trauma and it's certainly, in the short term, will require some fairly intensive interactions.

40
45

COMMISSIONER McEWIN: Thank you. So I assume from the past arrangement and into the current arrangement, that is a more positive experience?

5 MS McLEAN: Oh, absolutely. The advent of the NDIS has been life-changing, hugely life-changing in a positive way for my son and many other individuals that I support. It's definitely not perfect at the moment but, yeah, it just doesn't even come close to what we had to deal with previously.

10 COMMISSIONER McEWIN: Thank you.

CHAIR: Following on Commissioner McEwin's question, does the NDIS cover entirely the cost of the support that your son is receiving and that has led to such a positive outcome from your point of view?

15 MS McLEAN: Yes, they are.

CHAIR: Can I just ask one other question. At paragraph 67 of your statement, you say that:

20 *Too often, psychotropic medications including anti-seizures are prescribed as a method of behaviour control, which can lead to other behaviours of concern arising due to the side effects.*

25 Is that statement based upon your own professional experience?

MS McLEAN: Certainly it's - I couldn't say - because as a professional counsellor I'm not working with people with disability who are using psychotropic medication. But my many years as an advocate and working within teams where professionals participate, there definitely is strong evidence to show the need for what some of the previous witnesses have talked about, where a person has access to a team - a highly qualified team that could do a medication review, and medication reviews with a view to supporting either the organisation or the family to assist that person to reduce their medications if that's at all possible.

35 CHAIR: Ms McLean, thank you very much for giving your evidence and for sharing your story and that of your son. It has been of enormous assistance to us, and we are very glad that things have turned out much better than they used to be.

40 MS McLEAN: Thank you.

CHAIR: No doubt due to your effort and those of your son.

MS McLEAN: Thank you very much.

45 CHAIR: Thank you.

MS EASTMAN: Thank you, Ms McLean.

THE WITNESS WITHDREW

5

MS EASTMAN: Commissioners, next witness, we turn to Brisbane. Ms Zerner is taking the next witness.

10

MS ZERNER: Commissioners, the next witness is Dr Niki Edwards.

CHAIR: Thank you, Dr Edwards, for joining us and giving evidence today. If you wouldn't mind, follow the instructions of my associate who will administer the affirmation. Thank you.

15

DR NIKI EDWARDS AFFIRMED

20

CHAIR: Thank you. Ms Zerner will now ask you some questions.

EXAMINATION BY MS ZERNER

25

MS ZERNER: Dr Edwards, can you state your full name for the Commission?

DR EDWARDS: Nicole Stefanie Edwards.

30

MS ZERNER: Dr Edwards, it's correct, isn't it, that you provided a statement for these proceedings?

DR EDWARDS: I did.

35

MS ZERNER: And that is dated 10 September 2020?

DR EDWARDS: That's correct.

MS ZERNER: Have you had an opportunity to review that statement recently?

40

DR EDWARDS: I have.

MS ZERNER: Is it true and correct to the best of your knowledge?

45

DR EDWARDS: Yes, it is.

MS ZERNER: Commissioners, you will find Dr Edward's statement at Tender Bundle part A behind Tab 39, and I would ask that be marked as Exhibit 6-13.

Commissioners, there is also a number of annexures to Dr Edward's statement, and they are at Tender Bundle A behind Tabs 40 to 44, and I ask that they are marked as Exhibits 6-13.1 to 6-13.5.

5 CHAIR: Yes, thank you.

EXHIBIT# 6-13 - STATEMENT OF DR NICOLE STEFANIE EDWARDS

10

EXHIBITS# 6-13.1 THROUGH TO 6-13.5 - ANNEXURES TO STATEMENT OF NICOLE STEFANIE EDWARDS

15 MS ZERNER: Dr Edwards, you are a senior lecturer in the School of Public Health and Social Work at QUT?

DR EDWARDS: Yes, I am.

20 MS ZERNER: One of your focuses for your research is on intellectual and development disability and mental health, particularly the use of psychotropic medication and restrictive practices?

DR EDWARDS: That's correct.

25

MS ZERNER: It's the case, isn't it, that your actual PhD in epidemiology was a doctoral thesis which explored, prescribing psychotropic medications for adults with intellectual disability?

30 DR EDWARDS: Yes, that's correct.

MS ZERNER: And you've been in academia for about ten years or so, is that correct?

35 DR EDWARDS: Longer than that. Ten years in the current position though.

MS ZERNER: Okay, but certainly prior to that you also had some clinical experience, and that includes that you are a qualified social worker with post-graduate qualifications?

40

DR EDWARDS: That's true.

MS ZERNER: And that earlier in your career, you worked in psychiatric services as people with intellectual disabilities were moved from institutionalised care into the community?

45

DR EDWARDS: That's right.

MS ZERNER: You've also worked in public policy and public administration across the Government?

5 DR EDWARDS: That's true.

MS ZERNER: So it's fair to say you've got a wide spectrum, from a clinical background when people went from an institution into the community, and you continued working all the way through to your PhD in this particular area?

10

DR EDWARDS: That's right.

MS ZERNER: In your research, since the mid-2000s you've been involved in a number of studies related to the use of psychotropic medication for people with intellectual disability.

15

DR EDWARDS: Yes.

MS ZERNER: What I would like to do this morning is to take you to some of those articles that you've been --- or articles that you've written which demonstrate the research that you've undertaken.

20

The first article I'd like to take you to, please, is the article that was published in 2007 which, Commissioners, is at Tab 41, and that's titled "Queensland Psychiatrists' attitudes and perceptions of adults with intellectual disability."

25

It's the case, isn't it, that this particular research came after some earlier research in about 1995, 1996, looking at similar aspects in relation to psychiatrists' attitudes.

DR EDWARDS: That's right. The earlier studies had been done in Victoria and this was the first research on the views of psychiatrists in Queensland about people with intellectual disability.

30

MS ZERNER: Dr Edwards, there were 175 completed questionnaires, that's right? And there was 43% of a response to the total mail-out?

35

DR EDWARDS: Yes, that's correct.

MS ZERNER: In that mail-out it was to all psychiatrists and all psychiatric registrars in Queensland?

40

DR EDWARDS: That's right. There's about just under 500 of them.

MS ZERNER: And the psychiatrists were asked to respond to 16 statements about the management of adults with a concurrent intellectual disability and a mental disorder?

45

DR EDWARDS: That's right.

5 MS ZERNER: Now in your article, and I think you summarise it very well, there's a table and I would like for that table to please be brought up on the screen. Now, Dr Edwards, this is really a summary, is it not, of those 16 questions asked of the psychiatrist?

DR EDWARDS: Yes, these are the Likert scales.

10 MS ZERNER: And this is the survey results. I just want to focus on a number of those. In number 2 it says adults with a dual diagnosis received a relatively poor standard of psychiatric care, and the psychiatrists agreed that that was 68%.

DR EDWARDS: That's right.

15

MS ZERNER: In relation to dual diagnosis, what's being referred to there?

DR EDWARDS: This is a term at the time that meant co-existing intellectual developmental disability and mental illness. The newer term for it used in Australia is now "dual disability".

20

MS ZERNER: If I can take you to number 8 and it says there:

25 *8. "Antipsychotic drugs are overused to control of aggressive behaviour"*

And there were 75% of psychiatrists agreed to that statement.

DR EDWARDS: That's right, very strong statement.

30 MS ZERNER: And number 9:

"Inadequacy of community support services often makes the prescription of antipsychotic drugs necessary".

35 And 78% agreed.

DR EDWARDS: That's right, they saw the use of these medications in lieu of appropriate community treatment.

40 MS ZERNER: Does that include such things as other alternatives to medication, and we've heard over the last couple of days about behaviour support management?

DR EDWARDS: Yes.

45 MS ZERNER: If I can then have you looking at number 13 and it says:

"Psychiatrists receive sufficient training in behavioural management of adults"

with dual diagnoses".

And only 35% agreed.

5 DR EDWARDS: That's correct.

MS ZERNER: Then in number 14 it says:

10 *"A sub-specialty of psychiatry should be responsible for the treatment of adults with an [intellectual disability]".*

59% agreed with that. And number 15:

15 *"The Psychiatry of dual diagnosis should be offered as a training option for all psychiatric registrants".*

And 85% agreed to that.

20 DR EDWARDS: That's correct. Lack of training is a significant problem.

MS ZERNER: Now, Dr Edwards, just on that particular point, you didn't drill down in this particular research in regards to that training, did you?

25 DR EDWARDS: There was some open-ended questions at the end of this survey that we did where we did ask them about whether they're interested in more training and it was certainly an issue that came up there as well.

30 MS ZERNER: And they were interested in receiving more training in this particular area?

DR EDWARDS: They indicated very clearly that they didn't receive training in this area and that was a big problem.

35 MS ZERNER: Thank you. And then number 16, it says:

"I would prefer not to treat adults with an [intellectual disability]".

And there was 58% that agreed.

40 DR EDWARDS: This is a real problem about attitude.

MS ZERNER: Now that particular data, was that reflective of the Victorian data that was done in '95/'96?

45 DR EDWARDS: Yes, it's quite consistent with those findings which was concerning at the time, given about a decade had gone past and we had fundamentally the same sort of results.

MS ZERNER: All right. Now sticking with this table, it's the case, isn't it, throughout 2019 and 2020, you've conducted a followup survey or follow-up research in relation to this particular article.

5

DR EDWARDS: Yes, I have.

MS ZERNER: And so you've issued a further survey to Queensland-based psychiatrists and there was 133 psychiatrists that participated in that survey.

10

DR EDWARDS: Yes, the response rate was much lower than this survey, initial survey that was published here, but, yes, we did get those responses.

MS ZERNER: All right, so I think it was 175 in 2007. Was there any particular reason that's been identified for the lower participation at this stage?

15

DR EDWARDS: Yes, it's very difficult to recruit doctors of any type to participate in surveys. They are very busy and they have been oversurveyed in so many domains, particularly given social media and, you know, the quickability to email, et cetera. So I think that was a major issue.

20

MS ZERNER: And Dr Edwards, I understand that you are currently analysing that data, is that correct?

25

DR EDWARDS: That's right.

MS ZERNER: But you've been able to establish some preliminary findings in regards to that 2019/2020 data, and I just wanted to take you to a couple of those. Now if we go back to this table at number 8, and it says:

30

"Antipsychotic drugs are overused to control aggressive behaviour".

It's the case, isn't it, that your preliminary findings in 2020 is that it's slightly increased to 77% now, agree?

35

DR EDWARDS: That's right. So I've got this preliminary table in front of me and I have 77% in 2020 agreeing, and 75% agreeing in 2007.

MS ZERNER: All right. If we go to number 9:

40

"The inadequacy of community support services often make the prescription of antipsychotic drugs necessary".

What are the 2020 results so far, appreciating they're preliminary results, show?

45

DR EDWARDS: 84% are agreeing with that compared back to 2007, 78%, so there's been an increase.

MS ZERNER: All right. And then the last point is just in number 16 and it says:

"I prefer not to treat adults with an [intellectual disability]".

5

What results have you been able to establish now in 2020?

DR EDWARDS: The words changed slightly. So ---- the question we asked for the recent surveys, "I would prefer not to work with adults with intellectual disability", and we have 36% of the sample agreeing and 58% agreed back in 2007. However, my initial response to that is that we have a lower response rate, and it's more likely those that are interested in this population responded to this most recent survey.

10

MS ZERNER: And so that may have skewed that difference in the data there?

15

DR EDWARDS: Yes, but it's still very significant when you think about even those that were interested enough to respond, are still, there's still a significant proportion, 36%, saying "I don't want to work with this population."

20

MS ZERNER: Certainly. I ask that table to be taken down now, please.

Isn't it the case that consistent with the 1995/96 data, the 2007 data, your most recent data and 2020, it shows a real issue in regards to training for psychiatrists in this particular area, you'd agree with that?

25

DR EDWARDS: I do.

MS ZERNER: And not having the knowledge and skills to actually be able to necessarily work with these people?

30

DR EDWARDS: Absolutely. You know, diagnosing and assessing the mental health needs of this population are very complex.

MS ZERNER: I'm not sure if you were able to listen in on Tuesday but Dr Cathy Franklin said one of your studies would be able to show that doctors are aware that they lack capacity, and this would be that particular study, that's right?

35

DR EDWARDS: It is. Cathy's involved in this study, yes.

MS ZERNER: Okay. She also said, but what doctors say is that there are no services to refer anybody to, and that they don't know how to do it either. Would you agree with that?

40

DR EDWARDS: Absolutely. And adding to that is an antipathy or an antagonism between health services and disability services.

45

MS ZERNER: All right. We'll come to that because I would like to explore that

with you as we go on. I'd just - there was something that I wanted to just explore with you and it's something that you raised in your statement in relation to the 2020 survey, and you say the study will again show that some psychiatrists are providing diagnosis of conditions such as schizophrenia in order to prescribe psychotropic medication without it being considered chemical restraint and regulated as such. Can you just explain what that is all about?

DR EDWARDS: So we, my colleagues and I did some research back in 2014 and 2015, and I published two articles from that research. One article was views of families and the second article were the views and experiences of the public guardians, and we had 13 public guardians, all the public guardians contributed and what they clearly shared with us, that this was a problem that they were discovering in their encounters with prescribers in their roles as guardians for restrictive practices.

But doctors, prescribers, were very unhappy with the bureaucratic regime associated, and they found it much easier to circumvent that scheme by diagnosing mental illness where it didn't necessarily exist.

MS ZERNER: Okay. I'll come back to that shortly in your article there. I'd like to move on, if I can, please, to your 2014 article and that's at Tab 42, Commissioners.

That study was "A multi-level ecological model of psychotropic prescribing to adults with intellectual disability."

Now, in that particular article you talk about the prescribing practices, and you talk about that it's a linear notion in relation to prescribing, but perhaps that there needs to be a relook at how prescribing happens with intellectually impaired people. Can you perhaps explain the linear notion to the model you're suggesting?

DR EDWARDS: Of course I can. So, typically, if you ask anyone in the community when they think about prescribing, they will think about the point of contact between the prescriber and the patient, the point of contact where a script is written and handed over. That is actually very inadequate at capturing the prescribing process because really what needs to be involved are all the stakeholders in this process, and it needs to be put in the context of what's happening in the person's life.

So if someone with an intellectual disability, particularly people with communication impairments who are reliant upon others such as family members or paid carers to advocate on their behalf, their views and experiences are going to very much influence those prescribing practices. The same way, in terms of whether there are carers in the lives of that person with intellectual disability who might be providing 24-hour care seven days a week, their views and ideas about what that person with intellectual disability needs.

So we need to really explode, if you like, the notion that prescribing is just about writing a script. There's a lot more complexity involved that needs to be factored

into the equation and many more stakeholders than just the patient and the doctor.

MS ZERNER: Okay, and you're suggesting that there needs to be further research in that area?

5

DR EDWARDS: Absolutely.

MS ZERNER: All right. Dr Edwards, I've just been advised we just need to slow down a little bit, we've got interpreters and I know I'm at fault at times, so together we'll try to slow down a bit, please.

10

DR EDWARDS: My apologies.

MS ZERNER: No, that's okay.

15

If I can take you to your 2016 article, which is at Tab 43, and that article is restrictive practices on refugees in Australia with intellectual disability and challenging behaviours, a family's story. Now, this particular research was about one family but it was their journey and their story through the system, so to speak. And that it was the complexities of navigating with disability, and also with restrictive practices. Can you just tell briefly what the findings of that particular study were?

20

DR EDWARDS: That the complexity of the life of the person needs to be factored into the process, that there is a lot of powerlessness and terms of people with intellectual disability and their carers, that they're at the mercy of a very complex system, that they were afraid to challenge the system for fear that the person with intellectual disability would be punished or excluded from services, therefore the carers weren't confident - or the parents, the brother and the mother, weren't confident at speaking up and speaking out and they were very concerned for the wellbeing, the physical and mental health wellbeing of the person involved.

25

30

MS ZERNER: Whilst it was one family and one story, you are of the view that it was a powerful story in this space?

35

DR EDWARDS: Absolutely, and sadly it's not an unusual story.

MS ZERNER: I'd like to now take you to article 20, which was published in 2020, which is at Tab 44, and it's the "Chemical restraint of adults with intellectual disability and challenging behaviours in Queensland, Australia: Views of statutory decision-makers."

40

Now, Dr Edwards, that was what you were talking about just a little minute ago in regards to the issue of prescribing and what some of those statutory decision-makers had said to you in this study, that's right?

45

DR EDWARDS: That's correct.

MS ZERNER: Now, in this particular study it was the 13 statutory decision-makers in Queensland for restrictive practices and was it all of those statutory decision-makers or was it just a sample of them?

5 DR EDWARDS: No, it was all of them. So there were some that were located in south-east Queensland and others were located along the Queensland coast.

MS ZERNER: All right. And they were employed by the Office of the Public Guardian?

10

DR EDWARDS: They were.

MS ZERNER: All right. Now, in regards to consenting, were they involved in the consent process regarding restrictive practices?

15

DR EDWARDS: These were the guardians for restrictive practices.

MS ZERNER: So what did that involve in the sense that their involvement of monitoring, for example, chemical restraint?

20

DR EDWARDS: One of their responsibilities was to do reviews where medication - psychotropic medication had been prescribed for the purpose of the management of behaviours of concern, and therefore they would have to have contact with the prescribers to check the rationale for the prescribing and to review it's efficacy fundamentally.

25

MS ZERNER: Okay. Now, you've set out some of the findings in your statement and I just wanted to go through some of those with you. At paragraph 22 of your statement, you had that in front of you?

30

DR EDWARDS: Yes, I'm just getting it.

MS ZERNER: You say that:

35

Many prescribers were 'hostile' towards guardians questioning their decisions in regards to prescription of psychotropic medications to adults with intellectual disability.

DR EDWARDS: That's true.

40

MS ZERNER: Now, in your study, it says that a significant and somewhat concerning trend identified by the study participants was a diagnosis of mental illness by some medical practitioners to circumvent the legislative regulations for restrictive practices.

45

DR EDWARDS: Chemical restraint, yes.

MS ZERNER: And that's what you were referring to before by that example in relation to medication.

DR EDWARDS: Yes.

5

MS ZERNER: All right. You also say that similarly, many people with intellectual disability had no prior history of mental health problems being documented before review under the restrictive practices regime was required.

10 DR EDWARDS: That's right. Some of the guardians actually said the diagnosis would come out of the blue.

MS ZERNER: All right. So is that, for example, a person with an intellectual impairment that may have been, in an institution, or in the community, that then
15 when the restrictive practices regime came in, previously didn't have a label of a mental illness but then had a label of mental illness?

DR EDWARDS: That's correct, and this also links to the rationale for the prescription being suggested that it's more about the convenience of carers or to
20 protect carers than it is to manage mental illness.

MS ZERNER: All right. And in the study you say that a positive behaviour support plan meant, at minimum, the clients had treatment - had a treatment plan and it was reviewed annually, whereas if a diagnosis of mental illness was made, there was no
25 longer a need for a positive behaviour support plan or an annual review?

DR EDWARDS: That's correct.

MS ZERNER: And you also say a diagnosis of mental illness meant that people with
30 intellectual disability were out of sight?

DR EDWARDS: That's right.

MS ZERNER: So is it that you're saying there that if a person with intellectual
35 impairment is prescribed a medication, psychotropic medication, for mental illness, that they no longer have necessarily that oversight or review?

DR EDWARDS: That's correct, and that's of great concern because we know from the research there's a lot of polypharmacy, so multiple medications prescribed, and
40 there's a lot of problems with actually --- follow up and regular assessment for the need of that medication, side effects, profiles, et cetera.

MS ZERNER: So it would be correct, though, wouldn't it, that some of those people would have regular reviews, they might have an annual CHAP review and a review
45 with their doctor, but there would be a cohort that wouldn't have any review, is that your understanding?

DR EDWARDS: Some non-Government organisations have certainly adopted the CHAP but there are many people that live with families in the community or organisations that don't follow that.

5 MS ZERNER: If I then can take you to page 23 of your statement, you say that:

.... support plans were important, they could be very expensive to develop and were often undertaken by outsourced practitioners who may have had no contact with the person with intellectual disability.

10

So I want to, if I can, please, bring up on the screen page 206 of your article which just starts there with behaviour support plans. And it's just on the left-hand side of the screen there, can you see that there, "Positive Behaviour Support Plans"?

15 DR EDWARDS: Yes.

MS ZERNER: Just going down to the second paragraph there, and it says:

Plans were expensive to develop whether service providers outsourced....

20

But that the person may never be interviewed. What was that about, in the sense that a plan was being developed, yet the person with the disability wasn't interviewed? Is that what that's saying?

25 DR EDWARDS: Yes, it is, and actually I can specifically recall a number of situations where positive behaviour support plans were reviewed or families looked at them, and they had been cut and pasted from other people's PBSPs, and there was inappropriate information contained in the behaviour support plans that pertained to another client altogether.

30

MS ZERNER: And your research is that it was variable, that is, the quality of the plans were variable, some were up to 90 pages.

If I can go to the next page, and it just starts up the top:

35

.... '.... sit in drawer stay there for 12 months while they go on doing what they want to do'....

40 So was it that plans were being developed and there was no implementation of those plans?

45 DR EDWARDS: I think that's true, but what you have is a whole range in the quality of the plan, its suitability for the person, training of direct care staff who have to implement the plans, remembering these staff sometimes only have a Certificate III or may have no training whatsoever. And some of these plans contain some very complex information. So there is a whole variety of reasons why plans are not implemented.

MS ZERNER: All right. This data was collected in 2014/2015, is that correct?

DR EDWARDS: Yes.

5

MS ZERNER: And it says there that the clarity of plans appear to have improved, and that seems to have occurred at the same time when a template became available in relation to an enhanced positive behaviour support utility.

10 DR EDWARDS: Mm-hm, yes.

MS ZERNER: I'm not sure if we can scroll down on that page which is up on the screen at the moment, and if we can't, that's okay. What I just wanted to go to there, it's the paragraph that starts with "Participants", and it says there that:

15

.... sometimes this plan was written to meet administrative requirements associated with the legislation rather than best practice

So from your -

20

CHAIR: Ms Zerner, Dr Edwards is doing really well in slowing down. You, not so much --

MS ZERNER: Thank you, Commissioner.

25

CHAIR: --- so if you wouldn't mind slowing down a little, that will probably help our interpreters.

MS ZERNER: Thank you, Commissioners. And I apologise to the interpreters and to Commissioner McEwin. I will try and slow down.

30

What I was wanting to ask you then was, there is an example that says there that --- the meeting of legislative requirements. So I'm trying to understand good practice versus legislative requirements, why wouldn't the two go hand in hand?

35

DR EDWARDS: Because there are views that the restrictive practices regime is very bureaucratic, and very onerous and you also have to remember that in the field you can have five people with intellectual disability with very complex, high-support needs who might have one carer with them, one untrained carer with them, who has no capacity for training, non-Government organisations no longer employ clinical support teams so psychologists have been lost, social workers have been lost. So the expertise isn't there to make these plans and extremely relevant to the person's lived experiences.

40

MS ZERNER: Then you refer to, and it's there on the screen and it's the indented paragraph there, and it's the flip side to good practice. And it talks about a living document and the capacity to grow and change with the person. That's where you

45

were referring to the variability of those reports that are out there?

DR EDWARDS: And also, the fact that plans shouldn't be developed on 1
December and then left there until 1 December in the following 12 months. It should
5 be something that's used, consulted, changed, modified, made to work for the
individual, and therefore it's organic or living. It's real and useful.

MS ZERNER: I will ask that that article be taken down now, please.

10 Dr Edwards, I wanted to ask you about research generally in this space. You've been
carrying out research since the 2000s. As a researcher, I know you're going to say,
because I'm going to ask you what the challenges are, and I know you're going to say
the first one is funding. But can you just give an idea of what the challenges are in
15 this area in regards to research and particularly about data?

DR EDWARDS: Sure. First of all I'd like to say there's a lot of stigma and
discrimination associated with this population, and that actually transfers down to the
status or the acknowledgment it is given within research. So for example, it's not
seen as sexy, it's not attractive. Leukaemia, and you can put children on television
20 and seek funds for leukaemia. Everyone wants the COVID vaccine so research tends
to have a particular bent towards biomedical cures, if you like. So that's my first
comment. So if you want to go look at research funding through the NHMIC or the
ARC or the big National Government opportunities, there is - I have tried, others
have tried, there are no funding opportunities.

25 The other thing is that this population is seen as a very small niche population, and I
think that really needs to be challenged. 3% to 5% of the population have
intellectual disability, that is someone's brother, someone's - there's a mother
involved, there are carers involved, there are communities involved. So when you
30 think about it, it moves from just being a small problem looking at 3% to 5% of the
population when, you know, other people are involved in supporting that person.

But I also want to point out, our First Nations peoples are also 3% to 5%. Now if
you look at the funding, or even the mental health infrastructure available to our First
35 Nations peoples, it's underfunded, it's underresourced, but by comparison to this
population, it's virtually non-existent.

Now, if I was going for research funds for our First Nations peoples, I might have
some chance of success because it's a high priority. So, again, there's a status here
40 where people with intellectual developmental disability and their mental health needs
are way down the bottom in terms of priorities.

So, you know, my research, for example, was funded by the Office of the Public
Guardian who contributed \$10,000, and we ran that program with the smell of an
45 oily rag. I've also personally funded it from some of the research from my
consultancy account, because I see it as important. So I don't think this area of
research is acknowledged as important. Yet it has huge ramifications for the

wellbeing of those involved.

MS ZERNER: And is it the case that research in this particular area is driven by a passionate few?

5

DR EDWARDS: Yes, this is the other thing. There are a few of us, and I'm sure many of them will be giving evidence here at the hearing, who have, over the years, grown a great admiration for people with intellectual and developmental disabilities and their parents and carers who work in quite hostile environments in terms of funding and education and support. Unfortunately those in the area are driven by a personal passion, a personal interest. My life was touched many years ago working in the institutions and seeing some of the vulnerability there.

10
15
When we go, there is no one behind us, there is no succession planning, there is no there are some, a few specialists interested in this area, or specialist centres or specialist consortia where you can upskill and share your knowledge and skills with others. So it's a passionate few. Cathy Franklin is one of those people. Julian Trollor is one of those people.

20
MS ZERNER: Thank you, Dr Edwards. I want to turn on the suggestions, and I guess we've touched on a little bit of that in relation to the research issue. But you start there at paragraph 35 of your statement, but in particular I would like to explore with you paragraph 37. Do you have that in front of you?

25
DR EDWARDS: Yes, I do.

MS ZERNER: You say there:

30
I believe this population has fallen through the gaps in Australia as health and disability departments historically have played and continue to play a game of 'ping pong' with this vulnerable group

Can you just explain what you mean by that concept and what you see in practice and through your studies?

35

DR EDWARDS: Absolutely. So I have worked for Queensland Health Mental Health Branch, and I've also worked in policy in disability, so I have the unique experience of understanding both perspectives, as well as being a mental health clinician and have provided disability services.

40

So what typically happens is because it is dual disability, it is disability and coexisting mental illness, you have, if someone presents with mental health problems to Queensland Health Mental Health Services, and this is not unusual, this is not just Queensland, this is an Australia-wide phenomena, mental health say, "No, no, this is a disability issue. We call this diagnostic overshadowing and disability needs to pick up responsibility." So then disability say "No, no, no, this is a mental health issue."

45

So you have this game of pingpong going on between two very large well-resourced Government departments, and what happens is that people fall through the gaps.

5 MS ZERNER: And Dr Edwards, you've heard in evidence a little bit this week about the medical model and the social model. Now, that sort of seems to fit with what you're saying with health and with disability services. Can you explain that and what you think is perhaps the model we should be looking at?

10 DR EDWARDS: Sure. So I mean what happened - when I was first joined psychiatric services with the closure of the big institutions, the social model of disability was emerging and Australia was at the forefront of actually embracing that. What that was saying is that disability is really a social problem, it's an issue associated with environmental challenges, and the environment is actually responsible. There's nothing wrong with the person with disability. And what
15 happened is we threw the baby out with the bathwater because really, in reality, there are health consequences of having disabilities, and so particularly in terms of dual disability or dual diagnosis, as we called it, the psychiatrists and mental health clinicians were removed from providing services, and therefore the pendulum swung and we went to a pure disability model.

20 And that has had, you know, severe consequences for mental health and physical health and wellbeing of this population, that's why they've fallen through the gap.

25 MS ZERNER: And in the institutionalisation at that time, those practitioners working there, were they specialists in that field and permanently working full-time in that area with intellectually impaired people?

30 DR EDWARDS: It was run by psychiatric services. I'm not saying the services were ideal, I'm actually not pro-institutionalisation by any means. I'm very pro "feel supported in the community", but yes, there was some greater engagement with medical professionals.

35 MS ZERNER: But are you saying with the shift, that skill level and those services that were able to be provided have been lost in that transition?

40 DR EDWARDS: This is the problem. About a third of people with intellectual and development disability have a coexisting mental illness or mental health problems and that falls through the system if you only have disability service providers with no skills in that space.

45 MS ZERNER: Now, Dr Edwards, you set out a number of suggestions in your statement in regards to improvements that you say could be considered in regards to this particular area. I just wanted to take you, in conclusion, just to paragraphs 47 and 48 of your statement.

So above that you're talking about training and lots of other suggestions, but you say that you believe there needs to be a national network of centres or services like the

Queensland Centre for Intellectual Development Disability. And then you say in paragraph 48:

5 *A quaternary state-wide centre of this type needs to be affiliated with a university, multi-disciplinary in nature and cross the health/disability sector divide to cross over.*

10 Can you just explain what that means and I'm interested in this concept of a quaternary [sic] state-wide centre.

DR EDWARDS: Okay, it's quaternary --

MS ZERNER: Thank you.

15 DR EDWARDS: --- that's all right, meaning it's super specialist. That means it sits above - you go primary, secondary, tertiary care, and then you sit with quaternary above that, because this is a population that needs particular expertise. So what I mean by that is I believe that Queensland Health or health departments need to take some responsibility for this area and show some leadership and set up some specialist
20 expertise, and that be networked across Australia. And they should do that in cooperation and collaboration with disability services, but Queensland Health, health departments need to take the lead here. This is prescribing. This is, you know --- psychiatrists need to be involved, mental health clinicians need to be involved.

25 MS ZERNER: Dr Edwards, with all of the suggestions you've provided, with all of your experience and your academic background, what do you see as being the most pressing issue that needs to be addressed in this area?

DR EDWARDS: Mental health expertise in this population.

30 MS ZERNER: Right.

DR EDWARDS: We need, we need, mental health expertise.

35 MS ZERNER: Thank you, Dr Edwards.

Commissioners, that concludes Dr Edwards' evidence.

40 CHAIR: Thank you.

Commissioner McEwin, do you have questions? Commissioner McEwin has a question for you, Dr Edwards.

45 COMMISSIONER McEWIN: Thank you, Chair. I should have held up two fingers rather than one, I do have two brief questions. Thank you, Dr Edwards.

In your research into the development of positive support behaviour plans, what was

your understanding of how the person with a disability themselves were involved in that development, for example, how were they involved and what conclusions did you draw from that?

5 DR EDWARDS: Okay. In the --- there's an article in 2017 where we published the experiences of seven family members that came from the Office of the Public Guardian. They actually recruited them for us. When we look at the level of need or support that the people with intellectual disability that those family members supported, they all had high support needs or moderate support needs. That means
10 they were unable, the actual person with intellectual or developmental disability, was unable to participate in the problem behaviour support plan development.

What was difficult and sad about talking to those family members is most of them had not been involved. Most of them weren't even aware of the PBSP, they hadn't
15 been consulted, many of them hadn't even received a copy of it. So this is something that is being designed and constructed purely by the organisation, the nongovernment organisation, the service where the person lives.

COMMISSIONER McEWIN: Thank you. And one more question, and this is about
20 your research into psychiatrists and doctors prescribing medicine for the person with a disability. Did your research look into, or even show how supportive decision-making and the principles around that are playing out when the doctor or psychiatrist, et cetera, is interacting with the patient themselves?

25 DR EDWARDS: We're still to look at the qualitative data. So there was some open-ended questions in the most recent survey where they do ask some open-ended questions. There may be some information there. But this is some of the recommendations we have made in our papers. We have said that we need to do more research. We need to engage with all of the stakeholders involved in these
30 processes to better understand what works, what the barriers are, what the challenges are, and that funding hasn't been made available. So we don't know.

COMMISSIONER McEWIN: Okay, and just one final question on that point. Will
35 you be looking into how the person with the disability came to make an informed, well, consent with that supported decision-making in place?

DR EDWARDS: No. My current survey won't look at that, no, I'm sorry. That would be - it's very difficult to recruit adults with intellectual and developmental disability to this research, to any research by virtue of their communication
40 impairment. Many of them cannot provide informed consent, and this is where you have their carers or their family members or substitute decision-makers providing that consent on their behalf. It's a very challenging area to involve. But you could involve people with low support needs and that's one of the recommendations I've previously made in the research that we need to engage with them.

45 COMMISSIONER McEWIN: Thank you for that.

CHAIR: Commissioner Atkinson?

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

5 CHAIR: Dr Edwards, thank you very much for your very forthright evidence, if I may say so.

DR EDWARDS: Thank you.

10 CHAIR: We've had a great deal in the last 45 minutes.

DR EDWARDS: Thank you very much for listening.

CHAIR: Thank you.
15

THE WITNESS WITHDREW

20 MS EASTMAN: Commissioners, could we take a short adjournment now --- or perhaps not that short, 20, 25 minutes, if that's convenient.

CHAIR: 20 or 25?

25 MS EASTMAN: 20.

CHAIR: All right, then we'll resume at 11.35, and then we'll have Professor Dowse.

MS EASTMAN: Yes, in person, she will be here.
30

CHAIR: In person. Very good, thank you.

ADJOURNED [11.15 AM]
35

RESUMED [11.38 AM]

40 CHAIR: Yes, Ms Eastman.

MS EASTMAN: Thank you, Commissioners. Our next witness is Professor Leanne Dowse, and she's in the hearing room in Sydney.

45 CHAIR: Professor Dowse, thank you very much for joining us today and giving evidence. I'll ask you to follow the instructions of my associate for the affirmation you are able to take.

PROFESSOR LEANNE DOWSE, AFFIRMED

5

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

10 **EXAMINATION-IN-CHIEF BY MS EASTMAN**

MS EASTMAN: You are Leanne Margaret Dowse?

15 PROF DOWSE: Correct.

MS EASTMAN: And your professional address is at the University of NSW, and you're a university professor. You made a statement for the Royal Commission dated 7 September this year.

20

Might need you just to speak up so we can hear you and record you.

PROF DOWSE: That's correct.

25 MS EASTMAN: And you've read your statements?

PROF DOWSE: Yes, I have.

MS EASTMAN: Are the contents of the statement true?

30

PROF DOWSE: Yes, they are.

MS EASTMAN: Commissioners, you will find a copy of the statement in Tender Bundle A behind Tab 45, and there are a number of annexures. At Tab 46 you will find a complete copy of Professor Dowse's CV, and then there are a number of attachments between Tab 47 and 51. So Commissioners, could you mark the statement Exhibit 6-14, and then the various annexures 6-14.1 through to 6-14.6. Thank you, Commissioners.

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40 CHAIR: Yes, thank you.

EXHIBIT# 6-14 - STATEMENT OF PROFESSOR LEANNE MARGARET DOWSE

45

EXHIBITS# 6-14.1 THROUGH TO 6-14.6 - ANNEXURES TO STATEMENT

OF LEANNE MARGARET DOWSE

5 MS EASTMAN: Can I start with your qualifications. You've had a long history in disability studies and you've set this out in your statement. What is the current position that you hold and what are the areas of research that you are presently undertaking?

10 PROF DOWSE: Currently I'm a Professor of Disability Studies at the University of NSW and I also hold the Chair in Intellectual Disability Behaviour Support. Those two roles are complementary and they are both focused on mainly my research program. I do not do very much teaching, I have a mainly research role, and my research is really looking at the sort of complex intersections that people with
15 intellectual disability experience in terms of disability, social disadvantage in particular. I've done a lot of work around contact with the criminal justice system for people with disability, and certainly those areas have led me to understand that disability in and of itself is not the reason that many people find themselves in significantly disadvantaged circumstances. But rather the sort of social factors and social forces around them.

20 MS EASTMAN: I'm going to start by asking you some questions about terminology and expression.

25 PROF DOWSE: Sure.

MS EASTMAN: You've provided a very helpful and detailed overview in the statement, but can I start with complex support needs because you say in your statement that your research particularly relates to people with cognitive disability who have complex support needs. What are complex support needs and why do you
30 use that expression?

PROF DOWSE: There are several reasons we use that expression. One - the most particular reason is to avoid labelling people with their impairment. So we may need to understand the notions of impairment around learning, around sensory
35 impairments, those sorts of things. But the issue for people with disability, in a sense, which we understand from the social model of disability, is that it's the -

MS EASTMAN: I'll have to ask you to slow down a little bit as well, please.

40 PROF DOWSE: Will do.

MS EASTMAN: Thank you.

45 PROF DOWSE: --- that it's the social context that people with disability experience in which they experience disadvantage.

The term "complex support needs" really has sort of arisen from my work and the

work of others as a way to try to capture an understanding of what happens to people who have either multiple impairments, but who have a range of needs across a set of systems, or across a set of domains. It primarily came out of work looking at the experiences of people with intellectual disability in the criminal justice system.

5

One of the studies we did revealed that really, people who have intellectual disability who are in the criminal justice system very rarely only have one thing going on, that actually they will be people who will have had significant childhood trauma, they will have had significant circumstantial disadvantage, they may have experienced violence, abuse or neglect early in their lives.

10

They may also have multiple impairments, so while intellectual disability may be their main label, they may also have mental health issues, they may also have hearing impairments.

15

So it's a way of trying to capture the fact that people with disability themselves have a whole range of sort of social domains in their lives, and that the presence of disability, in a sense, makes them more likely to experience disadvantage.

20

MS EASTMAN: Just pausing there. When you talk about domains, is there a risk, though, that if we focus on domains that we can get a little bit narrow in focus, that we only look at a domain of education, that we only look at a domain of criminal justice? What do you do at looking at domains in the nature of your research and how you approach research where there might be multiple domains but they come together for the life of a person with disability?

25

PROF DOWSE: Certainly. I feel like there is importance in understanding what the domains are because our service system is actually organised around domains, so if we are to make changes in policy and service, we have to name those domains. But one of the characteristics of people who we think of as having complex support needs is that they have needs across a set of domains, and that --- often having support needs in one domain will actually make them more vulnerable to disadvantage in others, so that there's a kind of interconnecting, enmeshing and almost --- what would be the word, there's actually a dynamic process that happens.

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The idea of intersectionality, which is a sort of theoretical territory that people use, gives us this sort of idea that it's not just simply one plus one plus one, but actually the presence of one issue will make a person much more likely to have issues in other areas.

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So, for example, in the instance of the object of the hearing today, somebody who has behaviour support needs may well be very likely to be enmeshed in the criminal justice system because the lack of support for their social issues or the things that are causing them to stress leads them to come into contact with police, for instance.

45

MS EASTMAN: Against that background, we've heard the expression "behaviours of concern" or "challenging behaviours" and those two expressions, we've heard in

previous hearings, are themselves problematic, and you use the expression "behaviours of concern". So how do we deal with whether behaviours of concern and challenging behaviours have some pejorative context or convey some sense that the person who has the behaviours, it's their fault it's occurred? How do we address those and why do you use this expression? And if I was in a court, His Honour would say I've asked you four or five questions in one.

CHAIR: I was actually counting.

10 PROF DOWSE: I feel like the issue here is one that's common to terminology more widely in disability and in many areas of social debate, really, and it has, on the one hand, something to do with the fact that we do need terminology because we need to talk about things. The issue is what the shared understanding of those terms might be.

15 I, myself, share the views of many people who have already spoken to the Commission this week that these are not the terms that would be preferred to be used. And the issue, as I understand it, in a sense, is that we - by using those terms, we're centralising the problem on the person, and that is the absolute opposite of, I think, what you've heard from many of the other witnesses who have spoken this week and also from certainly the research work that many of us are doing, that actually what is critically important is the person in their context, in their social context.

20 We have a sort of complex interplay here because one of the thing that is we see emerging in disability is this notion of person-centeredness we do want to focus on the person at the centre. But what we have to avoid, importantly, is blaming the person or pathologising the person for who or what they are.

25 The way I would use terminology like this, is I would also, for many conversations, avoid those behaviours of concern, and probably would prefer to talk about people who have behaviour support needs. And the reason I do that is not that it's not people with something, but it's people, in a sense, who have support needs, and by operationalising the idea of support needs we actually bring into focus the support system, and in any interaction, particularly around people who have multiple connections with systems of support, it is also - the responsibility of the support and response system is equally in the mix, if not more for many people.

30 MS EASTMAN: In your statement, I think you make this point, it's paragraph 16, that if we stick with behaviours of concern, but they can be experienced from childhood through to old age and they can occur episodically, or they might be persistent. One of the issues of the expression "behaviours of concern" is that it sticks to somebody a bit like a metaphorical backpack, and they carry the "behaviours of concern" backpack label on them throughout their life. But you're saying that to attribute that expression attached to the person, without understanding the context, can have some concerns, and it doesn't appreciate that the behaviours of concerns might not be a permanent state of affairs --

PROF DOWSE: Of course, yes.

5 MS EASTMAN: --- and so there needs to be a better understanding in terms of how we use the language, is that right?

10 PROF DOWSE: Certainly, and I feel like the question with language is always a fraught one. We are never going to come up with a language that is acceptable to everybody, and language has shifted very much over time. We've obviously moved from "challenging behaviours" to "behaviours of concern" and probably will move to something else in the long term because nothing really captures the complexity of the issues that I think we face.

15 I think it's very important to really understand, at the heart of whatever terminology that we use, that a person's behaviour is about communication. And one of the issues, I feel, is really underlying the problem with terminology is that in identifying a behaviour with a person, we're often forcing people to understand the behaviour in a particular context. So it might be that a person is in the community and is acting out and the police are called. It may not be because that's one incident, a precursor
20 incident that's happened in the last 20 minutes; it might be that the person is very distressed. It might be that there's been an issue in the family, it may be that the person is traumatised and has seen something that's reminded them of a trauma.

25 So one of the problems with thinking about behaviours of concern, in a sense, is that they have to be contextualised, and in that context we have to understand history, we have to understand people's history. The Commission's heard, I think, over many weeks, many hearings, of the longterm disadvantage and abuse and neglect and exploitation that people experienced. We know that's going to affect a person well into their lives, probably for their whole lives. And so attributing a particular
30 antecedent issue to a behaviour of concern is really problematic because it lays aside consideration of that long-term traumatic, often traumatising and distressing life that people have.

35 MS EASTMAN: So that takes us into positive behaviour support. That's the next expression that I want to ask you about -

40 CHAIR: Sorry, can I - because it raises some really interesting questions that we've had to grapple with. And what you're pointing out is that it's the substance of the matter that counts. You're explaining that behaviour of a kind that has been referred to or is referred to frequently as "challenging behaviour" or "behaviours of concern" are not questions of blame, they're part of a social context and responses to people with impairments.

45 The trouble with focusing upon the significance of language is that in a way, I think, it may actually distract from the need to look at the substance. And it may be that by choosing a different label you're not actually solving very much.

PROF DOWSE: No.

CHAIR: You're just feeling better.

5 PROF DOWSE: I think the issue of language is one that has been - I mean we've
seen it in disability over multiple decades. You know, that is the nature of a moving
system of recognition, that we actually do need to change our language. But what we
also need to do is change our understanding and whether those two things are always
linked is not entirely clear.

10

MS EASTMAN: So to positive behaviour support and in your statement -

COMMISSIONER ATKINSON: Sorry, can I ask a question about the
language - sorry to interrupt you, Ms Eastman, --

15

MS EASTMAN: Sure.

COMMISSIONER ATKINSON: --- but you can't see me.

20 In the end, all these - the terminology we're trying to reach, they're all euphemisms,
aren't they, because they're not specific and they're trying to generalise across a wide
variety of behaviours that might be generational, that might be caused by childhood
trauma, attempt to say communicate, some of them in social ways, some of them in
very anti-social ways, and people try to cope with them as best they can, but in the
25 end the language is always an attempt, a respectful euphemism.

PROF DOWSE: I think that's correct but I think there's also some further issues.
Part of the issue, particularly in disability, is language. The disabilities is an
incredibly complex and diverse phenomena, if you like. There are people with a
30 whole range of different impairments who will have totally different life experiences,
and so to try to find one word or one term that recognises all of those different
contexts is always going to be incredibly difficult. So perhaps one of the things we
might think about doing is differentiating our language a little more.

35 The other point, I would say, is really a bigger picture question about who has the
power who determines what terms are used, and I think that's one of the things that is
of greatest concern, particularly to the disability community but also to researchers
and others and advocates, about who has the power to name. So in a sense, terms
like "behaviours of concern", they are associated with clinical or service-type
40 responses with professional language and they very much do not, as I understand,
reflect what people understand their own lived experience of. In a sense, it might be
more effective to talk about them as behaviours of resistance, but I feel like there is
no - in terms of any kind of public debate, that is the kind of debate that has to be
had, who has the power to do the naming, and what we see very much in the context
45 of disability services is that the professionals within the disability system, actually
have that power. We understand the medical establishment, the kind of clinical
establishment, that is the convention that those kind of scientific approaches use. I

don't think they really, in any way, will ever reflect lived experience of families and of people with disabilities themselves.

CHAIR: So that is to do, really, with respect and autonomy?

5

I'm sorry, Ms Eastman, for asking these questions, but it's a very important area.

PROF DOWSE: It has to do with more than respect and autonomy. It has to do with power. It has to do with the power of who has the power to name. And that's, in a sense, is determined by who you understand --- how you understand lived experience. I think what we are all trying to do in terms of understanding disability is to hear what lived - to understand what the lived - my myself, I do not identify as having a disability, so all I'm able to do is to privilege the voices of people who do have a disability in terms of their - and that may be within that there are people who are - who are more likely to be able to be articulate, even within disability there are debates about, even within the disability community, there are debates about who gets to call what what.

CHAIR: I understand that, I think, completely. How does one translate that into the same perception from people who are not part of the disability community?

20

PROF DOWSE: Boy, if I had the answer to that one, I would be --- you know, it's a much bigger sort of social question.

CHAIR: That's the next step, isn't it?

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PROF DOWSE: Yes, but I think those - changing language in and of itself will never change practice. I think that's the thing. I feel like there's always been a very strong move for the ideas around language and around attitudes, particularly, but without significant social change, without visibility of people with disability in the community, without general sort of respect for the lived experience of disability, you can change sort of language and attitudes probably all you like without really affecting the sort of social change that we see people argue is needed.

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CHAIR: We'll now allow Ms Eastman to ask some questions.

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COMMISSIONER ATKINSON: Sorry, I have another question.

CHAIR: Or we won't.

40

COMMISSIONER ATKINSON: Maybe a conclusion.

So this is actually about shifting power?

PROF DOWSE: In sociological arguments, that would probably be yes. Of course, that's a grand way of sort of thinking about things. I feel like the problem we have is that we have a whole set of social systems that put power in the hands of those other

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than people with disability themselves. We put power in the hands of the Judiciary, of the policing, of the service system, of professionals, of the medical profession. And we've seen a very, very long, decades' long history of those abuses and misuses of power to objectify people and to, I suppose, deny their own lived experience.

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I think the Royal Commission is a really good example of trying to address that issue in the broader sense, but certainly those same issues really do apply when we're talking about a very complex issue like, what are behaviours of concern? Who do they challenge? Who is challenged by them? And effectively a lot of the arguments that are against using things like challenging behaviour or behaviours of concern is, well, who is concerned about them? Who do they challenge? In fact, as many people in the disability community point out, that's the point of them, that they do challenge.

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15 CHAIR: Ms Eastman.

MS EASTMAN: I'm pausing, just in case.

20 CHAIR: If I were you, I would not pause.

MS EASTMAN: Professor Dowse, I am sure that the Royal Commission will need to hear from you about a range of areas. Can I steer you into the matters that are relevant to this particular hearing --

25 PROF DOWSE: Of course.

30 MS EASTMAN: --- and it's stepping out of that language, then, into what seems to be a way of addressing behaviours of concern. And so using that expression, the mirror to that is behaviour support, and the adjective "positive behaviour support" is there. So that's, again, another example of particular language being used to address the situation. And so why do we use positive behaviour support? What's the origin of that expression, and then I'm going to ask you about some elements of what best practice is in positive behaviour support.

35 PROF DOWSE: Rather than being just a language issue in terms of positive behaviour support, positive behaviour support is identified as a model of practice. So it's an identified model of practice that's been developed in a professional context. So rather than just sort of being a label, it actually comes with a set of thinking and a framework.

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Positive behaviour support has really emerged probably in relatively recent times, probably in the last 20 or so years, to be what's understood to be the better - the best way we have, not the most effective or by any means the most perfect or the perfect, but the best means we have to think about how responses and supports are provided to people who have behaviour support needs.

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MS EASTMAN: And so, looking at behaviour support, it's important to understand

that it's life course, and so that is support from childhood, to adolescence into adulthood, possibly even into old age, and the sorts of issues that we've seen in another Royal Commission in terms of the care of people in their old age. And that life course approach means that behaviour support involves early intervention for the person and the person's family.

You may have heard some evidence yesterday from Joanna Mullins who was talking about one of her clients, ABK, and the lack of intervention in his life early on. Can I ask you just to comment on the importance of capturing behaviour support at a very early age rather than sort of when it may become more an acute problem as a person grows up, they become a teenager, or the sorts of things in adulthood that might steer them towards a criminal justice response?

PROF DOWSE: There are a couple of issues, really, to explore there, I think. One is that it's difficult to - I mean, I think it's unlikely that it's - or not wise, in a sense, to think about behaviours of concern as a static thing, that actually they emerge at different times for different people for different reasons. And also they may well be, as we've heard for some of the other people who had spoken to you yesterday, they may be associated with particular impairment labels of intellectual disability, profound, severe --- you know, depending on support needs.

So when we're thinking about what those things are, they're not static. What we have to understand as the basis of that, I think, is that behaviour is about communication and so the early intervention idea --- you know, it's not - early intervention is not about somebody being young, it's actually about intervening when there is an issue - when an issue arises, not to leave the issue to escalate so that all you end up doing is punishing or responding to the person in crisis.

MS EASTMAN: And that's about building capacities in families, friends, social support networks, and then the places where people find themselves. So schools, in other settings, in employment, in their accommodation. So capacity building -

PROF DOWSE: Capacity building, yeah, and I feel like there are two parts to that. One is about capacity building in the person themselves. So for young children who may have communication disorder or delay, for instance, you know, a significant communication intervention early so that a person is able to have an alternative or augmented communication system to express their behaviour, their concerns or their resistance or their unhappiness or the things that they want in ways that are - that don't lead them to be understood to be expressing behaviours of concern.

I mean, for many people who don't have communication systems that others understand or recognise, they almost have no choice but to express a behaviour - something as a behaviour of concern because that's what gets people paying attention. So there are those kind of other sorts of supports, developmental supports that really need to be critically in place.

They are issues for the individuals themselves. I think the broader issues around

what a support system looks like is very, very critical, as you've raised. And those support systems are around where the person lives in their family context, perhaps, or in their residential context. One of the things I think that's very, very important to highlight, and I've heard many people say this over the past week, is that behaviours of concern effectively arise in environments of concern for many, many people.

MS EASTMAN: Is one of those environments transitions in life --

PROF DOWSE: Yes.

MS EASTMAN: --- and transitioning from education to employment or transitioning in terms of leaving a family home to a life that may be more independent, how do behaviours of concern and behaviour support arise in transitions?

PROF DOWSE: "Transition" is an interesting term because it's actually, in the work - I've done some work around transitions for young people particularly, and transition isn't just a move from one place to another. Transitions can be social, they can be emotional, they can be developmental, they can be psychological, and we often do see behaviours of concern, for want of a better term, arise at periods of transition, when somebody's moving into adolescence, for instance, which, of course, is what happens for every adolescent that we see behaviours of concern arise, anyone who has had adolescents will know that.

The problematic nature of how we pathologise those things is we fail to understand the added complexities that for young people who are moving into adolescence, they may not developmentally be at the point where they have the social skills to manage adolescence, but they may be in situations where they're also becoming interested in their sexuality, all of those sorts of things. And what we see very, very commonly is the pathologisation of those kinds of responses, because we don't understand them in the way we understand what we think of as sort of normal development. We have this normative idea of what transitions --- you should be coming into adulthood; what does that mean for somebody who has a developmental delay?

So our understanding of transitions really needs to be much more complex.

I think transitions can also be thought of as being associated with crises for many people. So transitions out of known places, moving from childhood services to adult services, moving from the family home into a supported residential context. These are all things that for people who particularly have fewer adaptive skills for whom sometimes these things happen quickly as well, sometimes, you know, suddenly there's a crisis and somebody's got to move from the family home quickly. Those are the things that very often are found to give rise to what people consider behaviours of concern, and they are, you know, they are environmental things that are happening. And often they are about the lack of forward planning for people. They're often associated with things that a person - that are not in a person's control. And so in a sense, they are perfectly natural responses to change and crisis.

MS EASTMAN: Restrictive practices. What is the role, if any, of restrictive practices in positive behaviour support?

5 PROF DOWSE: Restrictive practices, again, it's a term we need to use for a set of things that have been identified, generally speaking are things that restrict a person's liberty or their freedoms in some way.

10 We've seen internationally and in Australia multiple ways that restrictive practices are identified, but generally speaking we understand them across a range of categories of a physical restriction, you know, apply to a person of an environmental restriction where we change the environment to restrict a person's movement. Mechanical restraint, those sorts of things, and then we see chemical restraint.

15 It's been added in later years in our understanding of what a restrictive practice is.

MS EASTMAN: Are they part of positive behaviour support or are they antithetical to positive behaviour support?

20 PROF DOWSE: What we understand about restrictive practices, and the human rights context allows us to understand that they are a deprivation of liberty.

25 In the perfect world, I guess, they would never be used. I think one of the complex issues in this area that I think the Commission will really need to be dealing with is the complexity between our wish to eliminate restrictive practices, to not, in any way, ever deprive a person --- any person, of their liberty with the need to actually reduce restrictive practices.

30 And so part of what we see in the Australian context and elsewhere is a whole set of legislative and policy processes that actually deal with how to reduce a practice rather than eliminate it. And that leads us to having to have a whole set of processes that actually approve the use of a restrictive practice.

35 That's a very, very uncomfortable place to be, and I feel like that difference between reduction and elimination is a very fraught and difficult area, because on the one hand we recognise that in the human rights context there should be no deprivation of liberty, but on the other hand we find ourselves in contexts where restrictions are applied to people and that there is a need for some forms of regulation of it. But the very nature of regulation is, in fact, in a way, allowing the practice to occur. That is, 40 to me, a very, very difficult - I don't have the answers to that, I don't think anybody really has the answers to it, but I think it's really, for the Commission, a really significant underlying issue that needs to be carefully thought there.

45 MS EASTMAN: Chemical restraint is one type of restraint and you, in your statement, deal with the question for this particular public hearing, which is the use of psychotropic medication as a form of restraint. So what is the relevance to the use of psychotropic medication as part of positive behaviour planning and support? Is

there a role at all?

PROF DOWSE: There is a role almost by default, and that has to do with understanding what the nature of positive behaviour support is. In a perfect world, if positive behaviour support planning, assessment, et cetera, is done, the model suggests that what would happen for a person is that the behaviour that, you know, is causing this kind of restrictive response, would be replaced with another behaviour, would be - obviate the need for that by changing the person's environment. That is not always possible and we know it's not always possible, not usually because of the nature of the person or their behaviours, but because of the nature of the challenging environments that people are in. We can't change history for people, we can't change the experiences that they've had.

So in a perfect world, we wouldn't need restrictions, but we have an imperfect system that really does not particularly effectively respond to both the historical and the sort of contemporary ideas about why people's behaviours of concern arise.

MS EASTMAN: And you've said in your statement that if the psychotropic medication is being used to manage behaviour, then it has to come with a behaviour support plan, so they have to work together.

PROF DOWSE: They do.

MS EASTMAN: You've also said, though, that it's important to note, and this is what you say in paragraph 29.

.... disentangling the use of psychotropic medication for the treatment of a confirmed mental health diagnosis and its use for the purpose of managing behaviours of concern is a significant challenge.

Is the reason for that that you could end up in two pathways: if the psychotropic medication is used to manage behaviour, and it's accompanied by a behaviour support plan, then it follows a particular pathway.

PROF DOWSE: That's correct.

MS EASTMAN: If there is a diagnosis made of mental health issues that justify the prescribing of the psychotropic medication, then a behaviour support plan will not necessarily be part of when and how that medication is used, is that right?

PROF DOWSE: That's correct, yes.

MS EASTMAN: And so even if medication is prescribed to deal with a mental health condition, and that could be a chronic condition or it could be a short-term acute or episodic issue, that there may still be behaviours of concern notwithstanding the medical diagnosis, but there's an absence of behaviour support planning around it?

PROF DOWSE: That's correct.

5 MS EASTMAN: And would you accept, even in those circumstances, where it's going down the medical path, there still may need to be behaviour support around that person?

PROF DOWSE: Correct.

10 MS EASTMAN: And do you have an answer on how to disentangle this?

PROF DOWSE: I think it's impossible to disentangle, personally, partly because both things can be going on at the same time so they aren't disentangle-able. That's the idea of complex support needs, having a behaviour of concern, of having the experiences of discrimination, or violence against you will affect your mental health. But we also know that certain --- people with intellectual disability, for instance, diagnosis of intellectual disability are much more likely to also experience a mental health issue.

20 Whether those things are medical, whether they're socially caused, we can't disentangle any of those because they actually reside in the person at the same time.

MS EASTMAN: Then depending on where the person might actually be located --- so they may be in a family home, or they may be living in accommodation provided by service providers with relevant supports through NDIS or otherwise --- depending on where you might be, does that have a consequence on the disentangling in terms of what happens within a home as opposed to what might happen, say, in the accommodation provided by a service provider --- who has got a whole lot of rules and regulations about when and how restrictive practice might be used, and documentation is a feature of living in supported accommodation, but in a family home, is there documentation and behaviour support plans that work within a family home?

PROF DOWSE: I think it's important to disentangle a couple of different things there. One is that we certainly have a set of regulations for anybody who lives in a supported accommodation setting, but those are really about the nature of the setting, and the sorts of supports that are provided to them. That might be, in a sense, a behaviour support practitioner who comes into the home, who might work with the staff and others to develop a plan and work with the person themselves.

40 That same service can be provided to a person in their family home. I think it's important to disentangle the residential, as we now do more and more in disability. So as long as what we've ended up with is a system of regulation that is sort of driven by the practitioner, almost, that if a practitioner, a behaviour support practitioner is providing a behaviour support plan, that includes a restrictive practice, then it is the nature of that relationship that requires --- whether it happens in the family home or whether it happens in a service, is sort of irrelevant in a way.

I think but these are sort of quite complex jurisdictional-related issues as well, but from my understanding of the national approach at the moment, if a restrictive practice is overseen by a behaviour support practitioner, then it must be documented in a behaviour support plan, whether that plan --- and what we would hope for people is that behaviour support strategies that are set out in the behaviour support plan, would actually happen in every one of the environments that they find themselves in, their workplace, their communities, their social connections and their residential settings.

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CHAIR: The way in which we currently approach the disentanglement issue is just to leave it to the doctor, isn't it? It's the doctor who determines whether the medication is being given for a diagnosed mental illness or is being given for the purposes of behavioural management in some way?

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PROF DOWSE: Yes, that is correct. I mean we don't - I mean, psychotropic medication can only be prescribed by a practitioner, so, in fact, that is true, but ---

CHAIR: What strikes me, and I know Ms Eastman is getting angrier and angrier with me, but what strikes me is that the logic of what you were saying, which is a compelling logic, is that it's not really the function of a doctor at all to prescribe psychotropic medication for the purposes of behaviour management, except insofar as psychotropic medication might have adverse health effects, physical health effect. What you're saying is it's really a much more complicated interaction of social, environmental factors where doctors may not have any particular expertise at all.

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PROF DOWSE: They may have expertise. I mean there are many very, very good practitioners who work in this area. I feel that probably the bigger issue here is the information that they get on which to base their decisions, and I've heard others talk about it this week in giving their evidence to you, where who takes the person to the doctor and how is the material that's taken to the doctor presented. That's probably a more problematic area.

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So I feel as though people, doctors who are prescribing will do their very best to understand the context in which medications are being prescribed. They are the experts in diagnosing mental health issues, mental illnesses, that's what we want them to do.

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In the case where they cannot do that, and there are pressing issues that are being put forward by the supports around the person, then that puts them in a very difficult position if they don't have sufficient and significant information available.

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Often, what they will ask for is to see what sorts of behaviour support plans are in place, and that happens, you know, in a consultation, in a pretty short space of time. I heard somebody mention it may also be the people who are taking that person to the doctor also have a vested interest in actually having medications to control their behaviour in a group home. So it's very difficult to disentangle.

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That process of how prescribing doctors receive the information they need is one that really needs significant attention. I feel like that's where many things are sort of breaking down.

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MS EASTMAN: Can I just backtrack a little bit on the behaviour support practitioners, and you've said in your statement that as practitioners, they don't have a recognised professional designation in Australia. We heard evidence yesterday that there's a shortage of skilled behaviour support practitioners. So how do we deal with perhaps what might be a deficit in the number of skilled behaviour support practitioners in actually achieving these goals of positive behaviour support and what would you like to say about any view about a registration scheme for positive - sorry, for behaviour support practitioners?

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15 PROF DOWSE: What I would like to say first of all is to actually separate what we understand to be behaviour support practitioners as a specific professional group and direct support workers.

MS EASTMAN: Yes.

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PROF DOWSE: Because I think that's a very important distinction when we think about what support for people with behaviour support needs --- look, so a behaviour support practitioner is identified as a specialist. They've developed specialist skills and I'll talk about those in a second. What their role is, is to undertake an assessment, to look at the antecedents of behaviour and to write a behaviour support plan. They also will also generally be responsible for the approach to training and helping those around the person to understand the strategies that are prescribed in a behaviour support plan.

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30 But effectively, they are not the people there day to day doing the response to behaviours. It is usually either the family around the person, their coworkers or their direct support workers. And so I'd like to come back to the issue around how we support our direct support workers in the behaviour support context, and now come to your question about behaviour support practitioners.

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MS EASTMAN: All right, because I do want to ask you about what I might call the front line, and that is that support workers, in terms of their role in eliminating restrictive practices and understanding how the plans operate. I think we've heard some evidence over the last few days about plans being developed and then put on a shelf and we had an example of one plan yesterday which just described a whole lot of negative behaviours but no particular solutions in terms of looking at the environmental context.

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45 So just breaking it down, dealing with behaviour support practitioners, they need to have particular expertise to be able to ensure that they collect the right information, they guide in terms of the data to be collected, and they have a system in place to enable the implementation of that plan without having the personal responsibility for

implementation.

PROF DOWSE: For its day-to-day implementation, yes.

5 MS EASTMAN: And that group who are presently recognised in Australia as
behaviour support practitioners come from a background of allied health services, so
they may be psychologists, speech pathologists, people involved in occupational
therapy, those type of allied health disciplines. So has there been any discussion
10 about having a national registration scheme for behaviour support practitioners as a
specialised area of expertise?

PROF DOWSE: It's a very live issue, I think, and one of the ways I think that it's
been negotiated over time has been many of those professions that you identified,
15 social workers, psychologists, speech pathologists and occupational therapists who
become identified as behaviour support specialists, they already have professional
recognition, so there is a kind of an issue there but they have professional recognition
across a range of different professional bodies. So there's no sort of relationship
across those different professions.

20 People who become behaviour support practitioners become behaviour support
practitioners generally through experience. So they - and also there are a very
significant number of behaviour support practitioners who don't have any of those
professional qualifications necessarily, and who have perhaps started as a direct
support worker, and who have been mentored, trained, and learned over time.

25 So it's often a skill that one learns on the job, if you like, and I feel one of the issues
that's emerged with the registration process as part of the NDIS, was the need to
grapple with that. I think initially, one of the problems was that those professional
groups were identified, and there are a whole range of behaviour support
30 practitioners who had been working as behaviour support practitioners for quite some
time, who were looking at not being able to be actually registered for what they do.

MS EASTMAN: The NDIS Quality and Safeguards Commission has developed a
quality framework for behaviour support practitioners. Have you had any
35 involvement in -

PROF DOWSE: I've had some involvement in the development of that, although I
have to say I'm not intimately involved, and so I understand that that capability
framework was a way of trying to really set out what behaviour support practitioners
40 need to do in the absence of the fact that we don't have a registration body.

We don't have a training body, there isn't a place that you can necessarily go and
become a behaviour support practitioner.

45 One of the things that's really important to point out in that context is that where
behaviour support practitioners really did learn on the job was often in services. And
Government services, particularly, in the past, say, 20 to 25 years, have really taken a

front line leading responsibility for that. A behaviour support practitioner would have mentoring from a more senior person, supervision from others, where they actually can reflect on their practice and learn and within a service context, that's been really quite an effective way of building up the group of people who we call
5 behaviour support practitioners.

As we've seen the move to the NDIS and a personalised budgeting approach, which really effectively identifies budgets with a person, the scope within any business
10 model in any one organisation to provide for that kind of professional development for a practitioner, is, I feel, significantly reduced. So by definition, our service, our model of resource allocation for services now, where we have a budget tied to an individual and not to a service, which I don't debate is absolutely, in many ways, the right way to go.

15 We've seen almost no sort of market stewardship, if you like, about how we pick up some of these really important processes that --- particularly in NSW, certainly in my experience, the Ageing Disability and Home Care Department, and particularly its clinical innovation and governance area, was really focused on this process. In fact,
20 that was the unit that initially funded the Chair that I hold at UNSW, all of that is now no longer funded. It was specifically to identify that as an issue, to develop training.

The problem there, of course, is, in the training context is who does that training? Is it a tertiary skill? There are sort of selected and small courses. People sometimes do
25 courses offshore, in the US, around applied behaviour analysis which is a slightly different approach. But there is no one kind of recognised skill-set, and that's what the capability framework that the NDIS Quality and Safeguarding Commission --- its purpose is to really not say "You've got to have this thing to tick" box, it's not a capacity sheet or, you know, it's actually, what does a behaviour support practitioner
30 need to do?

That could well be effective. The question is, how do we actually ensure that we're creating a pool of people, not so much at the moment, although we've seen lots of
35 good behaviour support practitioners leave the sector because of the uncertainty around funding, but how do we keep a pipeline of behaviour support practitioners, I think, is a very, very significant issue.

MS EASTMAN: And for direct disability support workers, Professor McVilly, who I will speak to shortly, you're aware that he's done quite a lot of research in this area
40 and so I might defer asking him about some of those questions.

PROF DOWSE: Of course.

MS EASTMAN: Can I turn to a few final things, and that is your observation about
45 moving from a State regulated approach to a national approach, and accepting that the NDIS only applies to NDIS participants and not everyone with disability. In this area of regulating around the use of chemical restraint in particular, you've identified

that the regulations are piecemeal and that there isn't a national approach, although, I think you've just commented a moment ago on the proposed national framework to try to reach some agreement on definitions, but that national framework is more about working out what you can do rather than eliminating practices.

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PROF DOWSE: That's correct, yes.

MS EASTMAN: Can you assist the Royal Commission with in terms of what would be a good national regulatory approach, informed by a human rights approach, taking into account the obligations in the Convention? What would that look like?

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PROF DOWSE: Gosh, that's the \$64 million question.

MS EASTMAN: That's a big question.

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PROF DOWSE: Yes. I feel like one of the issues that has to be taken into account is that what we have is a system that is in transition. We've had State-based systems in different jurisdictions that may have worked fairly well, but in the move to the NDIS, some of the things that have been in place in the States have fallen away. So we're sort of, I think, in a bit of a no man's land at the moment, in fact, the States are mostly retaining responsibility for the regulation of restrictive practices.

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MS EASTMAN: Is it too early to jump on a national system of regulation to say nationally consistent laws there's the answer, or do we need to start to be looking at some national consistency?

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PROF DOWSE: I mean it's the chicken and the egg question, isn't it? In a sense, we see in every State of Australia there are discussions going on around regulation of restrictive practices. Some States are in a holding position, some States haven't had them and so are thinking about how to do it, and I feel importantly some national direction, and perhaps a national timeline to move to a standardised system, but the issue there, I guess, is it would require significant law reform across multiple jurisdictions, and that's, as any of the lawyers in the room will know, quite a long-term process.

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MS EASTMAN: One of the chicken and egg issues is even something as simple as what is a chemical restraint, depending on what State of Australia or Territory you might live in, has a consequence for then the data collection which is necessary to then work out what should be a national approach informed by evidence and data. And you've dealt with the difficulties of collecting data and information in your statement.

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PROF DOWSE: Correct.

MS EASTMAN: What would be your suggestion in terms of a better approach to data collection, and I assume by that, research in the areas of ---

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PROF DOWSE: Well, data is not just for the purposes of research, it's actually for the purposes of transparency and accountability, I feel, and so that's really something important. We've lost that in disability, the capacity to collect data because we now no longer have the national minimum data set which was collected in services via States, et cetera. We now have services provided by the NDIS and not a very well-developed system of data collection and data availability, although I recognise that there are lots of things going on in that process at the moment.

What I would say is that unless we collect data about something, and we collect the data in about the things that are important, not about the number of restrictions that are necessarily - so there are ways of collecting data at the moment about how many restrictions are approved, but that is the tip of the iceberg, as you've heard this week. What we don't know is how many people are being prescribed or taking or being given psychotropic medications outside the restrictive practices, you know, process. That is an absolutely enormous challenge.

And it is, in some ways, about the nature of the closed environments that many people live in.

I wanted to raise the issue, particularly of those closed environments, where we do have a system that's now emerging within the framework of the NDIS, but people with disability, particularly people with disability who experience behaviours of concern, are very often in the child protection system, they're very often in the criminal justice system, they're in the forensic disability system. They're in hospitals, they're in closed wards, they're in schools, they're in workplaces, and so we don't have any way of regulating or even understanding the use of psychotropic medications in those circumstances.

We need a national approach. I would suggest that one unifying national approach, which of course is the unifying national approach that's driving the Commission in the first place, is the *United Nations Convention on the Rights of Persons with Disabilities*. We are required to report our progress against the implementation of that. Within their there are opportunities to understand what deprivation of liberty looks like, rather than, in a sense, how we lawfully approve practices of restraint to think about what liberty looks like. There are examples, the UK, for instance, where they've gone down the track of deprivation of liberty. We could reframe, I think, the way we think about not just how we can give a tick box to the use of a restrictive practice, but I think taking a bigger, more human rights-driven process would allow us to both internationally report to be consistent internationally with that of the moves that are going on in terms of human rights for others and in other contexts, and to, in a sense, bring together what's an incredibly fractured system. And I know that, you know, it's very clear now that when there's a fractured system, those who are the sort of most precarious, I guess, and those often are the people we're talking about today, people who are identified as having behaviours of concern, they actually have the worst outcomes in fractured systems. So I feel like a national approach, which is informed by the human rights and the Convention is the best course of action.

MS EASTMAN: Professor Dowse, I feel like we've just got the tip of the tip of the iceberg with your evidence today, and you've provided a very comprehensive statement, and Commissioners we haven't dealt with some of the guidelines
5 produced, but they are part of the evidence before the Royal Commission and we'll carefully consider those matters. But thank you very much for your evidence today.

PROF DOWSE: Thank you for the opportunity, today, Commissioners.

10 COMMISSIONER McEWIN: Thank you, Chair.

Professor Dowse, thank you. In terms of your work and observation in behaviour support plan, and you mentioned if the environment is a significant factor, would it therefore not follow then, and in the context of choice and control and people with
15 disability choosing who they live with, that change in environment would be an important part, and have you observed that to be beneficial?

PROF DOWSE: Absolutely, Commissioner. I think we've seen evidence already of that. One of the promising practices within the sort of universe of behaviour support
20 practice is the notion of not just an individualised behaviour support plan but more a systems approach to behaviour support. So I've seen in very, very good examples where, for instance, in a group home where there are several people who have identified as having behaviours of concern, where staff are very stressed because they're trying to manage multiple plans and multiple strategies for multiple different
25 people. That one approach is to look at the whole house and not to just look at the people who are resident in the house, but to look at the staff. So there are systems approaches, whole-school approaches to behaviour.

Support is also identified as a significant I think that's a really useful part of practice.
30 One of the things we see, of course, is the system-driven problems where people don't choose who they live with. Where people are moved into group homes with people who have behaviours of concern, sort of on the assumption that they're somehow compatible because they have the same kind of problems, if that makes sense. Those things are nonsensical, of course.

35 COMMISSIONER McEWIN: Wouldn't it follow that a core part of an individual behaviour support plan would look at alternatives to the environment or to the home where they're living in?

40 PROF DOWSE: Absolutely. Absolutely. If that's the choice of the person, yes.

COMMISSIONER McEWIN: Thank you.

CHAIR: Commissioner Atkinson?

45 COMMISSIONER ATKINSON: No, thank you.

CHAIR: Professor Dowse, thank you so much for your evidence today and also for all the assistance you have provide and will provide to the Royal Commission. We've greatly appreciated your contributions which have been enormous, thank you.

5 PROF DOWSE: My pleasure, thank you for the opportunity.

THE WITNESS WITHDREW

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MS EASTMAN: Commissioners, Professor Keith McVilly from Melbourne University is our next witness, and I will start his evidence and we'll see how we go. I may need Commissioners and those following to bear with me, but I will see how we go reaching to 1.00 or shortly thereafter, if that's convenient.

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CHAIR: Professor McVilly, I think we can see you on the screen. I'm very sorry to have kept you waiting. It's undoubtedly the fault of the Commissioners for asking so many questions, particularly the Chair. So I'm sorry for the delay, but if you wouldn't mind following the instructions of my associate who will administer the oath to you. Thank you.

20

PROFESSOR KEITH MCVILLY, SWORN

25

CHAIR: Thank you, Professor McVilly. Ms Eastman will ask you some questions.

EXAMINATION-IN-CHIEF BY MS EASTMAN

30

MS EASTMAN: You are Keith Raymond McVilly?

PROF MCVILLY: That is correct, yes.

35

MS EASTMAN: And your professional address is the University of Melbourne in Melbourne?

PROF MCVILLY: Yes, that's correct.

40

MS EASTMAN: And you're a university professor and clinical psychologist?

PROF MCVILLY: Yes, I'm Professor of Disability and Inclusion at the University of Melbourne, and registered with AHPRA for the practice of clinical psychology.

45

MS EASTMAN: You prepared a statement for the Royal Commission dated 4 September this year, and you've got a copy with you?

PROF McVILLY: Yes, I do.

MS EASTMAN: Is the statement true?

5

PROF McVILLY: It is true and accurate.

MS EASTMAN: Thank you.

10 Commissioners, you will find a copy of Professor McVilly's statement behind Tab 52 and a copy of Professor McVilly's extensive CV behind Tab 53, and then there are two articles that Professor McVilly has provided to the Royal Commission behind Tabs 54 and 55.

15 If the statement can be marked Exhibit 6-15 and the Exhibits 6-15.1 through to 6-15.3.

CHAIR: Yes, thank you.

20

EXHIBIT# -6-15 STATEMENT OF PROFESSOR KEITH RAYMOND McVILLY

25 **EXHIBITS# -6-15.1 THROUGH TO -6-15.3 - ANNEXURES TO STATEMENT OF KEITH RAYMOND McVILLY**

30 MS EASTMAN: So, Professor McVilly, you've just said that you both have a research role at the university as a professor but you also have prior experience as a clinical practitioner and you still hold your registration as a clinical psychologist, is that right?

35 PROF McVILLY: That is correct, and my work vacillates between academic work and clinical practice working with disability service providers and people with disabilities themselves.

40 MS EASTMAN: And I wanted to ask you about your research work. At paragraph 5 of your statement, you tell the Royal Commission that you are a member of the Steering Committee for the University of Melbourne's Disability Institute, and this is a multi-disciplinary research institute. What role do you play as part of the MDI?

45 PROF McVILLY: As part of the MDI, I sit on the Steering Committee and I contribute to the development of strategic directions and deliberations concerning distribution of resources around disability-related research.

MS EASTMAN: And you're also an Associate Director for the Academy for

Education, Teaching and Research of the International Association for the Scientific Study of Intellectual and Developmental Disabilities. I think the abbreviation, albeit a long one, is IASSIDD. What is your role in relation to that organisation?

5 PROF McVILLY: Right. With regard to IASSIDD, it's been around since about
1964. It's the only organisation of its type internationally that is solely dedicated to
research and development in the area of intellectual and developmental disability. I
have served as the regional vice-president for the Asia Pacific and more recently as
10 the treasurer for the last seven years and currently as an associate director for the
Academy.

The Academy is responsible for conducting education and training around the world.
We work by bringing together the members of IASSIDD and their various
specialities and match them up with service needs around the world, quite often in
15 low and middle-income countries.

MS EASTMAN: In 2002 you published the book Positive Behaviour Support for
People with Intellectual Disability: evidence-based practice promoting quality of life.

20 That book has been revised in 2007 and again in 2012, and this book has become,
may I say, a very important tool from the research that we have done in the
preparation for this hearing for the Royal Commission, and your book outlines
strategies for assessment of causes of challenging behaviour, and the development of
evidence-based support strategies for people with intellectual disability for the
25 purpose of increasing quality of life, decreasing challenging behaviour, and
decreasing the risk of restrictive interventions such as chemical restraints.

So what can you tell the Royal Commission about how you came to write this book
and I understand this is bringing together both your academic work and also your
30 clinical practice?

PROF McVILLY: Yes. The book was originally commissioned by the Australasian
Society for the Study of Intellectual and Developmental Disability and I was asked to
bring together the best practice evidence that we had at the time to make it available
35 to practitioners and, in particular, to the front line workforce.

We recognised at the time that there was a great amount of evidence-based practice
that was available to people if they had access to scholarly journals, but very little of
that information was making its way through to frontline practitioners. So the book
40 was commissioned in order to translate the evidence into practice and to make it
available to frontline practitioners.

MS EASTMAN: A particular focus of your research work has been to conduct the
work in what you call an applied setting, and working with people with disability and
service providers to both develop and test innovations, and I wanted to ask you about
45 the concept of applied settings and also your work in what is described as active
support. What do they mean and how can you assist the Commission to have an

understanding about what that means for the nature of the research that you do and the findings following research conducted in that manner?

5 PROF McVILLY: There are many streams of research on which we can build our policy and our practices going forward, many streams of research to contribute to evidence-based practice.

10 One of those streams is certainly the area of database analysis and working with big data, and that can provide us with some very important insights. But a lot of my work has involved service innovations where we try out new ideas and we test what would be called, in the world of science, as the ecological validity. There are many bright ideas out there. There are many theoretically sound ideas but the important thing that we need to test is, can those ideas be put into practice? Can they actually make a difference in the lives of people themselves?

15 So a lot of my work is really focused on fostering these innovations and testing their validity, in particular their ecological validity, in applied settings. And my basic question is, can staff in disability services use the science, the good science that we have available to them, to translate that into good practice and quality of life for people with disability?

20 MS EASTMAN: And one of the areas that your research has focused on, and also your clinical observation, is the use of psychotropic medication for behaviours of concern, and you tell the Royal Commission in your statement that based on your clinical observation and research, you express some concern about overuse of chemical restraint and psychotropic medication as a way of managing behaviours of concern, is that right?

30 PROF McVILLY: That is correct. And here, this is a point where I draw a very distinct line between the treatment of psychiatric illness and medications that are used to suppress behaviours.

35 There are many people with intellectual disability that do have a psychiatric illness that is appropriately treated with medication. But we also see many people with intellectual disability who present with challenging behaviours, or sometimes referred to as behaviours of concern, for which medication is administered, not for the treatment of an identified and diagnosed medical illness, but rather simply to suppress the behaviour that may be of harm to themselves or harm to others.

40 MS EASTMAN: And what has your research revealed about the misuse of chemical restraint? And this is paragraph 18 of your statement. You identify a number of factors.

45 PROF McVILLY: What has become apparent is that there are many people who are being prescribed these medications for whom other educational, behavioural and environmental interventions might be more appropriate. And, indeed, what we've also observed is the fact that the overuse and the misuse of these medications

ironically prevents people from taking advantage of behavioural, educational and, indeed, environmental interventions.

5 MS EASTMAN: One of the factors also you identify is the under-resourcing of the disability sector, where poorly trained disability support workers are either left on their own or with very few people that they can, in turn, seek support or guidance or assistance on dealing with situations as they might arise for people with - sorry, people with intellectual disability who exhibit behaviours of concern. This is something that you've seen in your research, is that right?

10 PROF McVILLY: Look, over the last 30 years of clinical research and practice, time and time again I have seen very good meaning staff with very strong values and very appropriate values to inform their practice either left on their own or with very few supports available to them and they're asked to make very critical, clinical decisions in support of people with incredibly complex support needs.

15 The people we're talking about here are people with intellectual disability, but these individuals also usually have multiple healthcare needs. They have complex communication needs in that they find it very difficult to get their thoughts and feeling across in any other way than using behaviour.

20 And in addition to these clinical needs and these communication needs, their social needs and their social histories of trauma are so complex and yet we deploy staff, albeit with good values, without the necessary knowledge and skills to provide the skilful and complex support that's necessary.

25 MS EASTMAN: And part of your research is to identify where things go wrong and where there is a deficit in skills but also your research is focused on when things work and what particular innovations have been successful or might reveal promising practice. Is that right?

30 PROF McVILLY: Yes. And I think that's a very important part of understanding what good science can bring to bear in this situation.

35 A lot of scientific research focuses on identifying problems and trying to scope the extent of a problem, the size of a problem, the frequency of a problem. What I'm particularly interested in falls within a school of what I would describe as appreciative inquiry.

40 MS EASTMAN: What does that mean?

45 PROF McVILLY: So appreciative inquiry is all about finding circumstances and situations where things work, deconstructing those situations to understand why they work, what were the resources that were required to make something possible, and then to work out how you upscale that and apply it in other places in other settings.

MS EASTMAN: Sorry, go ahead.

PROF McVILLY: I suppose in my work I'm very much focused on finding out what the solutions are, and how we might generalise these solutions.

5 MS EASTMAN: And you were involved in a study commissioned by the Victorian
Senior Practitioner, and that was a study conducted over a 12-month period between
July 2007 and June 2008 and you wanted to undertake a process of investigating
baseline measures for the use of restrictive interventions in Victoria, and you wanted
10 to identify the characteristics of people who were subjected to restrictive
interventions and then begin to identify systemic changes to monitor and evaluate
changing patterns of restrictive intervention use.

So what was the outcome of this study, and what were the key findings that have
then informed the next part of your research that I want to ask you about in a
15 moment?

PROF McVILLY: So this study was based on a database maintained by the
Victorian Senior Practitioner, referred to as the Restrictive Interventions Data
System. This system was set up under the Victorian 2006 Disability Act. It required
20 service providers who were using regulated restrictive practices such as physical
restraint, mechanical restraint, seclusion, and for the purposes of today's inquiry,
chemical restraint, to report these practices to the Office of Senior Practitioner on a
regular basis.

25 We conducted this initial study looking at the very early reporting to this data system
and one of the - we had around about 2,100 people's circumstances recorded on this
data system. So it was a reasonably substantial sized sample. And what we found
was that 96% of those people on this database were subject to chemical restraint.

30 MS EASTMAN: That's a very large number. Did that cause any concern when you
made these findings?

PROF McVILLY: It was a finding that was not necessarily a surprise to those who
had instigated the research, but it certainly confirmed our worst fears that medication
35 was a primary means by which people's challenges behaviours or behaviours of
concern, were being managed in the service system, and this flies in the face of the
fact that we know that there are educational, behavioural, and environmental
strategies that could otherwise be deployed, yet people were reverting to the use of
medication as the primary means of responding to challenging behaviour.

40 MS EASTMAN: Has there been any ---

CHAIR: Sorry to interrupt.

45 From a methodological point of view, how did you distinguish between the use of
psychotropics as a restraint and the use of psychotropic drugs as a treatment for
mental illness among the cohort you were examining?

PROF McVILLY: That's a very good question and certainly one of the limitations of our study, one of our observations were that it was very difficult to make those distinctions. However, allowing for the fact that this was a sample of people who were exhibiting high-risk challenging behaviours, we know from studies conducted in the United Kingdom and the United States that maybe we can expect 20 or maybe 30% of people with intellectual disability to present with a mental illness that could be treated appropriately, maybe using medications. Yet, here we had a sample of people, 90% plus, who were subject to these medications.

MS EASTMAN: The study showed that the main reasons for chemical restraint was to prevent harm to a person or harm to others. Was there any aspect of that particular finding that gave you a sense of what the behaviours of concern were or what the nature of the harm was? Was there any pattern in terms of that finding?

PROF McVILLY: There was a very high incidence of selfharm, behaviours that related to self-harm and the like, but also behaviours that related to lashing out against staff, support staff, who were working with those individuals.

I think one of the important findings here was the high use of medication in situational crises, and this is something that has continued to be evident in the system. So these are not medications that are simply prescribed for a person on a regular basis once or twice a day, but these are medications that are administered by direct support staff to manage situational crises, referred to commonly as "PRN medication", medication provided as required.

I suppose one of the disturbing factors here is that the decisions to administer these PRN medications were being made by staff who largely, if not almost exclusively, would have had no medical training whatsoever. They're not nursing staff.

MS EASTMAN: I was going to say, did that lead into some further research that you did in looking at the effectiveness of staff training in the implementation of policy initiatives for PBS-designed processes to decrease the use of restrictive interventions using psychotropic medication? And so you looked at some later work done to try to train staff. What was the outcome of that research? Did you see that training having an effect on decreasing the rate or use of psychotropic medication that you'd seen in the earlier 2007/2008 study?

PROF McVILLY: What was increasingly evident was the poor quality or, indeed, the complete absence of a training and development for the professional staff, the frontline staff, that were involved in delivering services. I might say here that services have done a great job in emphasising the importance of values-based recruitment for staff. But I would suggest that values are necessary but insufficient component of what makes for effective staff. We need staff with knowledge and skills.

And it was in recognising that need for higher level knowledge and skills so that staff

could work with people with complex communication needs, complex healthcare needs, complex behavioural needs, that we instigated a pilot training program. We brought together staff from across the State of Victoria. Importantly, we brought them together in pairs from the various agencies and services that had employed
5 them because all too often we felt that staff were sent to short-term, very simplistic training programs but when they went back to their organisation they weren't in a position where they could actually use what they had learnt.

10 So we brought these direct care staff together with the authorised program officers, the senior people in the organisation, as pairs to the training program. We sensitised them to issues related to human rights. We gave them training in how to administer some basic assessments in questionnaires. And we sent them away to actually
15 administer these assessments and questionnaires with their clients. So our training wasn't just theoretical and classroom based but it incorporated homework so that they actually had to do some of this work in situ. They brought back the assessment results and we worked with them to interpret the assessments.

In particular, we taught them about the importance of what is referred to as
20 functional behaviour assessment. Functional behaviour assessment, we know from the research literature, is absolutely critical to making a difference in terms of planning - excuse me, I will grab a glass of water.

CHAIR: Ms Eastman, I see the time. Do you wish to continue until Professor
25 McVilly's evidence is concluded?

MS EASTMAN: Yes, I just invite Professor McVilly to tell you about the results of this research and then I want to ask him about a particular program that he's been rolling out in Victoria in 2020. Those are the remaining issues.

30 CHAIR: Can I inquire whether that's okay with interpreters and any other staff? Thank you. Go ahead.

PROF McVILLY: So we've taught the staff about how to conduct and interpret a
35 functional behaviour assessment, an assessment whereby we look at what is the message that the person is trying to communicate by use of their behaviour and on the basis of understanding what the person is trying to communicate. We are then better positioned to provide interventions that change the environment to better suit their needs and to teach them the skills that they need to either do things more
40 independently, to communicate their needs more effectively, or to tolerate circumstances where their needs can't be met immediately.

And what we found with this training was that when staff went back and we reassessed what was going on for their clients, we saw a decrease in instances of challenging behaviour and we saw a decrease in the use of restrictive practices,
45 suggesting that this focused training, which incorporated theory and practice exercises, was effective in bringing about a change in the circumstances for staff and for clients.

Now, with this piece of research, we were also able to include a control group. This is a rare circumstance in much of our applied disability research group. But we had a control group of people whose circumstances were being registered on the Restrictive Interventions Data System, and whose staff had not had the opportunity to undergo training.

Now, amongst the several findings that were of interest here, the one most relevant to the Commission's hearing at the moment is that what we observed in the data was where clients had had staff, support staff, attend the training, they were less likely to be subject to chemical restraint and, indeed, we observed decrease in the use of chemical restraint for those clients. And for those in the control group whose staff had not undergone the training in that exact same 12-month period, disturbingly, we didn't just see their medication use stay the same, we were actually seeing a trend for an increase in the use of chemical restraint.

MS EASTMAN: Have the findings from that research had any impact on any ongoing training or the development of any new training programs?

CHAIR: Yes. So since that training was conducted and evaluated. The University of Melbourne, in partnership with SCOPE Australia, have been commissioned to develop and implement a training, a comprehensive training program in the use of positive behaviour support. We are just in the process of rolling that out to between 400 and 500 practitioners across the State of Victoria, and following the evaluation of this program we hope to make that same program available to direct support staff across the country.

MS EASTMAN: So it's too early at this stage to form a view about whether the new training that's been rolled out will be effective. What are you proposing to do in terms of following through the training program and any evaluation?

PROF McVILLY: So we were due to commence the rollout of this program in the early part of this year and it was going to be a face-to-face training program across multiple sites throughout Victoria, and, of course, with the onset of COVID-19 and the public health restrictions we've had to pivot our delivery and we've changed it to an online delivery.

We beta tested the online delivery in July and have just commenced enrolling frontline staff into the training program in the last month.

What we plan to do over the next six months is roll out to between 400 and 500 people. Throughout the training program, people will be undertaking knowledge-based quizzes prior to and during the training program, and then following up to that training program we will also have a number of activities that the participants in the training program will need to do by way of homework, which will be evaluated. And this will include evaluating the quality of behaviour support plans that those staff are writing after they've completed the course.

MS EASTMAN: Professor McVilly, I think the Royal Commission will look forward to seeing the results of the rollout of this training, and I would not be surprised if we come back to talk to you about this again at some point in the future.

5

May I thank you for bearing with us with the little overrun that we've had on time today, and thank you very much for your evidence.

CHAIR: Thank you, Professor McVilly, for your very clear and cogent evidence. If I may say so, we appreciate your contribution to the work of the Commission. Thank you.

10

PROF McVILLY: Thank you very much, Commissioner.

15

THE WITNESS WITHDREW

CHAIR: We shall now adjourn. It's 1.10. Let us adjourn until 2.10, please. I think people need one hour after a fairly heavy morning, we need to have the extra 10 minutes that you were prepared not to give us.

20

MS EASTMAN: Thank you.

25

ADJOURNED

[1.08 PM]

RESUMED

[2.10 PM]

30

CHAIR: Yes, Dr Bennett.

DR BENNETT: The next witness is Jennifer Torr and she will give her evidence from Melbourne.

35

CHAIR: Dr Torr, thank you for coming to the Commission to give evidence. If you would be good enough to follow the instruction of my association who will administer the affirmation to you.

40

DR JENNIFER TORR, AFFIRMED

CHAIR: Thank you, Dr Torr. Dr Bennett will now ask you some questions.

45

EXAMINATION-IN-CHIEF BY DR BENNETT

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

DR TORR: Jennifer Jane Torr.

DR BENNETT: And you're a consultant psychiatrist?

10 DR TORR: Yes, I am.

DR BENNETT: And you've provided a statement for the Royal Commission dated 10 September 2020?

15 DR TORR: Yes.

DR BENNETT: Have you read a copy of that statement recently?

DR TORR: I have.

20

DR BENNETT: Are the contents true and correct to the best of your knowledge?

DR TORR: They are.

25 DR BENNETT: Thank you.

Commissioners, that statement can be found at Tab 56 of Tender Bundle A and there are three annexures to that at Tabs 57, 58 and 59. I will ask you to mark this statement as Exhibit 6-16, and the annexures as 6-16.1, 2 and 3.

30

CHAIR: Yes, thank you very much.

EXHIBIT# 6-16 - STATEMENT OF DR JENNIFER JAYNE TORR

35

EXHIBITS# 6-16.1 THROUGH TO 6-16.3 - ANNEXURES TO STATEMENT OF JENNIFER JAYNE TORR

40

DR BENNETT: Now, Dr Torr, do you have a copy of your statement with you?

DR TORR: I do.

45 DR BENNETT: Now, to start with, on the first page of your statement, you give your professional background as a consultant psychiatrist. Can you please tell the Royal Commission something of your background in terms of your clinical

experience and leading up to your current position today?

DR TORR: In particular with regard to people with intellectual disabilities?

5 DR BENNETT: Yes, please.

DR TORR: I have an MBBS and a Master of Medicine in Psychiatry, and I'm a Fellow of the Royal Australian and New Zealand College of Psychiatrists and an accredited member of the Faculties of Psychiatry of Old Age, Adult Psychiatry, and
10 Consultation-Liaison Psychiatry, and as Dr Franklin noted earlier in the week, there is no accredited specialist training program in the psychiatry of intellectual and related disabilities in Australia.

So with regards to my background in that area, I was Director of Mental Health at the
15 Centre for Developmental Disability Health Victoria which was an academic unit at Monash University, and I was there from 1999 to 2013 and I remain an honorary lecturer at Monash and continue to teach, to research and to publish, but much less so than in the past.

20 I have a boutique - what I call a boutique private practice which I established in 2013 and pretty much all of my patients, not all, but pretty much all of my patients have an intellectual or a related developmental disability.

More recently, I commenced work at MHIDI-A, and I will talk about MHIDI and
25 what MHIDI means a bit later. I commenced work there as clinical lead in November 2018, but prior to that I worked for 18 years in mainstream aged care and mental health services.

I have also worked for a long time in a mainstream memory clinic, and I'm also a
30 psychiatrist member on various tribunals including Victorian Mental Health Tribunal, the NSW Mental Health Review Tribunal and the Forensic Level Panel.

So basically my expertise is self-developed and has been acquired over 20 years of
35 clinical practice, scholarship and research, developing and delivering educational programs, advocacy and some medicolegal work, and I've acquired my clinical experience by working in specialist clinics in the UK, university-based clinics, interstate contracted clinics, commissioned assessments, my private practice model is a MHIDI and I've had what I call the privilege of being able to take my time with assessments, and that's a privilege in today's world to learn from my patients, their
40 families and carers, to take time to consult the literature to reflect, to hypothesise and to be able to provide that continuity of care and that's, I think that's essential in being able to develop that expertise that I have, which takes - has taken many years to develop, and what I consider a lifetime to maintain and improve. I don't consider that I have ever arrived. I am learning all the time.

45 And I've also learnt from doing the research, which is clinically-based, and it's been focused on the clinical presentations of mental illnesses but also about service

systems and pathways to care.

DR BENNETT: Thank you, Doctor. From paragraph 14 of your statement you do talk about the work you're currently doing and have been doing at MHIDI. Can you explain to the Commissioners what MHIDI is and how that came into being?

DR TORR: Just before I do that, I want to preface that I'm not here to represent MHIDI, I'm here in my own right, but MHIDI stands for Mental Health in Intellectual Disability Initiative. There are actual two in Victoria. I work at MHIDI-A, so that's the initiative for adults. There's another MHIDI which is MHIDI Youth, which is in another service. They are important initiatives of the Victorian Government and I guess at the moment they're more - they're demonstration projects as well so they're not available in all areas. So the one I work at covers the Monash Health catchment, which is about 850,000 people, and covers a large geographic area in southeastern metropolitan Melbourne.

DR BENNETT: Thank you. From paragraph 17, Dr Torr, you say that MHIDI is a multi-disciplinary service and you say it specialises in the assessment, clinical treatment and other support. Can you explain the nature of that service and how it works in relation to the team component?

DR TORR: We do work as a multi-disciplinary team. We call ourselves psychiatrists-led, and that's because we have very much a focus on assessing and diagnosing mental illnesses, and you need a psychiatrist to do that. But having said that, our assessments are multi-disciplinary and so are our targeted interventions, and we provide an interface between mainstream mental health services, community based like general practitioners, private psychiatrists, and the NDIS services.

DR BENNETT: You've said in terms of the people that come to your service, at paragraph 18 you've said that MHIDI's patients are people aged 16 years plus who have intellectual disability and a co-existing diagnosed or suspected mental illness. In terms of your issue of diagnosis, Doctor, later in your statement, I think you come to it at about paragraph 51, you refer to the classification systems of DSM-5 and also a system referred to as DC-LD. Can you explain to the Commissioners what those systems are and how you might use them in your role diagnostically?

DR TORR: Okay. So there's another system which is ICD, well, there's now ICD-11 which is the International Classification of Disorders and that classification is used to code for Governments. But Australian psychiatrists tend to have been trained to use DSM, which is why I've focused on DSM rather than ICD. So DSM is diagnostic and statistical manual for the diagnosis of mental disorders. So it provides diagnostic criteria for mental disorders.

The problem with the standard diagnostic criteria such as DSM or ICD-10 is they are not valid for use for people with intellectual disabilities. They may be valid for people at the very mild end, the mild to borderline end, but even then there are difficulties in the application of the criteria.

When you're doing a psychiatric assessment, it's about having the conversation with the patient and then also doing a mental state examination which is about trying to ascertain the contents of someone's mind. So you need to be able to talk with
5 someone about what their internal experiences are. So, for example, if you want to differentiate an obsession from a delusional thought or to ascertain if people have perceptual disturbances, you need to be able to talk with them about that.

10 So the cognitive and communication difficulties that people with intellectual disabilities have make that a difficult task or an impossible task if someone doesn't actually have language.

15 A lot of criteria are language-based, and they're also what I would - we talk about sort of like the cultural biases in diagnostic sets, but there is a bias towards people who have normal intellectual capacities, but also agency, you know, the money and the freedom and the ability to go and do various things that people with disabilities may not have. So what this ultimately leads to is an under diagnoses of mental illnesses.

20 And we also diagnose not just - we don't necessarily get the manual out and go through a checklist. We have it in our heads and we know what things look like but when people with intellectual disabilities present with a mental illness, it doesn't necessarily present how we think it should present, and the diagnosis then --- so we talk about atypical presentations or there's the manifestations of various criteria are
25 different, for example, grandiosity. If I presented with grandiosity, I might think I was, you know, the best psychiatrist in the world, I might have a delusion that, you know, I'm the psychiatrist for an American President and things like that. You don't necessarily see that level of grandiosity in someone with a mental disability.

30 So it might be more like no longer cooperating with guidance or requests, being demanding, being bossy, that can be a manifestation of grandiosity and that's not what we would generally think of as being grandiose, but for that person it's grandiose, with regards to how they usually are.

35 So there's inherent difficulties with the standard criteria and this is one of the major issues, in my view, about - with regards to psychotropics, that there's a lot of psychotropics which are prescribed and in a way that would be classified as being restrictive, but when actually, they're actually treating an undiagnosed disorder that the person has and that, at least in my experience, that's what I see.

40 That doesn't mean that that's the sum total because I see people who are referred to me --- so I see a selected group of people, but that is one of the commonest issues that I encounter, is there are the present mental illnesses there that have not been diagnosed.

45 DR BENNETT: Right. So in terms of - and I'm going to come to your referral pathways in a little while, but in the terms of the trigger events for the referral from

paragraph 21 you say that our patients are usually referred because of challenging behaviours. So in this sense, has that been a behavioural issue that has been a trigger event and it's up to you to work through the diagnostic issues? Is that the role of your service?

5

DR TORR: It's a role of our service. So, yes, our service has, yes, our role is to diagnose, so sometimes re-diagnose or un-diagnose. But then also it's looking at - we also look at medications, so we get asked to do ostensibly medication reviews, but you cannot do a real medication review without actually doing a diagnostic assessment, so the medication reviews are secondary to the assessment.

10

But I'd just like to point out that mental illnesses, in everyone, present with behaviour, they present with changes in behaviour which are driven by the changes in someone's mental state, and for people with intellectual disabilities it's no different, it's just the types of behaviour that people may have.

15

And challenging behaviour, or behaviours of concern, which is a term that's been used more generally during these hearings, tells you that something is not right but it does not tell you at all what is not right, and it can be anything from, you know, there's disagreements within a house, someone is being mistreated, someone's not being understood, someone doesn't have the right supports, all the way through to someone has an undiagnosed physical condition like Dr Law spoke about her patient who had cataracts and were blind. I certainly see similar sorts of things. Medical illnesses and deliriums which are not diagnosed which are some of the case examples, and mental illnesses.

20

25

There's also a whole range of disorders that we don't generally think about, which are the genetic disorders which present with characteristic types of behaviours. So some behaviours have basically a neurobiological underpinning and that doesn't really come out in the conversations about the use, appropriate use, and misuse of psychotropic medications.

30

So just going back to your question about our role, and from a multi-disciplinary point of view is to pick it all apart to try to work out what is going on. Sometimes it's pretty quick, but usually it's not and it's, well, I call it basically it's a slog. It is hard work to gather all the information, to do the multi-disciplinary. So I necessarily focus on the mental illness, other members of the team focus more generally on communication, OT, we look at behaviour supports, we look at what's missing in their implementation of their NDIS plan or, indeed, the design and funding of the NDIS plan.

35

40

CHAIR: Dr Torr, your clinic deals with only people with intellectual disability, is that right?

45

DR TORR: That's right. We see people with intellectual disability and autism spectrum disorder. We also have a cutoff of an IQ of 70.

CHAIR: Yes, that's what I wanted to ask you about. Is the cut off of an IQ of 70 or below, is that an internationally recognised standard?

5 DR TORR: It was. The definition of intellectual disability has changed over time. There are issues with the psychometrics assessment of IQ. So to have a hard and fast cutoff at 70 is artificial, and all sorts of factors will affect your IQ scores.

10 CHAIR: That's rather what I thought and that's what's behind my question. I rather thought that IQ tests had been somewhat discredited as a means of classifying people's intellectual capacity, not least because of cultural considerations and biases and what have you. So how do you adjust your IQ of 70, bearing in mind you say that if we used 75, then you'd increase the number of people eligible by approximately fivefold? It suggests that an IQ between 70 and 75 produces rather dramatic changes in the population.

15 DR TORR: It does, and because we are a very small service, servicing a very large population, 850,000 people, and the very good studies of prevalence of what is called mental ill-health and that includes behaviour disorder, and by behaviour disorder that means having behaviours of concern sufficient that it reaches a notion of it being a disorder, which is - I don't think that's been discussed. It's not a specific diagnosis but it's a recognition that someone's behaviours of concern are of a degree, a severity, to warrant clinical attention.

25 CHAIR: So you take into account the nature of the behaviour as reported to you that has led to the referral?

30 DR TORR: Yes. So there's - so when there's a study - I think it was originally referenced in my statement - a study by Anna Cooper in greater Glasgow, which is one of the best epidemiological studies ever conducted, as much as possible a whole-of-population study with, you know, it was a high-grade study, assessment and diagnostic processes, and the point prevalence, so that means at any one point in time, not the prevalence over a year, which is how prevalence of mental illnesses are often reported, it's the prevalence over a year. This is a prevalence at any one point in time, was 40%.

35 Now, half of that was made up of behaviour disorder, and that could be someone with an autism spectrum disorder with behaviours of concern which were not diagnosed as being due to a mental illness, per se.

40 So if you have rates of 40%, approximately 2% of the population identified as having an intellectual disability, you're talking about 1% of the population. 1% of the population have schizophrenia, for example, and we have whole mental health services constructed around providing services to people with schizophrenia. So we're a tiny team, potentially servicing the same number of people who have schizophrenia. And this population is very, very complex so it takes a lot of time to get the assessments right, and it can be an iterative process. You don't know if your assessment is right until you've gone through the process of intervening, monitoring,

and seeing if you're on the right track and if things are not improving you have to go back and say, "Well, are we wrong? What are we missing here? Maybe the person doesn't actually have this condition. We have to reappraise."

5 So we often have formulation meetings where we look at all sorts of, you know, all the factors and try to make sense of what is going on.

CHAIR: Do you administer IQ tests to all of your patients?

10 DR TORR: No. We actually go through, you know, I'm quite open about that our cutoff is 70 is artificial, and it was a service necessity to make sure that we were not completely overwhelmed, because there was always that potential, and then we would not be able to do the work that was required to actually make a difference.

15 CHAIR: People can have significant behaviour disturbances, to use the phrase you use, without necessarily having mental health problem or being a person with intellectual disability, is that right?

DR TORR: Correct. Yes.

20

CHAIR: So how do you distinguish those from the people that you regard as people coming within your criteria?

DR TORR: Sorry, I don't think I've understood your question.

25

CHAIR: If someone comes to you, or is referred to you because of what is said to be a significant behaviour disturbance, might that behaviour not be associated either with intellectual disability or a mental health problem, and if that assumption is right, how do you distinguish it?

30

DR TORR: That's a good question. But just we don't administer the IQ test. We look for, you know, evidence that supports the person's pre-existing assessment that they have an intellectual disability and if they don't have an IQ test we look at other things. We're not completely rigid about the 70. It's a guidance.

35

But when someone comes along, because usually it's rare that someone who doesn't have some sort of challenging behaviour or serious change in their behaviour, which could be being withdrawn, for example, and not doing things - sorry, I lost my train of thought on that.

40

CHAIR: Don't worry. We'll get you back.

DR BENNETT: I'll get us back on track.

45 DR TORR: People present with changes in their behaviour, and that is the challenge because, as I said, the changing behaviour tells you that something has happened or something's not right, but it doesn't tell you what. And as a medical student once

said to me, he was very annoyed with the lecture about what you do to sort out the causes, the determinants of behaviours of concern and he said to me "Well, it could be due to anything. " And I said, "That's right, that's the point. " So until you do the assessments you don't know. And there is the difficulty. We have parallel

5 paradigms, we have the psychosocial paradigm of behaviour, we have broadly, I say it carefully, you know, I guess a health and mental health paradigm of behaviour, we have parallel systems that don't work to get, and we have parallel notions about the use of psychotropics.

10 Yes, there are occasions when psychotropics are specifically used to restrain, but generally not. They're used to treat. So if you take someone to a doctor because someone's got behaviours of concern, it should be no surprise that doctors do what doctors do. They assess and they treat. And assess doesn't necessarily mean you arrive at a diagnosis, it means that they assess the situation and then maybe, as others

15 before me have pointed out, significant risks, risks of harm to the person, either self-harm, which can be really quite extremely distressing, accidental harm, like smashing windows, lacerations to arms as a result, or accidental harm arising from running away, or harm to others and I think it needs to be appreciated that these harms can be serious. So the question why do these medications get prescribed is

20 because there is actual risk or, you know, people are actually being harmed or there's a high risk of harm. And doctors, they are duty-bound to address risk and safety.

In the first instance, that is generally why these medications get prescribed without a diagnosis. It's what happens after that, and we just do not have the service system to

25 address it. The privilege that I've had in the places where I've worked to develop the expertise. My colleagues have not had that privilege. I've worked in mainstream health and you do not have the time, you don't have the time to reflect, you don't have the time to read the entire file and pick out the information and then analyse it. You have to deal with what is in front of you. You are on the timer and all the KPIs,

30 the system KPIs is driven by throughout.

CHAIR: Dr Torr, I think we should give Dr Bennett an opportunity to ask one more question before we ---

35 DR BENNETT: Look, I will take you back to the system you're currently working in, Dr Torr, and the processes by which people with intellectual disabilities get to use your services. In relation to the referral pathways, and they're the ones you refer to in paragraph 24, and going over the page, there are two referral pathways. Before I ask you to take the Commissioners to those two referral pathways, do you have any

40 data on the percentage of people that are already on psychotropics at the time of referral?

DR TORR: We didn't look at it, but I would say 100% or close to. It's not something I had even considered to be a question. There may be some who weren't,

45 but I can't think of any off the top of my head.

DR BENNETT: Okay, thank you. If you can take the Commissioners through the

two referral pathways.

DR TORR: Okay. So we have in-service referrals and we have community-based referrals. So the intra-service referrals come from the mainstream mental health
5 teams within Monash Health, and the community ones come from - well, it can be initiated by anyone. So from family, some circumstances, not commonly, but by the person themselves but that's pretty rare, by support workers, NDIS coordinators and - but we do require then a back-up referral from general practitioner or a specialist that we get referrals from, psychiatrists very occasionally and neurologists.
10 And the work that we do for those two pathways is quite different.

So we work collaboratively with the mental health teams, but we don't actually - we're not primary in the care so we don't prescribe medications. For the
15 community referrals, it varies. We're evolving our model of care, so some GPs we work very closely with, others it's more sort of like refer in we do an occasion of care, which can include actual treatment, but the ultimate aim is to discharge the person back to their referring and treating doctor, that's basically how we work.

DR BENNETT: Thank you. Now you've told the Commissioners something about
20 the diagnostic process and you've also referred to your own role in terms of looking at the medication regime that the person with the intellectual disability might be on. From paragraph 27 you refer to chemical restraint and behaviour support. And at paragraph 28 there you've set out the definition of "chemical restraint" from the NDIS Rules there, and you've just, to use the words there:

25 *The use of medication or chemical 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 or physical illness or a physical condition.*
30

Now, then over the page, Dr Torr, at paragraph 29, you've said:

35 *In practice, there is not a clear distinction between the use of psychotropic medication for the purpose of influencing behaviour and medication of treatment.*

So can you just say something to the Commissioners about how it is you go about that process in clinical practice?

40

DR TORR: Of making the distinction?

DR BENNETT: Yes.

45 DR TORR: Yeah, I make a distinction between a therapeutic use of a medication which can be for a diagnosed condition or not for a diagnosed condition. So I might and do prescribe psychotropics to treat symptoms and to alleviate distress or anxiety.

And I might do so using medications off-label, for example, Clonidine to treat anxiety, that's considered off-label.

5 So, basically, I aim to treat. So what I don't see is the distinction between the therapeutic use and a use to influence behaviour.

10 I rarely, you know, I'm just trying to think, I don't prescribe to influence behaviour. I prescribe to treat because the behaviour is a manifestation of, you know, if I use a psychotropic, a disturbance in someone's mental state that needs to be addressed, whether it meets the definition of a condition or not. So that's how I view it.

15 What concerns, you know, and I think with all psychotropic it should probably be reported because the issues are so complex. I don't know in reality how you actually, have a systems point of view, tease it out, but I don't prescribe to restrict, I prescribe to treat and to do the opposite of restrict. So it's kind of I'm not prescribing to restrain.

20 Because of the way I work, I don't - I'm not generally at that pointy acute end, but I would also prescribe, I guess, in the first instance to contain a situation. So that's one - that's a bit different to what I generally use. I'm not prescribing to restrain. I'm well aware that a lot of what I might do is reportable. I don't have a problem with things being reported. My concern is that because it's reportable, it's automatically considered restrictive and somehow wrong. It's not necessarily wrong and I think people have a right to treatments as well and that we need to find a way to
25 distinguish between a therapeutic use and a use to influence or control.

30 I got an email the other day saying the parent of someone is looking for a psychiatrist because they want medication prescribed as a restrictive practice and, I thought I doubt the parents think of it like that. It was just assumed, without an assessment of anything.

35 So I don't know if that quite answers your question, but I'm not - yeah, and I think this is where the paradigms don't meet. We need to look at, is it an appropriate use? Is it proportionate use? What are the review mechanisms? Have we balanced the risks and benefits of the medications? Does this now provide an opportunity for behaviour supports, and if they work is it possible to pull the medications out? My concern is that the way it's all framed it doesn't really capture the complexity or the nuances or how multifaceted.

40 DR BENNETT: I think, Dr Torr, at paragraph 32, part of what you've just said, I think, is there. You've said, "In my opinion, chemical restraint", and I think you're referring to the definition from the Rules there:

45 *.... should include the excessive use of psychotropic medication beyond that which is needed to treat, diagnosed or suspected mental illnesses or disorders.*

Now, can you give an explanation of what it is you've encountered for you to come

to that conclusion?

5 DR TORR: Well I see people who have diagnosed mental illnesses, and the diagnosis may or may not be correct, but the amount of medications that they're on is excessive and dangerous, literally dangerous. I mean, life-threateningly dangerous in some instances.

10 Also, you can have a diagnosis by a psychiatrist, which is incorrect, and because there is a diagnosis, a diagnosed condition, then those - the use of psychotropics will not be reported and vice versa. Sorry.

15 DR BENNETT: Just in the rest of the paragraph there, one of the solutions you've suggested in terms of the need to consider and monitor that situation is that one of the ways that monitoring might be achieved is requiring that all psychotropic medication prescribed to NDIS participants be reported in the same way that perhaps chemical restraints without a diagnosis of mental illness might?

20 DR TORR: Yes, I do, because it's so complex I can't see how you could operationalise it, and my conclusion is that it should all be reported because in the first instance we would see, at least in the NDIS participants, the extent of prescribing and then - and I think to lobby or to insist upon the services which are required to do the assessments and the right interventions. So I do.

25 DR BENNETT: Right, Doctor.

CHAIR: I see the time.

DR BENNETT: Yes, I've got three minutes to go.

30 CHAIR: Okay.

DR TORR: I'm sorry, I didn't realise.

35 DR BENNETT: I'm going to give you one last question.

40 Now, you've just given a recommendation there in relation to people who might be NDIS participants, but obviously there are a lot of people with intellectual disabilities who aren't participants. Have you turned your mind to how they might be protected in the sense of being monitored and assisted and supported and protected from the sort of excessive prescription of psychotropics?

45 DR TORR: I haven't, and it's a good question. I think we would need - one thing is to look at decision-making, but I don't have a quick answer to that at all. I don't know.

DR BENNETT: Thank you.

That completes Dr Torr's evidence, Commissioners.

CHAIR: Very good.

5 COMMISSIONER McEWIN: Thank you, Chair, I have one question for Dr Torr.

10 You touched upon this in some detail. I'd like to understand a bit more. The assessment that you undertake, to what extent does it take into account the extent of environmental factors that may be at play, for example, where they might be with other people who are bullying them that could lead to mental health issues? Could you just touch upon that in a bit more detail, thank you?

15 DR TORR: In the multi-disciplinary team we look at all of those things as much as we possibly can, and we do make strong representations to address those issues. In private, I do it as best as I can.

COMMISSIONER McEWIN: For example, going to visit the home or where they may be living?

20 DR TORR: Yes, our team does visit homes, not at the moment. In private I don't generally visit homes because of the nature of that work, but I do work with families and carers to address those broader issues. I'm definitely not blind to them. I try to be as holistic as I can but I also have to be a doctor as well. I hope that answers your question.

25 COMMISSIONER McEWIN: Thank you.

CHAIR: Commissioner Atkinson, is there any questions?

30 COMMISSIONER ATKINSON: No, thank you. As well as your oral evidence we've got some very detailed written evidence and case studies, thank you, doctor.

DR TORR: Thank you.

35 CHAIR: Dr Torr, thank you very much both for your written statement, which as Commissioner Atkinson said, is very detailed, and I notice we got up to about page in the last ---

40 DR TORR: I'm sorry, I had no idea ---

CHAIR: Not at all, it was very interesting. Thank you very much, and thank you for your evidence today.

45 DR TORR: Thank you.

THE WITNESS WITHDREW

CHAIR: Ms Eastman, do we have a break or are we coming up to -

5 MS EASTMAN: If we can turn to Queensland, to Brisbane.

MS ZERNER: Thank you, Commissioner. The next witness is Ms Courtney Wolf.

10 CHAIR: Ms Wolf, thank you for coming to the Commission to give evidence today.
I'll ask you to follow the instructions of my associate in order to administer the
affirmation, thank you.

15 **MS COURTNEY WOLF, AFFIRMED**

CHAIR: Thank you very much, Ms Wolf.

20 Ms Zerner will now ask you some questions and she is located in our Brisbane
hearing room.

EXAMINATION-IN-CHIEF BY MS ZERNER

25 MS ZERNER: Thank you, Commissioner.

Ms Wolf, can you please tell the Commissioner your full name?

30 MS WOLF: Sure. My name is Courtney Louise Wolf.

MS ZERNER: You have provided a statement to these proceedings and that is dated
7 September 2020?

35 MS WOLF: That's correct.

MS ZERNER: Is it the case that you've read that recently?

40 MS WOLF: Yes.

MS ZERNER: Is it true and correct to the best of your knowledge?

MS WOLF: Yes.

45 MS ZERNER: Commissioners, you will find the statement at Tender Bundle A
behind Tab 60, and I would ask that it be marked as Exhibit 6-17. There's an
annexure which is her CV, that is also at part A, Tab 61, and I request that be marked

as Exhibit 6-17.1.

CHAIR: Yes, that will be done. Thank you.

5

EXHIBIT# 6-17 - STATEMENT OF MS COURTNEY WOLF

10

EXHIBIT# 6-17.1 - ANNEXURE TO STATEMENT OF COURTNEY WOLF

MS ZERNER: Thank you.

15

Ms Wolf, you're currently - sorry, just before I do that. You've read that statement recently, it's true and correct to the best of your knowledge?

MS WOLF: Yes.

20

MS ZERNER: You are currently an NDIS Appeals Advocate at the Queensland Advocacy Incorporated?

MS WOLF: Correct.

25

MS ZERNER: And that organisation is an independent, and it looks at community-based systems and individual advocacy?

MS WOLF: Correct.

30

MS ZERNER: In relation to community-based systems, what are you looking at there?

35

MS WOLF: A lot of the time we're looking at not only community-based systems but also Government systems and trying to influence change to uphold people with disabilities' rights.

MS ZERNER: And in your role, that includes putting together systemic submissions on that very reason?

40

MS WOLF: Correct.

MS ZERNER: And you also provide tailored advice and ongoing advocacy to people with disability?

45

MS WOLF: Yes, and their families and informal supports.

MS ZERNER: All right. And their families and informal supports, does that include workers, support workers, for example?

MS WOLF: No.

MS ZERNER: So informal supports, what do you mean by that?

5

MS WOLF: Informal supports are people in someone's life in an unpaid capacity, that would be friends, cousins, grandparents, that's what we class as an informal support, and in order to provide advice or ongoing support to an informal support, we have to have consent from the person with disability.

10

MS ZERNER: And in regards to your role as an NDIS Appeals Advocate, does this mean that you're looking at review of, for example, NDIS decisions that may have been made about that individual?

15

MS WOLF: Correct.

MS ZERNER: And as I understand from your statement, when you're undergoing this sort of process it can be often a lengthy process?

20

MS WOLF: Yes, very much so. We can have our files open with clients for more than 12 months.

MS ZERNER: And so you get to know this particular person and their circumstances quite well, I imagine?

25

MS WOLF: Yes.

MS ZERNER: In your statement you've set out other roles that you've fulfilled, and they have included other advocacy services, that's right?

30

MS WOLF: Correct.

MS ZERNER: And it's also the case that you've had, I guess, a unique opportunity in some respects in that you've worked in the Department of Human Services on the NDIS interstate taskforce?

35

MS WOLF: Correct.

MS ZERNER: And in that role you were involved in the review and rebuilding of NDIS plans?

40

MS WOLF: Correct.

MS ZERNER: Can you just give a snapshot just in regards to that process in the sense that you became very familiar with how plans were put together, is that fair to say?

45

MS WOLF: Yes, that would be fair to say. As I was working for the Department of Human Services in a different role when this task force was put together, I was one of the people who have a lived experience of disability and so with that we did some training with other people who possibly didn't understand disability quite as much and needed some support to understand how disability presents itself in everyday life and how that may then interact with an NDIS plan.

MS ZERNER: And in relation to lived experience, what is that lived experience in relation to disability?

MS WOLF: So I have a parent who has a disability, and that happened - that occurred when I was 11, and I also have a sibling that has a disability that occurred during her adulthood.

MS ZERNER: And just in relation to that lived experience, did you have any involvement with the NDIS as part of that lived experience?

MS WOLF: We have had now. But prior to the NDIS, as a family we didn't have any funded supports, as there was not enough funding in Queensland and we were put on a register of need.

MS ZERNER: So there was a positive outcome in the sense of the NDIS for your family?

MS WOLF: Yes, definitely.

MS ZERNER: All right. If I can turn back to your role at QAI, I will call it, that's the term you refer to it, is it?

MS WOLF: Yes.

MS ZERNER: At paragraph 14 of your statement, you refer to that over the period of time of working with these people who are undergoing the reviews and through your advocacy work, that you've developed a number of concerns about the use of chemical restraints in Queensland in response to behaviours of concern. Are you able to share with the Commission from that very practical experience that you have, as to what concerns you've observed, formed your views about?

MS WOLF: Of course. So I should note that my experience comes from - a lot of it comes from being in the NDIS appeals space and so what we have seen here at QAI, especially, is that the chemical restraint can limit a person's freedom unnecessarily.

The other thing is, too, is that behaviour in the way that we see behaviour is that it's expressing a need, and when people are given chemical restraint it's just subduing the symptoms of a behaviour rather than actually addressing an unmet need or someone's desire for something.

I think the thing is, too, is that sometimes medication can be looked at as the easiest way to subdue someone's behaviour without actually going through and working with them and their family and their support team around how to best support them around their behaviours of concern.

5

MS ZERNER: And you've seen that first hand, obviously, in your advocacy experience, is that right?

MS WOLF: Correct, yes.

10

MS ZERNER: In paragraph 17 of your statement you talk about your clients and the cohort of people that you are working with, and you refer to them as being vulnerable people with disability, and the vulnerabilities, and there's a list of factors that you talk about, and they include a lack of informal supports, cognitive impairment, a high risk of abuse, neglect and exploitation. Are those experience intergenerational poverty and homelessness, domestic violence, and people from non-English-speaking backgrounds, and those with complex and high needs. I'm just interested in reference to the complex and high needs. Those people that you are dealing with, are they people that will have, for example, an intellectual impairment?

15

20

MS WOLF: So complex needs, we - the way that we refer to it is the same way that the NDIA refers to complex needs, in the sense that there is interlinking issues that could be that there is an intellectual behaviour, but there's also health concerns. There could be an intellectual impairment with behaviour that impacts health or safety, those types of things, because when there are more than one of those issues, it becomes really difficult to navigate the NDIS and those processes around it.

25

MS ZERNER: Okay. Out of the clients that you are working with, and that group - or cohort that you have referred to in your statement, how many would you estimate would be those people that have complex needs?

30

MS WOLF: That would be my entire caseload.

MS ZERNER: Okay, all right. Now, in regards to that caseload, obviously people are approaching you through, perhaps, their support networks or family and seeking your assistance to navigate an appeal, for example, with the NDIS. So I'm wondering if you can share with us some examples, and not naming people or cases, but some idea of what sort of issues are being raised in this space, for example, of chemical restraint for these people?

35

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45

MS WOLF: So a lot of the time people come to us to seek advice initially, and then the possibility of ongoing support if we have capacity, because their plans, their NDIS plans are inadequate, which means that there's not enough funding for whether it be basic support, meaning that day-to-day care, it could also be in relation to therapeutic support, so the usual list is occupational therapy, speech therapy, physiotherapy, psychology. But also when it comes to restrictive practice it could be that people either have very limited funding or no funding for a positive behaviour

support plan to be created and then implemented.

5 MS ZERNER: I just want to explore that last issue with you a little bit. So if someone is already prescribed a medication that has been classified as a chemical restraint, and a plan is put in, is it automatic that they would get the funding for a behaviour support plan? I'm just trying to understand if someone's already on a chemical restraint and it's been prescribed, and the requirement is that there needs to be - they need to have a positive behaviour support plan, they go hand in hand, how does that work if they're not having the funding?

10 MS WOLF: So it should occur --- in principle, it should occur without any questions asked. However, that's not always the case and that's why my job exists, to assist people with those appeals. It could also be the fact, though, that there has been funding put in place but that funding is inadequate. So that funding doesn't actually allow a positive behaviour support practitioner to do the full amount of work without requesting additional funds from the NDIA.

CHAIR: Who you are appealing to?

20 MS WOLF: So what happens is if someone is unsatisfied with their plan, it doesn't meet their needs, we have three months to complete an internal review, and that's where we go back to the NDIA and say to them "We think you got this decision wrong, we think this plan is inadequate." There's no legislated timeframe on how fast or slow they have to complete that review. Should they confirm that decision, we can then apply to the Administrative Appeals Tribunal within 28 days of receiving a decision to continue that appeal into an external merits review area.

CHAIR: And the initial review, is that done on the papers or do you get an oral hearing, or does it depend?

30 MS WOLF: So when you lodge an internal review, you also lodge any additional paperwork that supports your request. We also usually lodge the paperwork that was provided, you know, initially. And then occasionally there is a phone call to the participant or their advocate or their informal support, but then the delegate, or the reviewer makes those decisions.

CHAIR: And when you go, if you do, to the AAT, how long before a hearing takes place after you lodge your application for review or appeal?

40 MS WOLF: So quite a while. Once you lodge at the AAT, the next step is not to proceed to hearing. It's an alternative dispute resolution process which means that the participant, if they're supported by an advocate, will then meet with the NDIA's legal representative at a case conference. There will be discussions kind of back and forth around what additional evidence may exist to progress the matter so it's no longer in dispute. You usually have between two and four or five case conferences, and should you be unable to come to a resolution, then a matter will be listed for hearing and that would be usually anywhere in the mark of 9 to --- 9, 12, maybe even

18 months later.

CHAIR: And the formal issue is what you are requesting is a reasonable support, I forget the precise statutory language, but that's the issue, is it?

5

MS WOLF: Correct, if it's a reasonable and necessary support under section 34.

CHAIR: Okay, thank you.

10 MS ZERNER: Ms Wolf, picking up on that, if it's such a long period of time, going back to what I said before, if that person has already been prescribed a psychotropic medication that is deemed a chemical restraint, and you're going through that process to be able to obtain funding for a positive behaviour support plan, what happens in the interim with the chemical restraint and the administration of the medication?

15

MS WOLF: So sometimes we're able to work with the NDIA to have a plan altered to include at least initial funding for a positive behaviour support plan to be put in place. At other times, it's about being flexible with the funding and possibly needing to reduce other supports, other therapeutic supports in order to pay for that positive behaviour support plan. It also depends on the model of how that behaviour support plan's being put together.

20

So there was a case, not to get off-topic, but there was a case, Castledine, that was heard late last year where the agency disagreed with the therapeutic model, especially relating to behaviour. That did go to hearing and the tribunal upheld that was the model that worked for him so they had to fund it. During the process they did provide some funding for behaviour support. Some move quicker than others, and it depends on the evidence that's there before them.

25

30 MS ZERNER: Are you aware ---

CHAIR: It's even more complicated than that, isn't it? Because the service provider is under an obligation, under the *NDIS (Restrictive Practices and Behaviour Support) Rules* to put in place a behaviour support plan within a specified period. So you have the -

35

MS WOLF: Correct.

CHAIR: --- service providers under an obligation, you have the participant in the NDIS program that presumably wants to have a plan put in place, and you've got the NDIA, which is the decision-maker as far as money is concerned.

40

MS WOLF: Correct. It becomes quite a monster of a task trying to navigate service providers as well as the NDIA, as well as the behaviour support practitioner when the funding isn't there.

45

CHAIR: "Monster" sounds like quite an evocative term, really.

MS ZERNER: Ms Wolf, I want to go now to, I guess, if the funding is in place. So let's go to the scenario that there is enough funding in place for a positive behaviour support plan to be developed.

5

MS WOLF: Yes.

MS ZERNER: So the funding is sitting there with the person, but isn't it the case that you've experienced that the person then can't find a practitioner to actually write the report?

10

MS WOLF: Yes. So what we have found, especially with people who have multiple behaviours of concern is that it can be really difficult to find a positive behaviour support practitioner who's, number one, willing to work with them, number two, then has availability to work with them, and number three, has the experience to provide that positive behaviour support plan. Because the NDIA --- or the NDIS, sorry, has now provided more money into disability services, which is a fantastic thing, people are able to get their needs met now, it means, though, that there is more of - there's more money and positive behaviour support practitioners can pick and choose which clients they're going to work with.

15

20

MS ZERNER: And just on that, picking and choosing. So you said some practitioners may not be willing to work with a particular person, and they can pick and choose. Is it the funding is the same for each category? Is that an incentive? Or why do they get to pick and choose who they work with?

25

MS WOLF: So the funding can differ depending on how complex the behaviours are, how many behaviours there are to address. But there's not a very large variance. And especially, given that it's done on an hourly rate, you know, there is the ability to pick, you know, with someone that might just have one behaviour or something, that is not necessarily impacting all different aspects of their life. I think, also, the thing is, though, too, that the really experienced practitioners who have been in this space for a really long time, they just don't have any availability because they're having to pick up where the inexperienced practitioners are unable to meet that need.

30

35

MS ZERNER: And that would be particularly so in relation to those really complex behaviours of concern?

MS WOLF: Yes.

40

MS ZERNER: And it brings me to the next point, and that is in relation to the quality of plans and the clients that you've worked with. Have you had experiences where, for example, a family's been caring for their loved one for a very long time, and a behaviour support has developed and there's issues that's come out of that?

45

MS WOLF: Yes, so there's a couple of issues that come out of that is, I think especially for families who have been around for quite a while with behaviour

support, they've come to learn and know what a behaviour support plan needs to cover, and since the NDIS has come into effect, and there's now more behaviour support practitioners, there's been a decline in the quality of plans, especially around the innovation and the assessment of positive behaviour support plans.

5

So what happens is the family will meet with positive support practitioner A, they will do the assessment, they will go to do the implementation. They will have been paid for that assessment and implementation. And then the family look at the plan and go, "This isn't going to work, this isn't good enough. We've tried this. We told you we tried this, it didn't work," and now they need to go and source a second practitioner.

10

Then what complicates that as well, is because the practitioner has already been paid for their work, they need to go back to the NDIA and ask for additional funding.

15

MS ZERNER: And you said earlier in your evidence that there's not a lot of variability between different people in regards to the cost of those plans, as I understood your evidence, that's right?

20

MS WOLF: Yes.

MS ZERNER: Can you give an idea, dealing with complex needs people that you were dealing with, the cost of plans that you're looking at?

25

MS WOLF: Yeah, so we're looking at usually between \$20,000 and \$30,000 for a complex needs support plan. That has really been benchmarked by the NDIA and that works on a model that there's one positive behaviour support practitioner with possibly some collaboration with other allied health therapists.

30

MS ZERNER: And so once that funding is deplete from that first attempt, you have to go back and seek more funding to get a second plan developed?

MS WOLF: Correct.

35

MS ZERNER: Have you had that experience that you've dealt with those people that have had to go through that process?

40

MS WOLF: Yes, because what will end up happening is they come to us for an appeal, we are successful in, you know, having the money obtained to have a positive behaviour support plan drawn up and then I close the file. Six months later the client calls, or their informal support calls, and says "We need help. We don't have any money left and we're now on our second, third, fourth positive behaviour support practitioner for whatever reason it may be."

45

MS ZERNER: Just then turning to the issue of implementation and you said before that part of that process of the plan is to do the implementation, that's correct?

MS WOLF: Correct.

MS ZERNER: And have you had people that you've been advocating for that there's been issues with implementation?

5

MS WOLF: Yes, especially in rural and remote Queensland. It's definitely still an issue here in Brisbane, but we can attribute that to COVID because a lot of the training for implementing positive behaviour support plans occur face-to-face. But when you're working with a positive behaviour support practitioner who is two, 10 three, four hours away, it becomes a very difficult task to implement that plan and train staff to the quality that they need and to have the knowledge that they need to successfully implement that plan.

MS ZERNER: Has there been occasion where you've had to source either other 15 funding or another practitioner to do that implementation?

MS WOLF: Yes.

MS ZERNER: Then, just going to follow up once the plan has been implemented, is 20 there any scope or have you had any experiences where, for example, the plan is implemented and that's it or is there follow-up attached to the funding?

MS WOLF: So there is sometimes follow-up attached to the funding. There is 25 supposed to be follow-up attached to a positive behaviour support plan, as a positive behaviour support plan should grow and develop with the participant as they grow and develop. However, it really depends on the funding that has been approved, and if it's been exhausted, then they need to wait until either a scheduled or unscheduled review is completed.

MS ZERNER: And when you say exhausted, is it the case you get a bucket of 30 money for the plan and implementation and follow-up, and if it's the case that you've expended all of that bucket of money just in developing the plan, there's nothing left in relation to those further steps?

MS WOLF: Correct. 35

MS ZERNER: Does that come down to the individual practitioner in relation to how they use that bucket of funds?

MS WOLF: It can do. It can also come down to the fact that there wasn't enough 40 money in the first place.

MS ZERNER: Okay, thank you. If I can, please, I just want to take you to 45 paragraph 20, we're really moving onto a different topic now, and that is just in your reference to psychiatrists.

COMMISSIONER ATKINSON: If I could interrupt, I just want to ask a question

about the training and staff, we've heard that often service providers have casual staff and people may not have the same staff regularly, does this provide a problem in the training of staff in a positive support plan, behaviour support plan?

5 MS WOLF: Yes, that's quite a big issue is because the positive behaviour support practitioner may do the training with, you know, a group of staff and then those staff may not stay with the participant or they may change jobs. I think one of the big issues here, which I haven't actually spoken about in my witness statement, is supported independent living, where a lot of the time, the core support funding is
10 locked to one provider, and although there is supposed to be consistency with that one provider in providing that training, the staff turnover, it can be so high that it's very difficult to keep training up-to-date for positive behaviour support.

COMMISSIONER ATKINSON: Thank you.

15

MS ZERNER: Ms Wolf, just going to paragraph 20 and you talk about the psychiatrist and the role of the psychiatrist, and you say that:

20 *Often Psychiatrists are the practitioners which are prescribing chemical restraints, and without collaboration it is hard to comprehend how a positive behaviour support practitioner is supposed to develop and implement a plan*

25 Can you tell us what happens in practice when someone wants to involve their psychiatrist or they want to seek mental health in regards to that plan currently?

MS WOLF: So currently, under how the framework works for NDIS and the agreement that is have been put into place with government, is that NDIS does not pay for psychiatrist input, whether that be in relation to a positive behaviour support
30 plan or otherwise. That means that should the family or the participant want their psychiatrist involved with the development of the positive behaviour support plan, a lot of the time they then need to pay for that out of pocket. That can be at least \$350 per visit, and that can also be when the positive behaviour support practitioner is collaborating with the psychiatrist they can also charge for their time. Families and
35 individuals end up picking up that cost and when a lot of people are on disability support pension or carers payment or a government support, that can be quite a lot of money to pay for something that's related to their disability.

40 MS ZERNER: What about then going to the public sector for that support?

MS WOLF: The public sector waitlist is quite long, and also, with the public sector, there's the same issue of the continuity of care. You can be rotated through different psychiatrists who then may have different clinical opinions and, again, it's very
45 difficult for multiple psychiatrists who are assisting the one person to collaborate with a positive behaviour support practitioner when one's in a health realm and one's in a disability realm.

MS ZERNER: I just want to take you in conclusion now if I can, and it relates to what you just talked about. It's at paragraph 33 in your statement and you say there's a disconnect between disability and health supports. And you say since the NDIS, in your perspective in any event, that the gap is widening. Can you explain what you mean by that and what you see is the issue?

MS WOLF: Of course. Previously when people were under any type of restraint and their positive behaviour support plan needed to be developed, there was a collaborative approach from Disability Services Queensland, which could involve liaising with different departments and allied health therapists. Since the inception of the NDIS, all those different supports have become siloed and separated, which means that a person or their informal supports need to try and navigate between the psychiatrist, the allied health therapist, the positive behaviour support practitioner, the service provider and those supports, and some may have a support coordinator to help, but support coordinators do not do case management, and that means that people are having to repeat themselves and there's a disconnect between information flowing back and forth.

MS ZERNER: And you also say that there's a health interface as and they constantly face that's not our responsibility. That's between the NDIS and Health each saying "That's not our responsibility", and the person is in the middle ---

MS WOLF: Yes, the person is stuck in the middle.

MS ZERNER: All right.

Commissioners, that completes Ms Wolf's evidence.

CHAIR: Thank you.

Commissioner Atkinson, was there anything else you wished to ask? Commissioner Atkinson has disappeared.

COMMISSIONER ATKINSON: No, there's nothing else I wish to ask, thank you.

COMMISSIONER McEWIN: Thank you, Chair, I have two questions for Ms Wolf.

Ms Wolf, at the beginning of your evidence you talked about informal support, and that your client has a lack of informal supports. In your view and observation, what do you think needs to be done to increase the capacity for people with disabilities to have access to more informal supports?

MS WOLF: Yes, I think this is a little bit off-topic to restrictive practice but I think it can assist with restrictive practice.

The NDIA are very willing to fund group activities and disability-specific activities, however there is a reluctance to provide support to engage in new models that work

on, say, circles of support and developing relationships that are not in a paid capacity, as they see that that is somehow mainstream responsibility when we really don't have the community infrastructure set up yet to be providing that type of support. It would be fantastic when we do. But at the moment, people need support to grow their circles of support, and unfortunately that would probably only come from a paid capacity through, you know, family facilitation and those types of things.

COMMISSIONER McEWIN: Thank you. One final question from me about positive behaviours, the support plans that you were talking about. You talked about before and after, or now with the NDIS rollout. In your view, pre-NDIS, do you think the behaviour support plans were better and, if so, why so?

MS WOLF: I think there was more collaboration, and that's what made it - I don't want to use the word "better", it was different. I still think, though, that the level of collaboration that happened between psychiatrists, allied health, and other therapists that were engaged with the person and the family provided a more comprehensive overview of someone's need and someone was able to go back and discuss with the psychiatrist or the positive behaviour support practitioner about their positive behaviour support plan, or their loved one's behaviour support plan, without a dollar figure being attached.

There wasn't necessarily, and don't get me wrong, DSQ, you know, was definitely underfunded but still people had access to understand and get ongoing support, and there wasn't this dollar figure attached, you know; once your NDIS plan runs out of funding that's it, the door's closed on you.

CHAIR: How much do practitioners charge?

MS WOLF: I'm going off the top of my head, but I believe it's about \$213 an hour.

CHAIR: And practitioners aren't necessarily trained in any particular way?

MS WOLF: They do have to have certain allied health degrees in order to register as a positive behaviour support practitioner, but there's definitely room for additional training in positive behaviour support for sure.

CHAIR: Ms Wolf, thank you very much for your, if I may say so, extremely well-informed evidence for the detailed information you have provided us. I suspect you are rather a formidable advocate. Thank you very much for the work that you do.

MS WOLF: Thank you so much for having me.

45 THE WITNESS WITHDREW

CHAIR: What do we do now?

MS EASTMAN: Commissioners, if we take a break for about 15 minutes and then we will resume with our final witness for today.

5

CHAIR: We'll resume at 3.45.

MS EASTMAN: Thank you.

10 **ADJOURNED** [3.32 PM]

RESUMED [3.45 PM]

15

CHAIR: Yes, Ms Zerner.

MS ZERNER: Commissioners, the next witness is Mr Simon Wardale.

20 CHAIR: Can we see - we've got a number of people.

May I ask, is the pronunciation of your name Wardell, Wardale? That would be good if you had your microphone on.

25 MR WARDALE: Wardale, thank you.

CHAIR: Thank you, Mr Wardale. Can you please follow the instructions of my associate who will administer the affirmation to you.

30

MR SIMON WARDALE, AFFIRMED

CHAIR: Thank you, Mr Wardale. Ms Zerner will now ask you some questions.

35

MR WARDALE: Thank you.

EXAMINATION-IN-CHIEF BY MS ZERNER

40

MS ZERNER: Mr Wardale, can you tell the Commission your full name?

MR WARDALE: My name is Simon Dene Wardale.

45

MS ZERNER: It's correct, isn't it, that you've provided a statement in these proceedings which is dated 9 September 2020?

MR WARDALE: That's correct.

MS ZERNER: You've had an opportunity to review that statement recently?

5

MR WARDALE: I have, thank you.

MS ZERNER: It's true and correct, to the best of your knowledge?

10

MR WARDALE: It is.

MS ZERNER: Commissioners, Mr Wardale's statement can be found at Tender Bundle A behind Tab 68, and I ask that it be marked as Exhibit 6-18. There is also his CV at Tender Bundle A behind Tab 69 and I ask that it be marked as Exhibit 6-18.1.

15

CHAIR: Yes. And I think there's - is there not another -

MS ZERNER: Commissioner, there are two articles that I propose to take Mr Wardale to, I don't need to ask that they be made as an exhibit just as yet, although we might, in another tender bundle. But I do propose to take Mr Wardale to those articles and I will refer to those as we go along in the evidence.

20

CHAIR: Yes, thank you very much. That's fine. Thank you.

25

EXHIBIT# 6-18 - STATEMENT OF MR SIMON DENE WARDALE

30

EXHIBIT# 6-18.1 - ANNEXURE TO STATEMENT OF SIMON DENE WARDALE

MS ZERNER: Thank you, Commissioner.

35

Mr Wardale, since July 2019 you've been the Chief Clinical Practice officer at Multicap?

MR WARDALE: That's correct.

40

MS ZERNER: And you hold a Bachelor of Applied Science (Honours) and have a major in Intellectual Disabilities?

MR WARDALE: Correct.

45

MS ZERNER: And you've worked with people with intellectual disability who use challenging behaviours for the past 20 years and that's in frontline support, service

management, and practice and policy advisor?

MR WARDALE: Sadly it's closer to 30 years, but, yes, they're the roles.

5 MS ZERNER: All right. So you've had that obvious extensive experience. I want to
pointed out that in relation to that practice and policy advisor roles, it's the case, isn't
it, that you were the Director of Practice Leadership at the Centre of Excellence for
Behaviour Support at the Department of Communities, Child safety and Disability
10 Services, which was also with the University of Queensland, and you held that role
from 2011 to 2013?

MR WARDALE: Correct.

15 MS ZERNER: And it's also the case that you worked as the Regional Senior
Practice Advisor with the Office of the Senior Practitioner Disability Services in
Victoria, and you held that role from 2005 to 2011?

MR WARDALE: Correct.

20 MS ZERNER: You've also published an academic journals on issues relating to
behaviour support, training, quality, and outcomes for people with disability?

MR WARDALE: Correct.

25 MS ZERNER: Now, in your role at Multicap, and you refer to this in your
statement, you say 10% of customers receive targeted behaviour support. Later in
your statement, you go to --- and I'm going to take you to this shortly --- Levels one
through to Level four. When you're talking about targeted behaviour support, does
30 that link to those levels that we are going to talk about?

MR WARDALE: Yes, it does. Specifically it talks to levels two and above, which I
understand we'll get to.

35 MS ZERNER: Okay, thank you. Just in relation to that figure, you say that the
figure approaches 40% when -

CHAIR: Sorry to interrupt, Mr Wardale, can you check that there's not something
electronic that is on at your end and that is causing an echo?

40 MR WARDALE: I'm not aware of anything beyond this audio, but if you can just
allow me to stand up I'll make sure we don't have an air conditioner on and then I can
sit again.

CHAIR: You can certainly stand up, Mr Wardale.

45 MR WARDALE: Thank you, that is the only electronic device apart from this
computer in the room.

CHAIR: Okay, well, it seems that the echo has gone. So thank you to the air conditioner.

5 MR WARDALE: Thank you.

MS ZERNER: Mr Wardale, building on that 10% of customers who receive targeted behaviour support, you say the figure approaches about 40% when considering customers who access supported and independent accommodation through Multicap,
10 that's correct?

MR WARDALE: Correct.

MS ZERNER: Now, I introduced that topic by talking about Levels one to four. If I
15 can please take you to paragraph 25 of your statement, you have that before you?

MR WARDALE: Yes, I do, thank you.

MS ZERNER: And through your statement you set out the various levels that are put
20 in place in relation to behaviour support of Multicap, and so level one is in relation to a routine and annual survey. So is it the case that every customer --- that's what you refer to people that are in Multicap service --- undergo an annual review at a minimum?

25 MR WARDALE: That's correct. That's correct. That review looks at two areas. It looks at previously unidentified or emerging episodes of challenging behaviour or the potential for restrictive practices to have been introduced with regard to that person. So it's essentially to make sure that the other three areas don't miss anyone who we should become focused on.

30 MS ZERNER: And it's certainly not that you needed to have a restrictive practice in place to trigger that Level One review?

MR WARDALE: Quite the opposite. It's to make sure that there's not people that
35 we don't know about that are engaging in problem behaviour or subject to restrictive practices. So that's all Multicap customers.

MS ZERNER: And then in relation to Level Two, which you talked about, and Level Two is triggered when there's a regulatory requirement for behaviour support
40 plan, or there may be related to some funding support through the NDIA, can you just explain what happens with Level Two, and I'm going to come to you in more detail but briefly.

MR WARDALE: If we can think about Level One, Level One potentially identifies
45 people who need additional support. Level Two is the first stage of that support, and we may become aware of those people either because someone has recommended the use of a restrictive practice, but not always, or because of them requiring some more

targeted behavioural intervention. It's at that point that we would trigger the partnership between the positive behaviour support team here at Multicap and their operational colleagues to make sure that we begin collaborating on a more complete suite of supports for that particular individual.

5

MS ZERNER: And that suite of supports would involve development of a positive behaviour support plan, is that correct?

10 MR WARDALE: Correct, and it's very important to us that the development of such plans isn't limited to people who are subject to restrictive practices, so we want to get those supports in early. So the development of the positive behaviour support plan, the relevant stages of development of that plan, and then also the training and support of our operational staff who are supporting the person.

15 MS ZERNER: And that's what I was going to come to is in relation to, I guess, firstly the development of the plan, and if we deal in-house --- because I'm going to come to another scenario later on, but if we deal within Multicap, the development of the plan, the training, can you step through what that process is, please?

20 MR WARDALE: Yes, I guess there's three or four steps. So obviously there's the assessment phase, so all the people who know the person well with the clinician leading up from our team's perspective, there is then the development of the positive behaviour support plan. Actually the next two steps are almost more important.

25 So the third step is the training of the staff who were involved in the support of the person, and that's training on some more detailed theoretical aspects of positive behaviour support, but then also how those theoretical aspects apply to that particular individual and their particular circumstances.

30 And then the fourth step is the ongoing relationship between the customer, the operational staff and the clinician as we work through and troubleshoot the implementation of this plan. So I will talk a lot about coaching and mentoring by the clinician of the frontline staff, but there is two-way learning as well.

35 MS ZERNER: All right. Then I want to go to Level Three, and Level Three, as I understand, is bringing the whole organisation together to consider every month as to what's happening in this area of behaviour support and particularly restrictive practices. Can you just give a brief overview of what that process is?

40 MR WARDALE: Yeah, it's a broad view of potential risks, I guess. So one of the significant things we do is we look at incident report data across the organisation, just again to try to ensure that we are not missing a particular person or a particular area, perhaps, who would benefit from some additional support. And to be honest, we also look at unusual incident report trends. If there's very low incident reporting,
45 we seek to confirm that that is actually a true and accurate reflection of what's going on at the site. So it's just to check that we're not missing anything, and it's a collaborative approach between people from multiple functional areas across the

organisation.

5 MS ZERNER: And earlier in your statement you refer to the need of integration of services and I think that's what you're talking about with this Level Three, is that it's not only the clinician but it might be human resources, it might be management. So it's an integration of that whole service of ensuring that things are on track, so to speak.

10 MR WARDALE: Correct. So the delivery of positive behaviour supports, whilst it might be described in a positive behaviour support plan, that's essentially a work instruction for our frontline staff. So there's that necessary translation into the operational context and as soon as we do that, then, of course, we have the related factors of staff training, staff support, supervision, those various things. So at a minimum, for us to do this work effectively, we're intersecting the clinical, the operational and the human resource functions across the organisation.

CHAIR: Mr Wardale, how does Multicap come into the picture for someone?

20 MR WARDALE: So are you asking how people would hear about Multicap and join our services?

CHAIR: No. How do they engage you? Who engages you and for what purpose exactly?

25 MR WARDALE: So typically what happens, and particularly in the current environment, our customers have received their NDIS plan, they have specified to their planner that there is a range of supports that they are seeking, the planners deemed that that is an appropriate response to that person's needs, and then those customers essentially reach out to us through multiple mechanisms and ask us to deliver some or all of those services for them.

CHAIR: Are your customers, I think that's the word you used, are they all NDIS participants?

35 MR WARDALE: Not all of them but the greatest percentage are by quite a margin.

CHAIR: The ones who are not NDIS participants, how do they pay for the services you provide?

40 MR WARDALE: All of them are in some sort of funded mechanism. So whilst they might not be funded by the NDIS, they may be funded by some residual State Government funding arrangements as well. So either way, they are coming to us with state or federal backing for their support.

45 CHAIR: Has Multicap substantially expanded since the introduction of the NDIS?

MR WARDALE: Certainly with my team, we have. We've seen more people come

to us seeking specific behaviour support and so some of those funded areas related to NDIS activity support coordination are the same. We also have a program where we seek to build or acquire properties that would be suitable for people with disabilities to live in. So as we create houses, we often have people approaching us seeking accommodation as well.

CHAIR: So you're providers of group homes, are you?

MR WARDALE: Correct.

CHAIR: Thank you.

MS ZERNER: Mr Wardale, it's in addition to group homes and other services that you may have day clients or customers as well, is that ---

MR WARDALE: Correct. So we offer a suite of services. We offer some daytime activities, we offer employment services, we offer recreational services, we offer the behavioural and support coordination services through my team, as well as short, medium and long-term accommodation.

MS ZERNER: Just going back to these levels. If I go to Level Four, as I understand it, that is for the most complex customers you have, are they predominantly in supported accommodation?

MR WARDALE: Yes. I can't - off the top of my head I can't think of any who aren't.

MS ZERNER: All right, and so of those people in supported accommodation, there is a cohort of what are termed as having challenging behaviours. What's the purpose of this Level Four category?

MR WARDALE: So, we are wanting to see an escalating sophistication in response to people depending on the complexity of their needs. And at any given point in time across the population of customers at Multicap --- the population of customers at Multicap, we met some people who have some significant challenging behaviours and who require a more targeted focus across the rest of the organisation.

MS ZERNER: All right. And in the sense we've heard some examples through the week of when there's a crisis, and things are really escalating, and in some scenarios that the only alternative may be to go to hospital. I'm just wondering, you have this emergency forum. Is that for those sorts of circumstances?

MR WARDALE: Yes. So if you can imagine, the Level Four forum that we just spoke about is a routine and ongoing monthly forum for where we get to consider the Multicap customers who have the most complex of needs, but we maintain the capacity to convene that forum at very short notice, typically around four to five hours, should a customer find themselves in a crisis that our usual responses aren't

remediating for them. So in addition to the cohort we review monthly, there's the capacity for us to convene at short notice and consider things that might have occurred unexpectedly for one of our customers.

5 MS ZERNER: Mr Wardale, I want to return to that Level Two process we just talked about, particularly focusing on the regulation and we've heard time and time again this week that really the gateway in relation to chemical restraint is the prescription of the medication. You have some concerns in regards to perhaps medication being the first port of call. Can you just explain, given your background
10 in behaviour support management, what that concern is?

MR WARDALE: I think a lot of people, when they become worried or confused or unclear of what to do next, they reach out to their general practitioner or medical
15 community. Obviously that group of professionals then do their best to respond. What that can often mean is people are prescribed a medication or a chemical restraint prior to their perhaps having been in engagement with teams like my own.

So at that point, the provision of the less restrictive and preventative aspects of behaviour support start playing catch-up a little to a medication that's already been
20 prescribed.

MS ZERNER: And at paragraph 7 of your statement, you say:

25 *The collective concern regarding the use of Restrictive Practices arises due to the combination of both the paucity of clinical evidence supporting their use, and the ethical implications of imposing upon a person's human rights.*

Now, Mr Wardale, there is a study that you have referred the Commission to in regards to this evidence and use of medication in this group of people.

30 Commissioners, this particular article is called:

35 *Risperidone, haloperidol, and placebo in the treatment of aggressive challenging behaviour in patients with intellectual disability: a randomised control trial*

It was in the Lancet journal in 2008. Commissioners, you will find that at Tender Bundle B, tab 36D.

40 Now, this research acknowledges that despite the wide use of antipsychotic drugs to treat challenging behaviour, the evidence base is scarce. And so it's the case, isn't it, that these researchers undertook a study to look at the effect of some medications but had a control group where a placebo was administered. Can you just very briefly describe that, and then I want to come to the outcome but just very briefly describe
45 what happened in the study.

MR WARDALE: Yes, so there were groups of people that were allocated to

different research conditions and as you just spoke about, the medications that were being looked at were Risperidone, Haloperidol and a placebo control, and what was identified in the study was all scenarios saw an improvement in the circumstance with the person with a disability. And the researchers hypothesised, therefore, that the placebo effect and some of the things occurring around a placebo effect was actually having - was the causal agent of the benefit. And so there were some other things that they spoke about, you know, people getting the attention of clinicians and so maybe some psychological effect occurring there for the person as well. But fundamentally, across those three groups of medication, there was no difference and there was all benefit.

MS ZERNER: Can I ask, please, that page 6 of that article be brought up on the screen. It's just the conclusion that that research has concluded. And if we just have a look at that. They're not saying that there's no place for psychotropic medications, but certainly what they're saying is that routine prescription of the drugs early in the management of aggressive and challenging behaviour, even in low doses, should no longer be regarded as a satisfactory form of care.

Just on that, you said that before in your evidence that someone's got a problem or a worry, they'll go to the doctor, and from your experience, what happens when that scenario occurs and they go to a doctor?

That article can be taken off the screen, please.

MR WARDALE: Well, you know, as I'm sure you can imagine in those very, very early stages, they're typically not when we are involved but what I would suggest is that doctors don't see a lot of people with intellectual disability and complex challenging behaviour on any given year. So I would also suspect that their detailed knowledge of alternatives, such as positive behaviour support, is possibly limited. So, again, I would suspect, in the absence of being aware of perhaps of some more effective and less intrusive alternatives, the doctors would seek to assist in the way they know best.

MS ZERNER: And that's through prescription of medication, that's what you're suggesting?

MR WARDALE: Yes, I am.

MS ZERNER: Would you like to see some changes, if any, in that space?

MR WARDALE: It would be helpful, I believe, to extend the scope of our regulatory frameworks to include the people who prescribe restrictive practices like chemical restraint. So just as our sector, the disability sector has benefitted enormously from a focus on this topic over the last decade or thereabouts, I suspect it would also assist the medical fraternity to develop their skill in understanding and discussing alternatives to medical interventions with their patients.

I would love to see a situation where a medical professional gets on their database to consider what they might prescribe for a person, and something flashes up and says, "Are you aware of positive behaviour support? Do you know that this can be accessed through the NDIS? Here is the mechanism to do that." I wouldn't seek to
5 limit a medical professional's ability to prescribe. It would be great to highlight to them the issues around chemical restraint, and the effective alternatives available in preference to chemical restraint.

MS ZERNER: All right. I want to move, and we've spoken a lot about behaviour
10 support plans but there's a particular study which you were the lead author on in 2016 and that was published in 2018. And that article is titled:

The outcome of a statewide audit of acuity of positive behaviour support plans

15 Commissioners, that can be found at Tender Bundle A at Tab 66.

That study was looking at the Queensland context of the quality of behaviour support plans since the regulation came in that they were required for chemical restraint. Is that fair to say?

20 MR WARDALE: Correct.

MS ZERNER: Now, in that particular study there were ten organisations who provided 139 behaviour support plans for review.

25 MR WARDALE: Correct.

MS ZERNER: And of those, 123 contained restrictive practices, is that right?

30 MR WARDALE: Correct.

MS ZERNER: There was various, or a variety of authors of the plans. So there was the majority being written within the organisation, but there was 13% which were an independent consultant, 10.1% who were Government-based specialised behaviour
35 support, and 2.2% a staff member in an organisation in collaboration with an allied health.

Now, it's the case, isn't it, that the study didn't assess the author's qualifications or skill level but it was really looking at the quality of the plans?

40 MR WARDALE: Correct.

MS ZERNER: And the main tool used was BSP-QE II. I don't know if I've said that right?

45 MR WARDALE: You have said that correctly.

MS ZERNER: I think the NDIS is using that tool, as well, in really assessing the quality of a plan, is that right?

5 MR WARDALE: Yes. It assesses the likely efficacy of the behaviour support plan against the research evidence.

MS ZERNER: In addition to the efficacy of the support plan, the study also looked at a readability tool?

10 MR WARDALE: Correct.

MS ZERNER: We'll come to that in a moment.

15 In relation to the data collected and then the analysis of that data, the results were that the score was remarkably low at 6.53. Can you just explain what the score means and the reference to remarkably low?

20 MR WARDALE: So, the instrument that you're speaking about, the BSP-QE II scores 12 areas on a 0 to 2 scale. So therefore that's a maximum score of 24. Above the score of 12, there are threshold criteria that are set, so, indicating the relationship between the plain content and the research evidence on behaviour change. Below 12 there are no thresholds, it simply suggests the behaviour support plan should be rewritten because of its limited adherence to the research evidence.

25 So if we think that according to that tool, behaviour support plans should be rewritten at something under 12, an average score of 6.53 is, of course some concern. At around the same time the Officer of the Senior Practitioner in Victoria was using the same tool and publishing through their annual reports on the application of that tool for behaviour support plans in Victoria, and their scores were ranging at about 10 or
30 10.5 as well. Now I don't know what the more recent data is ---

MS ZERNER: Sure.

35 MR WARDALE: --- but the conclusion we drew was certainly in Queensland, and with evidence for other States at that particular point in time, there was limited adherence for the research evidence in the plans that we looked at.

MS ZERNER: And certainly in both Victoria and Queensland on that data there was significant room for improvement in relation to the quality of plans?

40

MR WARDALE: Correct.

MS ZERNER: And it was the case, isn't it, that that data, or the results, I should say, was the same against the various authors, so be it the independent consultant, be it
45 written in-house?

MR WARDALE: Correct.

MS ZERNER: Now I'm interested, that was data collected, I think, 2014/2015, correct?

5 MR WARDALE: Correct.

MS ZERNER: So at that time there had been in place in Queensland in any event, since about 2006, a requirement for these behaviour support plans, so why at 2015, when this is collected, are we still at that level of plans that are needing some further
10 work? What do you think that's put down to?

MR WARDALE: I think there's a principal reason and perhaps there's a subsidiary one as well. Positive behaviour support is a discipline that combines three areas, applied behaviour analysis as the technical approach to facilitating change in
15 behaviour, person-centred practice and normalisation theory as an approach that encapsulates the contemporary value base of disability service provision.

But it's the applied behaviour analysis aspects that are the technical aspects of positive behaviour support and positive behaviour support plans.
20

The international standard to be registered as a board certified behaviour analysis is to do approximately a Master's level qualification all in ABA course work and in the order of 700, 800 hours of clinical supervision during the course of your study.

25 In Australia, certainly throughout my career, we have never had the availability of that level of training and applied behaviour analysis. Now in the last few years there's been some changes at Griffith University in Queensland, and Monash University, I believe, in Melbourne, to start using some of these courses but it remains true to my mind that we adopted a discipline, positive behaviour support, but
30 then spent many, many years not training to a sophisticated level the aspects of positive behaviour support that's been around positive change.

Now there are people across Australia, and I was in one of those organisations at the Centre of Excellence for Behaviour Support, we've delivered some fantastic training
35 but they are one or three or four-day workshops; they're not likely to deliver the degree of clinical acuity that will be required to support someone with very, very complex behavioural presentations. You simply can't compare the benefits of a four-day workshop to Master's level coursework and 700, 800 hours' supervision. They're just different things.
40

MS ZERNER: And that's particularly related to, and we're talking about behaviour support practitioners, aren't we?

MR WARDALE: Correct.
45

MS ZERNER: And it's the case, isn't it, that at the moment there would be various allied health, and we've heard that in some recent evidence, that are tasked with

behaviour support plans, so various allied health, occupational therapists, physiotherapists, et cetera. Are you aware that as part of their coursework --- and you may not be able to answer this and please tell me if you can't --- do they have a component of that training before they actually undertake this sort of work?

5

MR WARDALE: To the best of my knowledge, no. I mean, the average undergrad or certainly early post-grad student is not going to touch on intellectual disability and challenging behaviour almost at all. But further, I mean in understanding that, what Multicap has designed is a really intensive induction and development program for our clinicians as they come to us.

10

We know they're not likely to have touched this subject matter, so we recruit people with the enthusiasm and aptitude to be able develop those skills, but then we understand we have to actively target that development. So typically there's a very specific three-month post recruitment induction plan that we apply to our new clinical recruits.

15

MS ZERNER: And there's a course they have to undertake, is that right?

20

MR WARDALE: Correct, so that's another course where the content has been structured and endorsed by the Behavioural Analyst Certification Board, that course is called Registered Behaviour Technician course, that's 40 hours. And in addition to the things that we expose them to and ask them to learn, we also ask they complete the registered behaviour technician's course.

25

MS ZERNER: And then there would be different training for your support workers, the frontline workers in regards to implementation?

30

MR WARDALE: Yes, correct. So, again, we stage that as well. So for all of our frontline support workers, they participate in training around understanding behaviour generally, responding to and defusing potential points of escalation and also how through environmental means they can best keep themselves and their customers safe. That's --- all of our frontline staff get that.

35

The targeted training around behavioural theory and what's in a behaviour support plan is the Level Two aspects that we spoke about earlier, but that wouldn't be for all of our staff.

40

MS ZERNER: But that's the clinician's task with developing all those behaviour support plans ---

MR WARDALE: Exactly.

45

MS ZERNER: Turning to the support workers and the frontline workers in that study of 2016 that you were lead author on, there was discussion about the intervention of plans, and the study said that approximately 75% of direct support staff hold only secondary school or vocational level qualifications, and many have

not been exposed to specialised training in the concepts of the technical aspects of behaviour support. That's right?

5 MR WARDALE: That's correct. That was data published by National Disability Services some years before then.

10 MS ZERNER: But it's also correct, isn't it, in paragraph 39 of your statement you say that increasingly, many of the support workers are from non-English-speaking backgrounds.

15 MR WARDALE: Correct. So I don't have data on that but anecdotally I can tell you that's the case.

MS ZERNER: And so the study which I referred to previously about the readability of that, it was found to facilitate effective implementation, the readability of the plans should be matched to the intended audience who are the implementers?

20 MR WARDALE: Correct. And that's not to diminish the significant contribution that the regulatory frameworks have made by holding us to account to the detail of our work. But there is a difference between a plan potentially that is written to a piece of legislation and that will meet the needs of a person whose job it is to check a plan against a regulatory framework. There's a difference between that audience and the person who is providing in situ support to a person with a disability who may not have finished high school and is certainly not someone that is going to read a 25 30-page document any time soon to help guide them in their support.

30 It's why for us at Multicap the relationship between the clinical and the operational teams are so important, because the coaching and the mentoring and the relationship typically brings about the capability development in our frontline staff in a way that, to be frank, a very theoretical and legal positive behaviour support plan might struggle to do.

35 MS ZERNER: And when you say legal, is it, for example, a support plan that's directed at the regulation rather than perhaps the implementation for the person? Is that what you're referring to?

40 MR WARDALE: Correct. Correct. And I know you know this, it's in my statement, but I start thinking to the next generation of regulatory reform and absolutely acknowledge what a massive difference the current generation has made, but I think the next stage can, in more detail, consider the operational context of disability service provision. Fundamentally, a positive behaviour support plan is a working structure for frontline staff. It's their tool. We need to make it useful for them in their day-to-day support of their customers and people with disability.

45 MS ZERNER: I said I was going to take you to the scenario when someone not in-house is involved in regards to behaviour support, and you set this out at paragraph 32 of your statement and you say that, and I think --- and you say that it

really creates conflict for you in the sense that under NDIS a person can choose to have a practitioner so they may choose to have an external third party to provide that service of developing a positive behaviour support plan. And you understand the choice, but with that brings challenges. Can you just briefly explain what those
5 challenges are and perhaps an example?

MR WARDALE: Yeah. So, and I think as I said before, we work very hard to integrate multiple functional areas of Multicap to bring about the best response for people with disability and challenging behaviour. Part of that is also some really
10 targeted development of our new clinicians, but also some highly structured and carefully considered approaches to training and mentoring our frontline staff.

When a customer chooses to select a behaviour support provider other than Multicap, we are less able to influence all of those factors that we have determined are
15 necessary to bring about really good outcomes for people. We have little control over the training, the capability or even the timeliness of the behaviour support clinician that may be involved.

In the example I gave in my statement related to a young man who was engaging in
20 behaviour that was hurting himself, sometimes hurting himself quite seriously. Across a period of about six months there was three changes in behaviour support clinician. Some of the conversations I was having with the clinician who finished up at the end urging that we had a more detailed response available to this man, the clinician was referring me back to the legislation and saying you shouldn't be too
25 concerned, you've got coverage from a compliance perspective. So, ultimately, by having a third party provider involved, we were not able to fully deploy the suite of strategies that we would use to support this person.

Now, as it happened, we stepped into the fold. Obviously we're not going to let a
30 person hurt themselves and have arguments about compliance and funding. But what that meant is in reality we stepped in to bring about a better response for this young man whilst someone else was being paid to do that work and had not delivered it.

MS ZERNER: And just on that funding issue. So that's in relation to the behaviour
35 support plan and the development of that, the implementation and the follow-up that's required. But in regards to those Level One to Level Four, and the emergency response, that's all still part of that integrated service. So if there's no funding for that development of the behaviour support plan, none of that at Level One to Four and emergency service is provided in that funding package for the development of
40 behaviour support?

MR WARDALE: No, that's right, and I think the funding mechanism is quite
45 transactional. There is some hours dedicated to an activity that is then discharged and paid for. Our experience is that the appropriate response to people with disability and challenging behaviour is far more complete and integrated than that and I spoke about the role of our HR area, I spoke about the role of our operational area and the role of my area working together and identify where any gaps might be

across our suite of responsibilities to ensure ---

CHAIR: Ms Zerner, I see the time. Are we nearly at the end?

5 MS ZERNER: We certainly are, Commissioner. This is just about to finish up.

CHAIR: Excellent.

10 MR WARDALE: So there are multiple areas that need to come together to deliver the right outcome for the people we're supporting. That transactional nature of simply funding a clinician to do one piece of work is not what is required in completeness.

15 MS ZERNER: Now I'm not going to take you to this but in paragraph 34 you talk about other funding issues in regards to, for example, the number of interventions and obtaining further funding if there's lots of interventions and it's not an incentive to control interventions. I won't go there but the Commissioners have got that there and they can have a look at that.

20 In your statement you make a number of recommendations and the Commissioners have your statement and they can go through that.

I just draw the Commissioners' attention to paragraph 17 of Mr Wardale's statement and he refers there in regards to some data that's available in Queensland and the possibility of reviewing the regulatory system in regards to the effectiveness of behaviour support plans and perhaps that may be a way of looking at, really, the effectiveness of this whole system that's been certainly in Queensland for some time and now is being rolled out nationally.

30 Commissioners, that concludes Mr Wardale's evidence.

CHAIR: Thank you very much, Ms Zerner. Thank you very much, Mr Wardale, for your evidence and your statement and we have, indeed, read your statement and we shall look more carefully at your recommendations. Thank you very much.

35 MR WARDALE: Thank you.

40 **THE WITNESS WITHDREW**

CHAIR: Ms Eastman, do we now adjourn until 9.30 tomorrow.

45 MS EASTMAN: Until 9.30 tomorrow. Thank you, Commissioners.

CHAIR: Thank you. We will adjourn until 9.30.

ADJOURNED AT 4.27 PM UNTIL FRIDAY, 25 SEPTEMBER 2020 AT 9.30 AM

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