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TRANSCRIPT OF PROCEEDINGS

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THE HON RONALD SACKVILLE AO QC, Chair

THE HON ROSLYN ATKINSON AO, Commissioner

PROF RHONDA GALBALLY AC, Commissioner

MS BARBARA BENNETT PSM, Commissioner

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

SYDNEY

10.12 AM, MONDAY, 24 FEBRUARY 2020

Continued from 21.2.20

DAY 5

**MS K. EASTMAN SC appears with MS S. FRASER and MS G. WRIGHT as counsel
assisting**

**MS K. MORGAN SC appears with MS A. MUNRO for the Commonwealth of
Australia**

MS G. FURNESS SC appears with MR I. FRASER for the State of New South Wales

MR G. WILLIS appears for witness Sabrina Monaghan

COMMISSIONER SACKVILLE: Good morning, everybody. I apologise for the slightly late start but there was an application the Commission had to deal with before the commencement of the hearing today. As on previous occasions, we wish to commence this hearing by acknowledging and paying our respects to the
5 traditional custodians of the land on which we are meeting, the Wann-gal people. And we also pay our respects to First Nations elders past, present and emerging, as well as to all First Nations people who are present today. I should say that later on today we will be hearing evidence about the First Nations people with cognitive disability and there will be specific evidence directed to that – or those issues. Yes,
10 Ms Eastman.

MS EASTMAN: Good morning, Commissioners. Good morning to those attending the hearing room and those following us on the webcast. I want to start by making a few opening remarks in relation to the commencement of the second week of this hearing. As the Royal Commissioners have explored over the course of the past
15 week, that we've examined a number of aspects of access to health care and preventable death for people with cognitive disability. During the course of this week, the Royal Commission will continue to hear evidence from people with cognitive disability and their families.

Today, the Royal Commission will focus firstly on access to dental care. You will
20 hear evidence about the importance of dental health to overall health and wellbeing, and you will hear about the significant impediments for people with autism and intellectual disability accessing appropriate dental health. This afternoon, the focus of the evidence will be on the experience of First Nations people. We accept that we are touching on this by way of an introduction and this will be a focus of ongoing
25 work of the Royal Commission in coming hearings.

Today you will hear evidence from Ms Narelle Reynolds about the challenges she has experienced accessing health care services for her adult sons. Dr Scott Avery will tell the Royal Commission about his research which has exposed significant gaps in health care services for First Nations people with disability.

30 During the course of this week, the Royal Commission will also hear evidence from experts and from advocates. Mr Jim Simpson will give evidence tomorrow. He is a senior advocate from the New South Wales Council for Intellectual Disability and he will speak about 16 very specific barriers to people with intellectual disability in relation to accessing health care and receiving the health care that they need. He will
35 tell the Royal Commission one of the barriers is that government initiatives do not take into account the specific needs of people with intellectual disability or do not sufficiently do so. And this includes health promotion campaigns and the area of preventative health.

You will also hear tomorrow from Dr Nick Lennox, a general practitioner of some
40 year standing. He will tell the Royal Commission about the work that he has been involved in, in developing what is called the Comprehensive Health Assessment

Program, called the CHAP tool. This was developed in 1997. But he will also address the barriers that he has witnessed in the course of general practice for people with intellectual disability.

5 Later this week the Royal Commission will hear evidence from New South Wales Health. In particular, the Royal Commission wishes to explore a range of issues with the witnesses giving evidence on behalf of New South Wales Health. This will include the model of specialised intellectual disability health teams. We touched on this briefly last week in the evidence of Dr Jacqueline Small. We wish to explore the model of tertiary intellectual disability and mental health hubs. We wish to explore
10 the differences between health care services in rural and regional areas in New South Wales and the cities.

We wish to explore the funding of particular services and the funding of research in New South Wales. We wish to look at the interaction of health, disability services and the NDIS. And we will also examine how New South Wales have responded to
15 some of the systemic issues and the suggestions for change that have arisen by witnesses during the course of the hearing. You will note that many of the issues raised by the witnesses are not new, and New South Wales Health has also examined them in the past, together with the New South Wales Ombudsman.

The Royal Commission will also hear evidence from the Commonwealth Department
20 of Health. In particular, the Royal Commission will seek to explore the following issues: first, recent initiatives, including the National Roadmap for improving the health of Australians with intellectual disability, and the development of the new primary healthcare 10 year plan. We may ask those appearing for the Commonwealth why 10 years is a necessary timeframe and why some of these issues
25 cannot be dealt with in a more timely fashion.

Secondly, we're interested in exploring with the Commonwealth the national training and education initiatives, including any commitment to funding of training and relevant timelines. We also wish to explore preventative health, the role of primary health networks, and funding of national research. We also wish to explore, as we
30 will with New South Wales, the interaction of health, disability services and the NDIS. And we will also examine with the Commonwealth how the Commonwealth has responded to systemic issues and the suggestions for change raised by witnesses during the course of the hearing.

Also on Thursday you will hear from the NDIS Quality and Safeguards
35 Commissioner. He will give evidence about the role of the Commission in protecting and managing healthcare issues for people with intellectual disability. We accept that his role is broader than this issue, but the focus of his evidence for this hearing will be on questions of health. We want to ask the Commissioner about the roles and responsibilities that he has and the Commission has with respect to people
40 with cognitive disability. We want to examine in particular reportable incidents of death and how the Commission has responded to these reports, and we want to know

what action the Commission proposes to take in response to what he has learnt from the data collected to date.

We want to explore with the Commissioner the role of collecting data and the importance of research, including touching upon some of the research projects that
5 have been initiated by the Commission. We want to look at the relationship between State and Territory health services and the NDIS Quality and Safeguards Commission. We want to ask the Commissioner what improvements can people with cognitive disability expect to see from the work of the Quality and Safeguards Commission, both in the immediate future and beyond.

10 Our hearing will conclude on Friday – I will put in round brackets “all being well” – with evidence from the mothers of Kylie Scott, who opened the hearing last week, and Tara Elliffe who closed the evidence last Friday. The mothers will talk about their roles as advocates on behalf of their daughters. But the hearing will close with the evidence of Mr Robert Strike AM. Mr Strike has been described as a trailblazer.
15 His own story is compelling but the work that he has done for advocacy for people with intellectual disability is really one of great example and great persistence. He will talk to you about the things that have emerged during the course of the hearing over the two weeks and he will tell you that he believes that it is essential for people with intellectual disability to have the confidence in their own ability in order to
20 better their lives. If the Commission pleases, those are my remarks in opening the second week of the hearing.

COMMISSIONER SACKVILLE: Thank you, Ms Eastman.

MS EASTMAN: So if I can move immediately to the evidence for today. And our first witness is Sabrina Monaghan. Ms Monaghan will – come up. She will give
25 some evidence. Initially she wanted her name to be the subject of a pseudonym and non-publication order, but she has given instructions this morning she wishes to have that order lifted in relation to her own identity but the order to remain in relation to her two children. So I just preface that and then we will deal with Ms Monaghan’s evidence.

30 COMMISSIONER SACKVILLE: Good morning, Ms Monaghan.

MS MONAGHAN: Good morning.

COMMISSIONER SACKVILLE: If you wouldn’t mind taking either the oath or affirmation, as you wish.

35 <SABRINA ALKISTI GISELLE MONAGHAN, AFFIRMED [10.22 am]

MR WILLIS: I seek leave to appear for Ms Monaghan. My name is Willis.

COMMISSIONER SACKVILLE: Thank you, Mr Willis. Thank you very much.
And if there is any doubt about it, you do have that leave.

MR WILLIS: Thank you, Commissioner.

COMMISSIONER SACKVILLE: Thank you.

5

<EXAMINATION BY MS EASTMAN

MS EASTMAN: Commissioners, just in light of the developments this morning,
there is an order that has been made and I will attend to a variation of that order in
10 relation to both the non-publication aspects of the statement and also the identity of
Ms Monaghan. But I proceed on the basis that the pseudonyms will remain in place
for Ms Monaghan's two children. So Commissioners, a copy of Ms Monaghan's
statement you will find in part A of the tender bundle behind tab 31, and there are
some accompanying documents at tab 32 and tab 33. And eventually this document
15 will be exhibit 4.15.

COMMISSIONER SACKVILLE: Yes. Thank you.

MS EASTMAN: All right. Ms Monaghan, you've got a copy of your statement
with you.

MS MONAGHAN: I have, yes.

20 MS EASTMAN: All right. So your name is Sabrina Monaghan.

MS MONAGHAN: Correct.

MS EASTMAN: And you're a registered nurse.

MS MONAGHAN: Correct.

MS EASTMAN: And you made a statement to the Royal Commission?

25 MS MONAGHAN: I have.

MS EASTMAN: It's dated 12 February this year.

MS MONAGHAN: Correct.

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

30 MS MONAGHAN: They are.

MS EASTMAN: All right. So you want to talk to the Royal Commission about the experience of the health system and navigating that system for your son, who is described in your statement as AAL.

MS MONAGHAN: Correct.

5 MS EASTMAN: All right. So if we just call him L or your son, would that be - - -

MS MONAGHAN: That's fine.

MS EASTMAN: - - - helpful, just to manage that?

MS MONAGHAN: Yes.

MS EASTMAN: And if you have a slip, that's fine. We will manage that as well.

10 MS MONAGHAN: Thank you. Thank you.

MS EASTMAN: What you want to do in giving your evidence this morning is to share the experience in health and dental care, and to highlight the significant shortfall in services for people with extreme behaviours and, importantly, you want to identify the cumulative traumatic experiences for people when they receive

15 substandard care.

MS MONAGHAN: Correct.

MS EASTMAN: You might have to keep your voice up just a little bit.

MS MONAGHAN: Sorry. Correct, yes.

MS EASTMAN: Okay. And you want to point out from your experience that there are long-term effects, and these effects can be substantial and life-long, and have a heavy impact on all areas of a person's life, both physical, emotional, mental and social; is that right?

20 MS MONAGHAN: Correct.

MS EASTMAN: And you say that for far too long people with cognitive disability have been left behind with no voice.

25 MS MONAGHAN: Yes.

MS EASTMAN: And families like yours have had to battle their way through the system, with endless letter writing to Ministers, telephone calls, knocking on doors, to find services; is that right?

30 MS MONAGHAN: Very much so.

MS EASTMAN: And you want to make sure that the Royal Commission hears your experience loud and clear.

MS MONAGHAN: Yes.

5 MS EASTMAN: And your expectation is that there will be many families who have had similar experiences to you.

MS MONAGHAN: I'm sure there's plenty out there, yes.

MS EASTMAN: Alright. So have I adequately set out the evidence that you want to cover?

MS MONAGHAN: Yes.

10 MS EASTMAN: So I want to ask you a little bit about yourself before we start - - -

MS MONAGHAN: Sure.

MS EASTMAN: - - - to look at your son AAL's experience in the health system. And the focus of your evidence today is going to be very much on access to dental care.

15 MS MONAGHAN: Correct.

MS EASTMAN: That's not to overlook those parts of your statement where you've addressed many other aspects of his access to care.

MS MONAGHAN: There are. Yes.

MS EASTMAN: So if we touch on those issues quite briefly.

20 MS MONAGHAN: Okay.

MS EASTMAN: That's not to say that they haven't been comprehensively covered in the statement.

MS MONAGHAN: Okay. That's fine.

MS EASTMAN: We can work with that?

25 MS MONAGHAN: Okay.

MS EASTMAN: Okay. Terrific. Let's start with you. So you're a registered nurse.

MS MONAGHAN: I am.

MS EASTMAN: And you've had 33 years' experience working in hospital settings in Melbourne and Ballarat; is that right?

MS MONAGHAN: Correct.

5 MS EASTMAN: And you've mostly worked in medical surgery in the operating theatres?

MS MONAGHAN: Yes.

MS EASTMAN: And you also worked in the areas of neurology, oncology, and administration.

MS MONAGHAN: Yes. And there's many others but we will leave it at that.

10 MS EASTMAN: So in some senses, you come to give your evidence with the perspective of what might be called sometimes both sides.

MS MONAGHAN: I have. I mean - - -

MS EASTMAN: What training did you have when you studied to become a nurse - - -

15 MS MONAGHAN: Well - - -

MS EASTMAN: - - - in the area of disability?

MS MONAGHAN: - - - I was school trained at a major metropolitan hospital. We did blocks of theory and then practice, a lot of practice involved with it. And in regards to learning about disabilities, that was really just touched on, really.

20 MS EASTMAN: When you say "touched on", what exactly do you mean?

MS MONAGHAN: I mean, it might have just been a couple of hours of, you know, different types of developmental disorders. In fact, I knew nothing about autism until I had a child myself who was on the spectrum and that was left for me to go and do further research, as a lot of people do, obviously, but as far as addressing that formally through training, and bearing in mind that I did my training a very long time ago, so I can't comment on what is being taught now to health professionals, but back then it was very, very minimal, yes.

25 MS EASTMAN: And you're still working as a registered nurse; is that right?

MS MONAGHAN: I am, yes.

30 MS EASTMAN: And so in terms of the changes that you've seen – again, on the side of practising as a nurse - - -

MS MONAGHAN: Yes.

MS EASTMAN: - - - have you noticed any changes over time?

MS MONAGHAN: In all honesty, I haven't really come across many people with disabilities in the area that I've worked in for the last 10 years. There has been a few
5 that I've cared for that have had a cognitive disability, and I think because I've got that background, I'm able to sort of know how to approach them and support them best I can in a different environment. And there are guidelines and, you know, inclusiveness and access, policies within hospitals that staff are, you know, expected to be doing a module on and learn to help support those people.

10 Of course, none of that was available many, many years ago, so there has been some change in the industry in, you know, addressing those important issues, that, you know, everyone deserves to – equal rights to access to health and, you know, not everyone needs to have a support worker come with them if they're going to an appointment or – and that's where I think health organisations need to be aware and
15 need to have access in variable formats available for people to be able to understand what their plan of care is, what, you know, post-procedure care it might be, what's going to happen to them whilst they're in hospital. So alleviating a lot of those anxieties and what have been barriers in the past, you know, simple wording format for people with cognitive disabilities, availability of, you know, visual aids or
20 hearing impairments when you're in hospital.

MS EASTMAN: Sorry to jump in there.

MS MONAGHAN: Yes.

MS EASTMAN: These are things I want to ask you about in a little bit more detail as we go along.

25 MS MONAGHAN: Okay, that's fine.

MS EASTMAN: Because you've had that first-hand experience - - -

MS MONAGHAN: Yes.

MS EASTMAN: - - - in looking at how your son has sought to access health services.

30 MS MONAGHAN: Yes.

MS EASTMAN: - - - where those things you've been talking about have been missing; is that right?

MS MONAGHAN: That's right, yes.

MS EASTMAN: Okay. Shall we start with AAL.

MS MONAGHAN: Yes.

MS EASTMAN: So you deal with this part of your evidence at paragraph 8 and following, Commissioners. So he was born in October 2000 and he was a healthy
5 baby boy.

MS MONAGHAN: Correct.

MS EASTMAN: And you say that at the time of his birth there were no complications and he developed like any other baby, meeting the milestones in terms of sitting and crawling; is that right?

10 MS MONAGHAN: Correct, yes.

MS EASTMAN: But when he was about 14 months you started to notice that his development started to regress.

MS MONAGHAN: That's right.

MS EASTMAN: And he lost eye contact and started to show obsessive compulsive
15 disorder traits.

MS MONAGHAN: Yes.

MS EASTMAN: And no interest in his toys.

MS MONAGHAN: That's correct, yes.

MS EASTMAN: So as a – as his mum you decided, "I need to do something about
20 that".

MS MONAGHAN: Of course, yes.

MS EASTMAN: All right. So was it the case that you received a diagnosis that there was moderate to severe autism?

MS MONAGHAN: That's correct.

25 MS EASTMAN: And about what age was AAL when you received that diagnosis?

MS MONAGHAN: He was three by that stage. We had a long wait. We were living in Ballarat at the time and they actually lost our name on the waiting list, and he was due to start early intervention. I wanted him to. So he eventually went on a waiting list in Melbourne and they accommodated us, that – they rushed it through
30 fairly quickly. So he was three, yes.

MS EASTMAN: And you say in the statement that he also has a moderate intellectual disability but he wasn't formally tested in relation to intellectual disability - - -

MS MONAGHAN: Yes, well - - -

5 MS EASTMAN: - - - until the – until he started school; is that right?

MS MONAGHAN: Correct. So when they start school, to get the funding for students with disability support, they usually do two sets of tests, one when they're entering into primary school and another one when they're going into secondary school. So that's, you know, multi-allied health assessment with speech
10 psychologists and OTs to assess their adaptive behaviour. So the tests that they deliver has a very strong component that that person cognitively is able to understand language at an age-appropriate age, which of course people with – a lot of people with autism, that is their deficit, that they're unable to perform a lot of the tasks that are asked of them and therefore the accuracy of that IQ test is questioned. So whilst
15 they would say he has got, you know, such and such or he's got intellectual disability, they would say, "In my opinion they anticipate by not being able to perform the tasks on the tests, that he lacks adaptive skills of so many deviation points below what their measuring value is", and therefore they assume that, you know, there is an intellectual disability there.

20 MS EASTMAN: So you've not had any firm diagnosis of the nature - - -

MS MONAGHAN: Well - - -

MS EASTMAN: - - - and extent of intellectual disability?

MS MONAGHAN: No, and this is what I'm actually in the process of doing, is I've sourced a neuropsychiatrist who will do like a non-verbal test that's more
25 appropriate, that might give a better reflection of, you know, his – if he does have an intellectual disability, because, I mean, just because he has got complex language disorder doesn't necessarily mean that his mind's not working. He just may not be able to express, like a lot of people can't, what – you know, what his thoughts are and what his needs are and things like that. So as a parent of a mostly non-verbal
30 autistic person, you have to be a detective. You have to watch every behaviour, every nuance they do looking for signs that, you know, they may be in pain or they're hungry or, you know, they're not happy about something. And it's important to note that challenging behaviours is a form of communication for people who have no other voice, no other way of expressing it. So obviously, they've learnt that way
35 to communicate their needs.

MS EASTMAN: So can I ask you some questions just about communication.

MS MONAGHAN: Yes.

MS EASTMAN: So in your statement you say at paragraph 12 that he is predominantly non-verbal.

MS MONAGHAN: He is.

MS EASTMAN: But he understands almost everything you say to him - - -

5 MS MONAGHAN: That's correct.

MS EASTMAN: - - - when you speak simply and you give him time to process.

MS MONAGHAN: That's right, yes.

MS EASTMAN: And you say on occasions he has surprised you with a few five word sentences.

10 MS MONAGHAN: He has, yes.

MS EASTMAN: So as a mother of a non-verbal child, you've developed an instinct for communicating with him and you use a range of different tools to communicate?

MS MONAGHAN: We do, yes.

MS EASTMAN: So you have your own key words of signing, and you use things

15 around the environment to communicate. So can I just ask you – can you explain that a little bit? So how does that work in terms of day-to-day - - -

MS MONAGHAN: Okay.

MS EASTMAN: - - - living and the management of some teenagers in a household?

MS MONAGHAN: Yes. So AAL knows how to use the traditional method of what

20 they call picture exchange communication system, PECS so - - -

MS EASTMAN: So how does AAL use that?

MS MONAGHAN: Well, he doesn't really. I mean, as soon as you bring it out he gets really dysregulated because he feels, I think, there's a demand – or anticipate a demand is going to be made on him and therefore his behaviour escalates. So we've

25 stopped using that. But throughout the schooling system and – they just kept persisting with that. They used schedulers and we've tried schedulers at home. So, you know, today is Tuesday, you know, you're going to have a shower. You're going here or whatever. So they're the sort of things that have been trialled with him in the past.

30 MS EASTMAN: So what works for him at home and at school?

MS MONAGHAN: So what works for him at the moment is actually just using environmental cues. So for instance if it's like I want him to come and have a shower, I will run the shower and I will make a sign for it, or I will get the towel – he will get up if we want him to – ask him if he wants to go out somewhere, we will

5 show him the keys and say drive. And – because he doesn't always want to leave the house. If he gets up and puts the shoes on you know it's a winner, you're going to go out for that day, but otherwise we give him plenty of choice and control in the environment, particularly given his strong history of trauma that's happened, yes.

MS EASTMAN: You say at paragraph 14, other than that, he's just like any other

10 teenager.

MS MONAGHAN: He is.

MS EASTMAN: His favourite things are to ride his bike.

MS MONAGHAN: Yes.

MS EASTMAN: He goes pretty fast.

15 MS MONAGHAN: He does.

MS EASTMAN: Not so good on the brakes; is that right?

MS MONAGHAN: No brakes. It's the Flintstone brakes.

MS EASTMAN: He loves swimming.

MS MONAGHAN: He does, yes.

20 MS EASTMAN: He loves cruising in the car with music.

MS MONAGHAN: Yes.

MS EASTMAN: And music is a very big part of his life; is that right?

MS MONAGHAN: It is, yes.

MS EASTMAN: So some days he can just spend days listening to music.

25 MS MONAGHAN: He will, yes. He will just sit there and listen to music from morning tonight, smile to himself, laugh, very, very, very – I think music is that expression of emotion. And he likes all sorts of music, when I say, not just – you know, it's not just children's music. He likes anything from Engelbert Humperdinck to 50s rock and roll, so – and he will just sit there and listen to it, so yes.

MS EASTMAN: You say also like most teenagers, he has a love of the iPad and watching YouTube.

MS MONAGHAN: He does, yes.

5 MS EASTMAN: And how have you found just using that technology in terms of his communication?

MS MONAGHAN: Yes.

MS EASTMAN: And just awareness of the broader world around him?

10 MS MONAGHAN: So, you know, there's various apps on the iPad. One of the more popular ones is Proloquo2Go, that a lot of people with autism seem to use. He's very good at picking out choices as far as food, what he would like to eat. But as far as conveying what he's feeling or whether he would like to do an activity, we've not extended on to that yet. There's that reluctance of when he goes to use it, "Am I pushing the right thing", or sometimes just that social engagement. It's very hard for them to step over that line and we found that in particular with using the picture card system because you actually have to get someone's joint attention and obviously that involves some social skills to be able to do that.

15 MS EASTMAN: So just in this environment – and you haven't addressed this in your statement and if you feel you can't answer this question - - -

MS MONAGHAN: Yes.

20 MS EASTMAN: - - - let me know. But some might say this Royal Commission should be hearing directly from people with disability - - -

MS MONAGHAN: That's right.

MS EASTMAN: - - - including people with autism. And I think you did give some thought as to whether or not AAL might come with you to give evidence or give evidence.

25 MS MONAGHAN: Yes.

MS EASTMAN: But you made a decision that this might be an environment that would be really tricky for him; is that right?

MS MONAGHAN: That's half the problem, yes.

30 MS EASTMAN: Do you want to talk a little bit about just your views about how someone in AAL's position, a young man, might be able to access a forum like this - - -

MS MONAGHAN: Okay.

MS EASTMAN: - - - and give evidence based on your experience.

MS MONAGHAN: Yes, sure. So obviously the sensory issues are going to play a big role in it, coming to a roomful of people, bright lights, lots of equipment,
5 computer screens. Very distracting. So I think probably if someone wanted to give evidence that way, if the questions were given to them well ahead, that they could prepare on their communication device, perhaps it could be through teleconference in their own environment where they're safe with a support person there. And, obviously, it would take them some time to answer questions. So allowing that time
10 if there were questions prepared in advance that they could, you know, answer by teleconference in an environment with a support person that they were familiar with. And that's not to say that all people with autism are like that, but if it was my son and if he was capable of giving evidence, that's the way I would have asked for him to be accommodated in that way.

15 MS EASTMAN: And I think you made a decision that for this occasion - - -

MS MONAGHAN: Yes.

MS EASTMAN: - - - that you were happy to speak for him, but it's very important that this is about AAL's experience. Is that right?

MS MONAGHAN: That's correct, yes.

20 MS EASTMAN: All right. So can we look at what good health care means for AAL.

MS MONAGHAN: Yes.

MS EASTMAN: And you've dealt with this starting at paragraph 17 of the statement.

25 MS MONAGHAN: Yes.

MS EASTMAN: So good health care is person-centred and individualised.

MS MONAGHAN: That's correct.

MS EASTMAN: And treating AAL first and foremost as a person and respecting him as an individual who understands and comprehends what is happening is
30 important.

MS MONAGHAN: That's correct, yes.

MS EASTMAN: And is that the number 1 starting point?

MS MONAGHAN: Of course it is. It has to be, because, you know, you can listen to the patient's advocate and you can listen to them if they're able to communicate their needs. You know, spending time, observing behaviours is often a clue of what that person is feeling, and, you know, if they're fidgeting around or, you know, starting to stim a lot, that's obviously a sign they're becoming dysregulated. So allowing plenty of time for a consultation to occur and just give that person some breathing space, because quite often transition is a huge issue for a lot of people with autism, whether it's, you know, from school to home, but it could also be, you know, quite micro sort of managed within the environment, someone getting up and leaving, an object being moved on a table because they like things where they seem to think they like things. So all those little nuances can tick them off, and little things are big things to them. So - - -

MS EASTMAN: So I think you say in 18 that good health care for AAL is well-planned and coordinated.

MS MONAGHAN: That's right.

MS EASTMAN: So that's part of minimising the trauma for him but building up familiarity with an environment.

MS MONAGHAN: That's right. And I think also the assumption should always be that a person with disability has the capacity to understand. As I said previously, just because you've got a severe language disorder, there's no way of measuring what cognition is actually going in – on in the mind and what they're understanding.

MS EASTMAN: So good health care also means that his health team are collaborative among themselves and with you.

MS MONAGHAN: Yes.

MS EASTMAN: Is that important?

MS MONAGHAN: Very important, yes.

MS EASTMAN: And so his team presently involves a neurologist.

MS MONAGHAN: Yes.

MS EASTMAN: A paediatrician.

MS MONAGHAN: Correct.

MS EASTMAN: And I might ask you about the transition from paediatrics to adult care in a moment.

MS MONAGHAN: Yes.

MS EASTMAN: A psychiatrist. And they talk to each other and take a planned approach to AAL's health care.

MS MONAGHAN: Yes.

MS EASTMAN: Is that right?

5 MS MONAGHAN: So the psychiatrist has been off and on. Because a psychiatrist's major role is usually prescribing, the neurologist has taken on that role for the sake of clarity and not having two people sort of clash, but we do have assistance with a mental health system at the moment, yes.

10 MS EASTMAN: And you say that AAL's neurologist is an example of good health care for AAL. He treats AAL as a person.

MS MONAGHAN: Yes.

MS EASTMAN: The neurologist is aware of the communication levels.

MS MONAGHAN: Yes.

MS EASTMAN: He knows autism in and out.

15 MS MONAGHAN: That's right.

MS EASTMAN: And he develops a plan that's flexible and adaptable to AAL's needs.

MS MONAGHAN: Correct.

20 MS EASTMAN: And in your statement you deal with the examples of good health care in terms of the neurologist's practice at paragraph 21 to 25. And I don't think I need you to go through all of that in detail.

MS MONAGHAN: Yes.

MS EASTMAN: But what are the standouts for you in terms of AAL's mother and being able to navigate the health care system?

25 MS MONAGHAN: Yes.

MS EASTMAN: And also, what has made a real difference for AAL in relation to his neurological care?

30 MS MONAGHAN: Well, to start off with, I guess the attitude. It's very obvious that when we do go for an appointment, he always calls AAL first. He lets him choose which chair he wants to sit on. He talks to AAL first before - - -

MS EASTMAN: So we just go AAL.

MS MONAGHAN: AAL. Sorry, I slipped.

MS EASTMAN: It's okay.

5 MS MONAGHAN: Yes, sorry. Yes, so it's those little things that just alert you to the fact that he is very conscious that he is a person, he is capable of understanding, and that he's a priority. And if he starts to fidget or tends to get a bit anxious, he will reassure him, "Not long to go. You're doing a really good job", you know, "I'm just going to do this and we're going to finish up." So, yes, I think because he has got that training, he's able to have the observation of how the – how the consultation is
10 progressing.

MS EASTMAN: And for you, receiving a letter after each consultation - - -

MS MONAGHAN: Yes, mostly we do.

MS EASTMAN: So knowing what decisions have been made and why that you feel involved in the health care decisions, but you also know what decisions have been
15 made; is that right?

MS MONAGHAN: That's right, yes. So – and he's very different the way he does things. And I've never experienced this at another consultation where he will actually write what he calls his ramblings, so his rationale of what he's thinking, the reason why he thinks certain medication might be an option, and he will write down
20 a plan. Like, he will say, "Try this for a week. And if it doesn't cut it back, we'll bump it up." And then he will give us an alternative plan because quite often there's a gap between going to see a specialist, you know, three to six months, so he will say, "If that doesn't work, you can try this", or, you know – and it's very clear, it's very concise. You've not gone away with just one thing to try and toolbox. You've
25 got time – and then having to wait another three to six months to go and see a specialist again, because quite often it's a long wait-list for those specialist – specialist services. So in that way it's very, very good, yes.

MS EASTMAN: All right. Let's move to the topic that is of particular interest of this part - - -

30 MS MONAGHAN: Yes.

MS EASTMAN: - - - of your evidence to the Royal Commission, which is AAL's experience with dental care.

MS MONAGHAN: Yes.

MS EASTMAN: And I think you say having seen examples of good health care
35 practice with the neurologist, that has allowed you to make some conclusions in your

own mind about the way in which AAL has been able to access dental care; is that right?

MS MONAGHAN: That's correct, yes.

5 MS EASTMAN: So part of looking at this from your experience of comparing examples of good practice against examples where you say things could have been done better.

MS MONAGHAN: That's right.

MS EASTMAN: Is that a fair way of putting what we're about to talk about?

MS MONAGHAN: Definitely, yes.

10 MS EASTMAN: All right. So in terms of dental care, the starting point is that from about the age of three until AAL was 12, that he attended a special needs school in Melbourne.

MS MONAGHAN: Correct.

15 MS EASTMAN: And to that school, arrangements were made for annual dental check-ups - - -

MS MONAGHAN: That's correct.

MS EASTMAN: - - - of the students. And so that involved a dentist visiting the school. And through the Department of Health and Human Services in Victoria, the dentist then provided the check-ups to the students at school; is that right?

20 MS MONAGHAN: That's correct.

MS EASTMAN: And those check-ups occurred annually, but you were not part of the check-up. So you didn't attend the check-ups; is that right?

MS MONAGHAN: No.

25 MS EASTMAN: And you weren't involved in giving any direction or providing any information prior to a check-up as to what might be the particular dental concerns that you had; is that right?

MS MONAGHAN: That's right, yes.

30 MS EASTMAN: And in terms of the school's organising the dental check-ups, you did receive some information and you've included in your statement some example of some reports that you received from time to time; is that right?

MS MONAGHAN: I did. And they mostly did write a report, but it usually just involved an oral check-up and there was no real intervention needed or - - -

MS EASTMAN: Had you assumed that in terms of the annual dental check-ups, that that was sufficient to deal with AAL's dental care during that period from age 3 up to age 12?

5 MS MONAGHAN: Yes. No, because at times – and as he got older, some of the reports would come back that he was very anxious and that a familiarisation visit would be needed. But as far as that occurring, I'm not aware because the checks were done one-yearly. So there was no notice sent home that he had a familiarisation visit within that time. And if you were to leave it a year to do one, then it would defeat the purpose, I think, because they would need a few goes short times together to actually learn that this is a safe space and it's okay, "I know this person", for a successful exam to be done, I think.

10 MS EASTMAN: And in terms of the nature of those check-ups, they didn't involve taking any X-rays or any sort of detailed examination; is that right?

15 MS MONAGHAN: No. There was just one time – and this is a problem, I guess, with some people with autism, that they're very oral-sensory, so they can chew hard objects, crack their teeth, you know, grind away at their teeth. So there was a sharp edge on one of my son's teeth that was – that they just smoothed off. So that's – that's the only intervention that I'm aware that he had in the 12 years that they were coming to see him.

20 MS EASTMAN: And I think you say in paragraph 33 of the statement that he didn't have any oral health issues of significance other than when he was seven he had a fall - - -

25 MS MONAGHAN: That's right.

MS EASTMAN: - - - at home. Is that right?

MS MONAGHAN: Yes.

MS EASTMAN: And so he didn't need to see a dentist outside the services provided through the school; is that right?

30 MS MONAGHAN: I didn't think so, yes.

MS EASTMAN: Then when he was 12, so this is about 2013, he attended a new special school and the particular health service, the dental van service, didn't provide check-ups at that school, so a different area; is that right?

MS MONAGHAN: That's right, yes.

MS EASTMAN: And so that then required you to make some new arrangements.

MS MONAGHAN: I did.

MS EASTMAN: So you organised to have a dental check-up for him through the local community health centre, which in turn had an allocated special needs dentist;
5 is that right?

MS MONAGHAN: That's right, yes.

MS EASTMAN: Called the Special Needs Clinic; is that right?

MS MONAGHAN: Correct.

MS EASTMAN: And so the first time you at attended the Special Needs Clinic to
10 see this dentist, what happened?

MS MONAGHAN: Well, it wasn't actually within the building itself. It was actually, like, a caravan that was parked alongside it in the laneway. So I thought that was a bit odd. And I thought, well, maybe that might have been part of the visiting service, that they maybe had, you know, decommissioned and they've just
15 put that there. But eventually, it did move into the building in the health centre itself. The - - -

MS EASTMAN: So the first time you went, you had to fill out some forms.

MS MONAGHAN: Yes, so every time - - -

MS EASTMAN: There was a process. So tell me about the first time you went.

MS MONAGHAN: Yes. So the first time we went, obviously, like anywhere when
20 you go to a clinic, there's, you know, information gathering. So it was just regular forms, you know, name, Medicare number, and health – health issues. But there was nothing to specifically address for special needs. So if you were a special needs clinic, you would think that you would be asking the patient what supports they
25 might need.

MS EASTMAN: So these are the matters that you've set out at paragraph 40 of the statement.

MS MONAGHAN: That's right.

MS EASTMAN: Have you got that?

30 MS EASTMAN: Yes. So - - -

MS EASTMAN: Do you want to speak a little bit about forms and what they included, based on the material that you've got in that paragraph?

MS MONAGHAN: Yes. So, I mean, in view for – I mean, I don't see how they could make reasonable adjustments to call themselves a Special Needs Clinic when
5 none of those items were addressed, as far as what aids someone might need for a successful exam, if there was a communication disorder, how was instructions going to be conveyed to them or what to expect or post a procedure, whether there was any behavioural issues and how, you know, the organisation might best address those needs beforehand. So I would have thought it would have been run a little bit
10 different to just the regular clinic, but it appeared just to be the regular clinic with the title Special Needs Clinic.

MS EASTMAN: All right. And the first appointment, you recalled that the dentist was nice to AAL but the consultation was quick; it only lasted about 10 minutes. Is that right?

15 MS MONAGHAN: That's right, yes.

MS EASTMAN: And the dentist on that occasion didn't ask AAL whether he had any special needs. So you had to tell the dentist that AAL had autism.

MS MONAGHAN: That's right, yes.

MS EASTMAN: And on this occasion, AAL didn't sit in the dental chair or open
20 his mouth. He didn't want to - - -

MS MONAGHAN: He never did, yes.

MS EASTMAN: All right.

MS MONAGHAN: Yes.

MS EASTMAN: And so you had to explain to the dentist that over the course of his
25 life, up to about age 12, that he had been involved in a number of incidents concerning access to health care services that had caused him some trauma.

MS MONAGHAN: That's right, yes.

MS EASTMAN: And so it was going to take a little bit of time for AAL to feel comfortable - - -

30 MS MONAGHAN: Correct.

MS EASTMAN: - - - about a dentist looking in his mouth - - -

MS MONAGHAN: Correct.

MS EASTMAN: - - - sitting in the right chair - - -

MS MONAGHAN: Yes.

MS EASTMAN: - - - and allowing any procedures to be undertaken.

MS MONAGHAN: That is correct.

5 MS EASTMAN: And that first consultation – that’s the first time that you had gone with AAL for dental care; is that right?

MS MONAGHAN: Yes, yes.

MS EASTMAN: And so that caused you to reflect on, “I wonder what might have happened” - - -

10 MS MONAGHAN: That is correct.

MS EASTMAN: - - - when you had assumed that the dental van service had been undertaking the check-ups and the like.

MS MONAGHAN: Correct, yes.

15 MS EASTMAN: All right. So in terms of what happened after the first visit, you persisted, is that right, and you thought, “We need to make sure that AAL has a check-up every six months or at least yearly”? Is that right?

MS MONAGHAN: We did, yes.

MS EASTMAN: Okay. And tell us of how things have changed over the period since the first check-up in 2013? How has that gone?

20 MS MONAGHAN: Well, as I said, the clinic was physically moved inside the building, but nothing had changed in that time as far as, you know, filling out the form. None of the special needs items that I mentioned before had been addressed. And, in fact, there were a few times – we had seen the same dentist initially for a number of years, with the same response, but on another occasion there was a
25 different dentist. The environment was loud. I had to actually ask them to turn the radio down. And I don’t know if they confused autism with being deaf, but they were talking extremely loud. And on two occasions I had to ask both the dentist and the dental assistant, “Can you please lower your voice? You don’t need to talk loud.” So there was no difference in the time from 2013 to now in regards to the
30 environment or accommodations that were made for someone with special needs.

MS EASTMAN: And outside six-monthly or yearly check-ups, you’ve been managing AAL’s dental hygiene at home by yourself; is that right?

MS MONAGHAN: I have, yes, and it is a challenge in itself. And, like, he doesn't mind his teeth being brushed, but it's just that if you fiddle too much with him and you want to get in there and give it a good clean, that's when he starts to get a bit dysregulated, and I'm really the only one who can do it properly because, you know, support workers don't want to be hit or don't have the capacity to do it. He doesn't have the, you know, oral motor skills to sort of, you know, move his lips around so you can get down in between the gum area to clean. I can do it.

5 So, obviously, I don't want my son walking around with calculus. He's a young man. He's very handsome. Nobody should have to put up with that. So I took it on myself to try a few different things, like using super floss doubled over, an electric dental – interdental brush that I can use. Tried the Waterpik, but that was no good.

10 MS EASTMAN: No good?
MS MONAGHAN: No.
MS EASTMAN: Okay.

15 MS MONAGHAN: Too much water.
MS EASTMAN: Have any of the dentists given you some resources or any assistance as to what you can do at home? Anyone talked to you about that?
MS MONAGHAN: No. I mean, "Very encouraging that you're doing – you're doing a good job, keep doing what you're doing." But as far as giving the actual practical advice, no. And, I mean, I come from a health background, so I have that – that knowledge anyway. But if it was a layperson, then, certainly they should have been supported a bit better with some more practical ideas, I think.

20 MS EASTMAN: So you had to find those techniques and systems out yourself - - -
MS MONAGHAN: Yes.

25 MS EASTMAN: - - - and work on a bit of trial and error. Is that right?
MS MONAGHAN: That's right. Yes.
MS EASTMAN: All right.
MS MONAGHAN: Yes.

30 MS EASTMAN: Now, I want to then turn to sometime in 2015. So AAL is about 14 or 15 years old, and you noticed that his bottom teeth were growing very close together.
MS MONAGHAN: Yes.

MS EASTMAN: And it became more difficult in the flossing and brushing department; is that right?

MS MONAGHAN: That's right. It was difficult.

MS EASTMAN: And you noticed that there was some bleeding from his gums.

5 MS MONAGHAN: Correct.

MS EASTMAN: And you also noted that the edge of his teeth looked rough and they were jagged.

MS MONAGHAN: Yes.

10 MS EASTMAN: So what you wanted was a referral to somebody outside the special needs clinic to just look at these issues for him in a little bit more detail and a little more closely; is that right?

MS MONAGHAN: That's correct.

MS EASTMAN: And what were the difficulties that you had in terms of accessing a referral to a broader service?

15 MS MONAGHAN: Well, there was no one. There was nothing. You know, I had asked, expressed my concern about – especially people with autism, dental pain has been identified as a major trigger for camouflaging challenging behaviours, so you don't know. My son does like to bite his hand a lot, and that's been identified also as a symptom of – of children trying to alleviate dental pain, by just putting pressure on
20 – on those teeth. So I had expressed to the dentist that I was concerned that he was getting decay between his teeth, that it needed to be cleaned off, and in view of so many unsuccessful visits to the clinic that he be referred to the dental hospital. And she said to me, "Oh, calculus is protective of dental disease." And I thought - - -

MS EASTMAN: How did you take that advice?

25 MS MONAGHAN: I was just like, "Why is she saying this?" I was just like – I was gobsmacked. Because you and I have the right to get, you know, our teeth cleaned. Even if you've got good oral care, you still need to go to the dentist six-monthly to a year to get your teeth cleaned. And by this stage – what was he, seven
30 to 15 – you know, it's a good seven years that he hasn't had any sort of intervention. I just looked at her and I just said that, "If that's the case, then why are we cleaning it off everybody else's teeth? Why – why is that the case?" And she sort of said, "Oh, I don't feel that cleaning my son's teeth warranted a general anaesthetic or sedation or further referral to other agency, other organisation."

MS EASTMAN: So what options did that leave you with?

MS MONAGHAN: Well, none. None, because, obviously, having someone with challenging behaviour, and would most likely need sedation, takes someone very, very experienced to administer sedation. With any sedation there's risk. And going to a private dentist, whilst, you know, I would have borne the cost, I didn't think it would be fruitful. I don't think they would be equipped. I would expect if – if the unit was calling themselves a special needs unit, that they would have other things prepared to address for people with behaviours of concern, and that they would act upon that in a reasonable time frame, time manner. You know, there was no consideration given to the fact that for – well, now recently it's been 12 – 2012 to '19. So that's seven years of unsuccessful visits.

MS EASTMAN: All right. So can I bring you up to December last year. So you deal with this at paragraph 61 and following of the statement. So in December last year you suspected that AAL had dental or jaw pain.

MS MONAGHAN: That's correct.

MS EASTMAN: And so you attended the special needs clinic for a consultation, because your concern was that maybe AAL's wisdom teeth might be causing him some difficulty.

MS MONAGHAN: Correct.

MS EASTMAN: And on this occasion, so this is December last year, you saw a new dentist and you say:

I felt finally listened to about my concerns and the dentist was very understanding.

And the dentist, you say, looked astonished when you recalled the information provided by the previous dentist about the calculus and tartar being protective to the teeth and gums.

MS MONAGHAN: She did.

MS EASTMAN: And the dentist also expressed concerns about whether there had been any X-rays taken over the intervening six-year period; is that right?

MS MONAGHAN: Correct.

MS EASTMAN: And you told the dentist that as far as you were aware, the only X-ray that had been taken was 12 years before when the fall had occurred when AAL was seven; is that right?

MS MONAGHAN: Correct.

MS EASTMAN: Do you recall that the dentist looked shocked and was speechless?

MS MONAGHAN: She was, yes. She was almost embarrassed, I'd say, yes.

MS EASTMAN: And you recalled that the dentist asked you, "How would you feel if AAL was referred to a dental hospital to have an examination under a general anaesthetic?" And you said, "This is what I've been waiting for for years."

5 MS MONAGHAN: Correct.

MS EASTMAN: So the dentist then said to you the following words – this is paragraph 65:

The system is a bit of a tough system where you have to have certain criteria, and it's not a preventative one.

10 And the dentist said to you:

We have to harvest the fact that AAL is in a pain and push for urgent review.

Can you just explain to me, what did you understand that to mean?

MS MONAGHAN: That they've got very strict criteria for triaging, obviously, people with special needs. So, I guess, you know, category 1 would be there would be quite obvious signs within the mouth that there was some sort of disease going on. Category 2 was, you know, suspected pain. So, you know, the thing was there was a sign out the front of there – that I walked in that wasn't there previously and it said something along the lines of, "Don't wait to be in pain. We're a community health centre. We have a dentist here." And I just thought – I just shook my head because, I mean, we've been trying for so long to – to get a check done. So she - - -

20 MS EASTMAN: So that dentist in December did a 40-minute check.

MS MONAGHAN: She did. And when I mentioned the sign to her, that was her response. She looked really, you know, embarrassed and she said, "Unfortunately, that's the system. It's not a preventative one. There's, you know, the – the lack of facilities for – for that." She also said that we had to harvest the fact that he had pain.

MS EASTMAN: What does that mean, "harvest the fact"?

MS MONAGHAN: I think that – to push it along that he would get seen quicker, to perhaps make the pain out that it was worse than what it actually was. And so – yes. So play along – play the system to get along so that you can get seen – I mean not – obviously, because he was in discomfort, but also the fact that he actually hadn't had a proper oral exam in 12 years.

30 MS EASTMAN: So at the time of writing this statement – so that's 13 February this year.

MS MONAGHAN: Yes.

MS EASTMAN: AAL has a referral to a dental hospital. That's been accepted, and an initial appointment has been arranged. What's the current state of affairs 11 days after you made this statement?

5 MS MONAGHAN: I received a letter saying that he's on the waiting list for an appointment. And the dentist did prepare me. She did say to me that, "Look, you could be waiting a year for the appointment. They will try to do an oral exam. And if that's unsuccessful, then you could be waiting another year for an actual booking in for – to have, you know, an oral exam under – under sedation. So perhaps you're
10 looking at an upwards of another two years."

MS EASTMAN: Before he has - - -

MS MONAGHAN: Yes, yes.

MS EASTMAN: - - - the check that the dentist - - -

MS MONAGHAN: Yes.

15 MS EASTMAN: - - - in December last year - - - - -

MS MONAGHAN: That's right.

MS EASTMAN: - - - suggested needed to be done.

MS MONAGHAN: Yes. She said it would be a long process.

MS EASTMAN: And this is following harvesting the information - - -

20 MS MONAGHAN: That's correct, yes.

MS EASTMAN: - - - to try to get some priority for him.

MS MONAGHAN: Correct.

MS EASTMAN: Is that right?

MS MONAGHAN: And the other advice she gave me is that if – "Obviously, if you
25 thought that he was in pain or he had obvious symptoms within his mouth, then to take him to the doctor – GP to get oral antibiotics and pain relief." So not take him to the dental hospital, but take him to the GP to have those things done, not off to, you know, wait in the waiting area or – because it is very difficult too, I think, long waiting times when you've got – the A and E there, their accidents that come and
30 things like that, so - - -

MS EASTMAN: All right. The Royal Commission will hear some evidence about the impact of dental health on a person's overall health and how important that is for people with cognitive disability. And in your statement you've referred to a number of areas where you've experienced significant challenges in terms of accessing

5 general health systems.
MS MONAGHAN: Correct.
MS EASTMAN: So I just want to very briefly touch - - -
MS MONAGHAN: Okay.
MS EASTMAN: - - - on each of these issues. The first which you identify at

10 paragraph 70 and following is issues around pathology, and that involves issues in terms of getting blood tests and other testing. And is it fair to say that this is an example where a lack of familiarisation both with the environment and the nature of the procedures to be performed on AAL have caused him some distress, and you've observed impacting on the overall trauma to him?

15 MS MONAGHAN: Correct, yes.
MS EASTMAN: And then prescribing practices and uses of restraint. You've dealt with this at paragraph 78 and following. And you've said much to your reluctance, AAL started antipsychotic medication to deal with his aggression in 2013. And this arose in relation to an incident that had happened at school.

20 MS MONAGHAN: Correct.
MS EASTMAN: And is it fair to say – and you give a lot of evidence about this in your statement.
MS MONAGHAN: Yes.
MS EASTMAN: But a real concern for you is the fact that AAL has taken

25 antipsychotic medication, that there have been restraints in relation to managing his behaviour, and again you say that this is part of compounding the trauma for AAL with his experience both at school and also in the health system.
MS MONAGHAN: Correct, yes.
MS EASTMAN: And one of the concerns that you want to raise in your statement

30 is about how an education environment works with the health system to ensure that kids like AAL with autism are properly understood in the intersection of those two areas.
MS MONAGHAN: Correct.

MS EASTMAN: Health and education. Is that a fair summary of those paragraphs?

MS MONAGHAN: It's a very good summary of it, yes.

MS EASTMAN: Then you talk at paragraph 85 about the issues of obtaining an MRI. And there had been a very traumatic incident for the family when AAL was
5 three.

MS MONAGHAN: Correct.

MS EASTMAN: And that involved a matter where he barely survived; is that right?

MS MONAGHAN: Yes.

10 MS EASTMAN: Okay. And then that incident, in terms of the incident at the pool, has really caused you some concern about the impact on AAL, and you wanted to have an MRI so that you could have a sense of comfort as to whether there had been also any brain injury to him; is that right?

MS MONAGHAN: Correct, yes.

15 MS EASTMAN: And this has been an ongoing issue for you, and that the attempts to obtain an MRI up till April 2018 have been very challenging.

MS MONAGHAN: They have.

MS EASTMAN: And so what's the outcome in terms of obtaining the MRI and the results of that MRI?

20 MS MONAGHAN: Well, when the accident initially happened we had asked for one, and we were told, "Oh, there's no significant loss of skills so, therefore, he doesn't need one." I would have thought if someone was suspected of a hypoxic brain injury of an unknown amount of time, that that would just have been part of the course of your care, but we were denied that. As time went on, obviously, we didn't
25 know what impact that was having on his behaviour as well, and how we'd approach that.

But the MRI came around because of two things. We suspected that he was having seizures again, and we were told to seek neurologist advice during a period through puberty that that could have been happening. He was also having side-effects to
30 medications, and part of that side-effect also I had raised my concern with regards to the antipsychotic drug that he was developing swollen nipples. So it can cause high prolactin levels and – and especially in a prepubescent boy, has impact. There have been cases overseas where there is class actions against a certain company for boys developing breasts. And the other thing that can happen is it can affect the pituitary
35 gland.

So since we were having the MRI finally, I asked them to look at his pituitary gland as well. And so that showed that there were some mild changes there for him. And given those changes are there, any sort of antipsychotic, in my view, is just – not going to be able to give it to him because I’m not willing to take that risk with him,

5 but, unfortunately, first-line treatment for most children with autism and challenging behaviours are antipsychotic. But you’re supposed to have a baseline ECG, bloods, a whole barrage of tests before you start, which were not able to be achieved in AAL, not so much because the doctors didn’t order it but there was no system in place to manage that sort of thing.

10 MS EASTMAN: I think this then touches on – if I jump over – I’m not skipping over this.
MS MONAGHAN: Yes.
MS EASTMAN: This is all before the Royal Commission, but the access to health assessments.

15 MS MONAGHAN: Yes.
MS EASTMAN: - - - which is paragraph 118. So you think that what would have been of great assistance is a coordinated, collaborative approach, and to have a thorough health assessment is a very important matter.
MS MONAGHAN: Yes.

20 MS EASTMAN: And your hope was that with the NDIS that you would have the funds for him to be able to undergo a comprehensive functional behaviour assessment, together with understanding his overall health in the context of his condition and behaviour; is that right?
MS MONAGHAN: Yes.

25 MS EASTMAN: I summarised that very quickly, but - - -
MS MONAGHAN: Yes.
MS EASTMAN: - - - let me know if I haven’t done a fair summary of that.
MS MONAGHAN: Yes. So as a result of the – it was quite a comprehensive behaviour assessment. It came out that physical causes for distress should be ruled

30 out, and even regards to another mental health service that I rang, they said the same thing. But finding someone that can do that has been very, very difficult. So there is a couple of agencies that do it, but it’s more intent on educating your own GP or your own clinicians to be able to manage that themselves. They do take in a couple of people a year. So we got a referral from the GP and faxed it off there, and then we

35 got a response back saying, “No, that’s not enough. You actually have to fill in, like,

an assessment intake”, which is very, very involved. It’s, like, 25 pages, plus you’ve got to provide all the past histories, any tests and things like that.

So it’s almost like you’ve been asked to do, like, a clinician’s-type referral, but you – if you’re just a mother or, you know, a layperson, that would be very onerous on

5 someone who if they weren’t well organised, for them just to get something that should be available to everyone. And, you know, it’s not like my son is the only person that this is happening to. I’m sure there are hundreds of families that are in dying need of just basic health care. Like, you know, just to reassure the family that, you know, that – you know, that there is – you know, they’re not having an earache
10 or, you know – it’s, you know, little things that could be overlooked and that you and I take for granted. It should be available to everyone equally, and it’s not happening.

MS EASTMAN: Commissioners, we’ve got about another 10 minutes or so to just cover with Ms Monaghan’s evidence, and I’m mindful that we’ve been going for a period of time. So I’m happy to continue if Ms Monaghan is happy to continue.

15 MS MONAGHAN: That’s fine.

COMMISSIONER SACKVILLE: Is that okay with you?

MS MONAGHAN: That’s fine.

MS EASTMAN: And just for those following the webcast and in the room, if we plan to adjourn around 11.30, would that be convenient?

20 COMMISSIONER SACKVILLE: It would be convenient.

MS EASTMAN: Thank you, Commissioner. Ms Monaghan, can I turn now to the impact of this experience with the health system for you over the past 19 or so years. You’ve set out in your statement the impact on AAL, and I think we’ve covered some of that as we’ve gone through - - -

25 MS MONAGHAN: Yes.

MS EASTMAN: - - - your evidence. But I want to ask you about the impact on you personally and your family. At paragraph 138 you say very candidly that you are:

Consumed with anger at the injustice and everything that has happened to AAL, and that he has not had timely access to dental and health care needs.

30 *Organisations can write glossy statements and protocols, guidelines, and say they are meeting all legislative framework for equal access, but in practice this is not happening, especially for people with complex behaviour issues.*

And you set out in the statement that there’s no normality for you, AAL or your family, and you say:

We've never been a normal family.

I think for those listening to your evidence, that's heartbreaking.

MS MONAGHAN: Well, what's normal for me is what I know. So – but what I don't expect is that, you know, my son is treated any less, especially when it comes to important things like health care, yes.

MS EASTMAN: But do you feel that you've had to step in on all aspects of health care?

MS MONAGHAN: Yes. You have to be very proactive.

MS EASTMAN: Well, you say – you tell the Royal Commission that you feel like you need to live forever.

MS MONAGHAN: I do.

MS MONAGHAN: That's you're the carpenter, the plumber, the lawyer, the nurse, the full-time - - -

MS MONAGHAN: Yes.

MS EASTMAN: - - - advocate, but you just want to be a mum to your kids.

MS MONAGHAN: Yes. I know we're just talking about health here but in every sector we've come across, whether it's education, community service, there has been episodes and serious episodes of neglect that have prompted me to actually have to write letters to Ministers, to Disability Service Commission. We've got a few things happening at the moment in regards to an episode earlier last year where he - - -

MS EASTMAN: And that's unrelated to health.

MS MONAGHAN: It's – well, yes. So it's a culminative response from, you know, every interception that we've had with every service. So, you know, he was left on the school bus for half a day in 2007. You know, the school responded with – rather than me asking for – I knew things weren't right with him. He regressed. He became incontinent. He was never – in fact, he was never aggressive before this episode. The school at the time used seclusion and restraint and that's how they dealt with his behaviour.

MS EASTMAN: So those sorts of issues that occur for him at school, you see directly at home - - -

MS MONAGHAN: Yes.

MS EASTMAN: - - - as an impact in terms of his health and wellbeing; is that right?

MS MONAGHAN: Of course.

MS EASTMAN: All right.

5 MS MONAGHAN: Because obviously there's a distrust of outsiders then, you know, and, you know, people with – a lot of people with autism are very, very sensitive and have very, very good memories, and so if something goes a certain way when you visit a certain environment they have the expectation that that same thing is going to happen in the same way, and so that's the cause of a lot of anxiety.

10 MS EASTMAN: And you're a little bit cynical with being told, "Well, this has never happened before. We've never had an incident like that". And you've been told that a number of times - - -

MS MONAGHAN: I have, yes.

15 MS EASTMAN: - - - haven't you and you've questioned whether that might be the case.

MS MONAGHAN: That's right. I mean, we've seen in recent years that, you know, so many children have been left on the bus. My son was left on the bus. They say it's never happened before, but it has. Unfortunately, the tragic incident at the start of last week with the young boy, and I always said it would take the death of someone before it would change. You know, he has been left in the swimming pool unattended, despite his near drowning accident when he was three, and that was with a community – with an agency. There was no accountability of responsibility after that. The person lied, just decided that she wasn't going to come in for a meeting to find out what happened and, you know, obviously there was letters written to
20 Disability Service Commissioner and Child Safety Officer working with children, the police. No one was able to do anything. So I hope with, you know, the NDIS Quality Commission that things like that will be addressed. But there's all these things. There are a number of things that have happened to him, yes.

25 MS EASTMAN: Happened to you. All right. Can I bring you back particularly to health.

30 MS MONAGHAN: Yes.

MS EASTMAN: And you make some suggestions for change in the area of health.

MS MONAGHAN: I do.

35 MS EASTMAN: And that starts at paragraph 146. So the first is that you identify education and training. This is page 28.

MS MONAGHAN: Yes.

MS EASTMAN: And you think that medical, dental and nursing staff are probably given very little education or training regarding managing people with disability, let alone specific training in autism.

5 MS MONAGHAN: Correct.

MS EASTMAN: And so one of your suggestions is that there needs to be some training, but not just the technical know-how.

MS MONAGHAN: No.

10 MS EASTMAN: But also improvement in the attitude and the mindset of clinicians; is that right?

MS MONAGHAN: That's right, yes. I think some, you know, hands-on practical experience, whether working in, you know, a residential care setting or a special needs school, I think that would be really warranted. And I think the social model of disability care needs to be imprinted on medical training as well, so as they're not
15 looking at it from a medical model. You know, just to assume that, you know, they can be cured or, you know, that sort of thinking.

MS EASTMAN: Okay. So you talk also about some suggestions around hospital environments.

MS MONAGHAN: Yes.

20 MS EASTMAN: But you make some fairly specific and – suggestions and accommodations that could be made in the context of dental check-ups.

MS MONAGHAN: Yes.

MS EASTMAN: Could I ask you to have a look at paragraph 162. That's on page 31 of your statement and starting at (a), and then over the page through to
25 subparagraph (j), you set out a range of adjustments. Can I just touch on a few of these - - -

MS MONAGHAN: Sure.

MS EASTMAN: - - - and ask you about it.

MS MONAGHAN: Okay.

30 MS EASTMAN: So is it fair to say that one of the primary issues is the physical environments, both of the waiting room and the way in which the dental surgery is fitted out.

MS MONAGHAN: Correct, yes.
MS EASTMAN: And so small things like having things that might be familiar for a child, to use social stories.
MS MONAGHAN: Yes.
5 MS EASTMAN: To use dimmed lighting, to just make the environment one that feels safe and comfortable. That's important?
MS MONAGHAN: Very much so.
MS EASTMAN: And related to that is reducing the background noise.
MS MONAGHAN: Yes.
10 MS EASTMAN: And you suggest the use of appropriate music that might help with relaxation.
MS MONAGHAN: Yes.
MS EASTMAN: And for AAL you've said earlier - - -
MS MONAGHAN: Yes.
15 MS EASTMAN: - - - music is so important for him. How does the use of music - - -
MS MONAGHAN: Yes.
MS EASTMAN: - - - then help him translate into an environment? Would that make a difference for him?
20 MS MONAGHAN: Yes, I think so, yes.
MS EASTMAN: So then you think just having a child-friendly space would be very helpful for children with autism; is that right?
MS MONAGHAN: Correct, yes.
MS EASTMAN: Okay. Then you also suggest, as a way forward, is to have novel and flexible approaches to managing children and adults with autism. And so you
25 want to suggest that sometimes these novel and flexible approaches are not very costly or expensive.
MS MONAGHAN: No.

MS EASTMAN: But it's just simple things. For example, taking medication or drinks and using a familiar cup.

MS MONAGHAN: That's correct.

MS EASTMAN: So something as simple as - - -

5 MS MONAGHAN: So – yes.

MS EASTMAN: - - - just having standard things that could be used over and over again to build in that familiarity and comfort; is that right?

MS MONAGHAN: That's great, yes. You know, a lot of this is documented in some policies that I've seen as well, but they're not acted upon or considered. So it's
10 those very little things that – for instance, my son, he won't take anything from anybody else. This was forewarned. We knew having the MRI that he was going to be sedated. I tried to be proactive. I rang and spoke to the preadmission nurse, sent over blood tests in regards to he's got slow metabolism for certain medication, which would be very important for the anaesthetist to know. She said, "I will get the
15 anaesthetist to ring you". And I wanted to know whether I could give him a premedication before coming in because he was ordered something. But there was no call.

On the day we got there, we had a conversation with the anaesthetist. They tried to give him oral Midazolam. I said, "He's not going to take it". I said, "If I had known,
20 you know, I could have given it in the car park or we could have tried something different at home". So I am aware of some organisations having that flexibility where they're quite aware of the sensory needs. They've actually coordinated a response where sedation is given in the car park in a familiar environment in the car and they've had staff on standby for safety reasons, in case something happens, and
25 then they've taken the person up to where they need to go in a more relaxed state.

MS EASTMAN: Just having some appropriate approaches rather than the one-size-fits-all; is that right?

MS MONAGHAN: Correct, yes.

MS EASTMAN: Okay. You also say in your statement that the current standards
30 for access to quality health care for some vulnerable and unrepresented groups set out in the Australian Commission on safety and quality of health care is a matter of concern, and you say there needs to be formal standards written into those standards for people with disability; is that right?

MS MONAGHAN: That's right, yes.

35 MS EASTMAN: Okay. And you also talk about the importance of having access to health care, and that's the right to know one's own health information.

MS MONAGHAN: That's right.

MS EASTMAN: And you deal with this at paragraph 177. Now, one of the issues that has arisen for you since AAL has become a teenager and now has moved into adulthood is just the – and I want to finish on this one – just the challenges for you
5 being able to support him and how rules around access to information and privacy - - -

MS MONAGHAN: Yes.

MS EASTMAN: - - - have impeded you having access to AAL's health information to in turn be able to help AAL access other health services. So I think you say you
10 just go round and round in circles on this.

MS MONAGHAN: You do. You do.

MS EASTMAN: Just finally, what did you want to tell the Royal Commission about the way in which access to health data could be improved?

MS MONAGHAN: I'm - - -

MS EASTMAN: So not what's happened, what should be improved.

MS MONAGHAN: Okay. I think if you are appointed someone's legal guardian and administrator, that you should actually be allowed to access their MyGov accounts. The current rule is no one's allowed to access anybody else's MyGov account, even though it happens. So what's supposed to happen is, for instance, with
20 Centrelink, I have my MyGov account. His Centrelink account is attached to mine and his NDIS account is attached to mine. But you cannot do that with Medicare. And even if you are a Medicare nominee, you cannot do it.

So therefore, if you can't attach their Medicare account to your MyGov account and you can't access their Medicare account through their MyGov account, there's no
25 access. So you physically either have to go into a Medicare office, which are few and numbered, or ring up and be on hold for a long time, and then wait for the forms if you want a repeat statement, for instance, or something, you would need for them to be mailed out to them. Or if it was an item that was not able to be claimed at the time of service, how are you going to do that if you don't have online access to
30 Medicare? So then you don't – you have to fill out a paper form, it gets sent off to Medicare, for some people who are living on a disability service pension, it means there could be a shortfall before they get a refund, and, you know, 20 or \$30 could be a lot to that person till they get one.

MS EASTMAN: So you want to see - - -

MS MONAGHAN: Yes.

MS EASTMAN: You want to see some streamlining of being able - - -

MS MONAGHAN: Well, access - - -

MS EASTMAN: - - - to bring all of these government systems together - - -

MS MONAGHAN: Correct.

5 MS EASTMAN: - - - in a way that is accessible and appropriate for people with cognitive disabilities; is that right?

MS MONAGHAN: And convenient for them. I mean, everyone else has the convenience of 8 o'clock at night, if you want to do some claiming, to do that. At the current rate, no, you can't because you might actually have to go into a Medicare office to be able to do that, if you don't have the cognitive ability to navigate through the website and you're not allowed to have someone help you. I don't see any fairness in that or, you know, accessibility. So - I mean, that's just a little thing. But, you know, health information is a huge thing as well. There's the My Health Record. Initially we were told even if you were a legal guardian you weren't allowed to access it but I think they've changed the rules recently when I last spoke to them.

MS EASTMAN: All right.

MS MONAGHAN: But - - -

MS EASTMAN: Ms Monaghan, thank you very much for your evidence and sharing your experiences with the health system and helping us have a sense of how AAL has journeyed through that system.

MS MONAGHAN: Thank you.

MS EASTMAN: Thank you very much for your evidence.

25 COMMISSIONER SACKVILLE: Don't go just yet. Do you mind if I just ask you a question?

MS MONAGHAN: Sure.

COMMISSIONER SACKVILLE: Your description of your experiences of the health system, I take it you've been referring to the public health system.

MS MONAGHAN: Correct.

30 COMMISSIONER SACKVILLE: Has the private health system ever been an option for you?

MS MONAGHAN: Not really, no. We don't have private health insurance, so yes. I mean, I pay privately to see the consultants. So in that way it's quicker, yes, than if I was to wait, for instance, for a public health outpatient, and that was part of the delay in getting the MRI. It was a referral made in late 2016, and we weren't seen by the neurologist in May 2017, and the actual MRI didn't occur until April 2018.

COMMISSIONER SACKVILLE: Thank you.

MS MONAGHAN: Yes.

COMMISSIONER SACKVILLE: Can I add to what Ms Eastman has said, our thanks for you coming today.

10 MS MONAGHAN: That's okay.

COMMISSIONER SACKVILLE: Can I make a comment on your paragraph 138. You refer to your sense of injustice. More decades than I care to think about, when I was a law student, I read a book called The Sense of Injustice by a man called Edmond Cahn, who was a tax lawyer who then became a professor of jurisprudence or legal philosophy, which shows to go you can move from the dark side. And in that book he explained the power of a sense of injustice, that it can lead to all sorts of changes when the sense of injustice is shared with other people, and you have shared your sense of injustice. And it can be a very powerful catalyst for change.

15 MS MONAGHAN: Thank you.

20 COMMISSIONER SACKVILLE: So thank you very much for coming and sharing your experience with us.

MS MONAGHAN: Thank you.

MS EASTMAN: Commissioners, the statement will become exhibit 4.15. We just need to make some amendments to the statement. It is presently redacted in relation to Ms Monaghan's name. So we will attend to that and then I might return to its formal tender and marking later in the day.

25 COMMISSIONER SACKVILLE: All right. We will take the morning tea adjournment for about 15 minutes. Thank you again, Ms Monaghan.

MS MONAGHAN: Thank you so much for listening.

30

<THE WITNESS WITHDREW [11.34 am]

ADJOURNED [11.35 am]

RESUMED

[11.53 am]

MS FRASER: Commissioners, we will now hear from Dr Richard Zylan and Mr Nathan Despott, who are here as our dental experts. They will speak to a joint
5 submission in relation to oral health.

COMMISSIONER SACKVILLE: Thank you.

<RICHARD ZYLAN, AFFIRMED

[11.53 am]

10 **<NATHAN DESPOTT, AFFIRMED**

[11.53 am]

COMMISSIONER SACKVILLE: Yes, please.

MS FRASER: Can you, Dr Zylan, state your full name for the Commission.

DR ZYLAN: Richard Zylan.

15 MS FRASER: Are, Richard, are you happy for me to refer to you as Richard?

DR ZYLAN: Yes.

DR ZYLAN: And, Mr Despott, your full name for the Commission?

MR DESPOTT: Nathan Despott.

DR ZYLAN: And you're happy for me to refer to you as Nathan?

20 MR DESPOTT: Yes.

MS FRASER: Turning to you first, Richard, you have a Bachelor of Dental Science, you are a fellow in orthodontics of the International College of Continuing Dental Education. That is - - -

DR ZYLAN: Yes.

25 MS FRASER: - - - a summary of your education.

DR ZYLAN: Yes.

DR ZYLAN: You've been a principal of a private dental practice since 1994.

DR ZYLAN: Yes.

MS FRASER: And you are a member of the International Association of the Scientific Study of Intellectual Disability.

DR ZYLAN: Yes.

5 MS FRASER: You are a Victorian State committee member of the Australian Society for Intellectual Disability.

DR ZYLAN: Yes.

MS FRASER: And you are a committee member of the Australian Society for Special Care in Dentistry.

DR ZYLAN: Yes.

10 MS FRASER: Nathan, you are the manager of policy and projects at Inclusion Melbourne.

MR DESPOTT: Yes.

MS FRASER: And you've held that role since 2010.

MR DESPOTT: Yes.

15 MS FRASER: What does that role entail?

MR DESPOTT: Yes, so inclusion design lab, particularly my role as the manager, is the – that's the arm of research and development at Inclusion Melbourne – regularly gives advice to government inquiries, writes submissions, runs training and brings together interdisciplinary professionals to understand gaps between the

20 disability sector and other sectors. We also do project work in areas as diverse as LGBTIQ+ inclusion - - -

MS FRASER: Nathan, can I just - - -

MR DESPOTT: - - - voting and dentistry.

MS FRASER: - - - ask you to just slow down just as much as possible.

25 MR DESPOTT: No worries. Thank you.

MS FRASER: Thank you.

COMMISSIONER SACKVILLE: Yes, we have to both use Auslan for translation purposes and we have to keep a running transcript. So just a little slower.

MR DESPOTT: No worries.

COMMISSIONER SACKVILLE: In fact, quite a deal slower, really.

MR DESPOTT: No worries. And we – Inclusion Melbourne also performs project work in areas as diverse as LGBTIQ inclusion, voting, oral health and access to the justice system for people with intellectual disability.

5 MS FRASER: So you're very much involved in the development of government policy and sector reform.

MR DESPOTT: Yes.

MS FRASER: You also have extensive personal experience as a support worker, including in group home settings.

10 MR DESPOTT: Yes. I started my career 15 years ago in direct support work in residential settings and in child respite settings, moving on to day supports at Inclusion Melbourne, and then in equality management at Inclusion Melbourne.

MS FRASER: And you're both here today speaking to a joint submission to the Royal Commission dated 13 February 2020. That is a joint submission from the
15 Disability and Oral Health collaboration, Your Dental Health project, the Australasian Academy of Paediatric Dentistry, and the Australian Society of Special Care in Dentistry. Commissioners, for the record, that submission appears at volume B, tab 9, and will be marked exhibit 14.16. The curriculum vitae of our two
20 witnesses will be marked exhibit 14.16.1 and 14.16.2, and I wish to formally tender those.

EXHIBIT #14-16 JOINT SUBMISSIONS OF THE DISABILITY AND ORAL HEALTH COLLABORATION, YOUR DENTAL HEALTH AND AUSTRALASIAN ACADEMY OF PAEDIATRIC DENTISTRY DATED 13/02/2020 (SUB.100.00532.0001)

25 **EXHIBIT #14-16.1 CURRICULUM VITAE OF DR RICHARD ZYLAN (EXP.0021.0001.0001)**

EXHIBIT #14-16.2 CURRICULUM VITAE OF NATHAN DESPOTT (EXP.0021.0001.0001)

COMMISSIONER SACKVILLE: Yes. Thank you, Ms Fraser.

30 MS FRASER: Richard, can you tell the Commission about the work of the Disability and Oral Health collaboration?

DR ZYLAN: Yes. The Disability and Oral Health collaboration was established in 2018 with the aim of undertaking research and develop strategies that will lead to the improvement of the oral health of people with disabilities across all ages. The

membership of the group is composed of Deakin Uni, University of Melbourne, La Trobe University, the University of Queensland.

MS FRASER: Can I just ask you to just slow down just a little bit.

DR ZYLAN: Sorry, my colleague's and my passion sort of jump through.

5 COMMISSIONER SACKVILLE: Is this a general characteristic of the dental profession?

DR ZYLAN: University of Western Australia, Inclusion Melbourne, the Australian Society of Special Care in Dentistry, North Richmond Community Health, Australia and New Zealand Academy of Special Needs Dentistry, and representatives of
10 Dental Health Services Victoria and Autism Queensland. It includes a range of public health professionals, disability service providers, oral health service providers, academics, special needs dentistry specialists, paediatric dentistry specialists, oral health therapists, speech pathologists and health economists from across Australia. Priorities for action for the group include enhancing health literacy for dental health
15 professionals, non-dental health professionals, support workers and carers, people with disabilities; enhancing educational programs in the curriculum of health professional courses; and developing continual professional development courses for health professionals. In a recent systemic review I would like the Commissioners to note that no research was found that explored non-dental health professionals'
20 perspectives of oral health-related education training interventions for people with intellectual disabilities. Professor Calache, who's the Chair of the Committee, prepared a statement:

25 *The integration of oral health into general health is key to improving the oral health of people with disabilities through implementation by non-dental health professionals who care for people with disabilities, of procedures that will prevent oral disease from a very early age in people with disabilities.*

MS FRASER: Thank you. And we will come back to revisit some of those themes as we move throughout the evidence. Richard, could you start by just telling the Commission about the work of the Dental Health Project team.

30 DR ZYLAN: Sorry, was that Nathan?

MS FRASER: Sorry, Nathan.

DR ZYLAN: Sorry, just - - -

MS FRASER: My apologies.

MR DESPOTT: That's okay.

MS FRASER: There's two witnesses at once.

MR DESPOTT: The Your Dental Health project was formed by Inclusion Melbourne approximately six years ago, funded by very, very small grants that we received from philanthropic and corporate philanthropy. We were surprised by and
5 dismayed by the prevalence of basic signs of poor oral health in the people we support at Inclusion Melbourne and the lack of interdisciplinary awareness between the dental and disability systems. Our project team eventually grew to include Monash Health, Carrington Health and Deakin University, and we produced a number of resources. We wanted to connect both the sectors - - -

10 COMMISSIONER SACKVILLE: Can we ask you again - - -

MR DESPOTT: Sorry.

COMMISSIONER SACKVILLE: - - - if you don't mind, just to slow down a little, especially when reading material. When one reads material, we all tend to move a little more quickly.

15 MR DESPOTT: No worries.

COMMISSIONER SACKVILLE: So err on the side of slowness.

MS FRASER: And if it assists, I'm happy for you to speak generally about the work of the project.

MR DESPOTT: Yes. Yes. So we found that vocabulary relating to disability
20 support in a lot of the resources for support workers and for people with disability themselves was either not in easy language and/or not in the vocabulary relevant to disability support workers. So we sought to create resources that would bridge that gap. We also wanted to create resources that would introduce concepts of communication and positive behaviour support concepts to the dental sector, while
25 also building capacity for general dentists to be able to work more with people with intellectual disability in a way that would allow them to relate with the supports around the person as well.

MS FRASER: The Australian Society of Special Care in Dentistry is a group that commenced approximately 30 years ago and was initiated by a small number of
30 dentists with an interest in providing better treatment to people with complex oral health needs. Can you tell me, Richard, how are these practices now promoted?

DR ZYLAN: The - the practices are now - so the - the aims are to take an active role in educating the dental profession and other health care workers, to provide
35 resources for oral health professionals seeking information, lobbying for oral health services for people with special needs, and supporting oral health promotion - sorry, I'm blanking on the word - oral health promotion activities. I think it's really important for the Commissioners to realise that the oral health submission before you

today has been driven by the disability sector, and that without the impetus from the disability sector I don't believe this would have been before you today, that the dental sector has responded really well. But I think it's really telling that this need and demand has come from the disability sector.

5 MS FRASER: Thank you. So now that we've identified most of the groups behind the submission – and thank you for that background as to the contributors – I'd now like to move more generally to consider the concept of oral health in both people with disability and without. And some of this evidence, Commissioners, will touch on matters that have already been addressed by the previous witness, but nonetheless, I feel it's important to reinforce. Good dental health is important to the maintenance of overall health whether a person has a disability or not. That's the case, isn't it?

10 DR ZYLAN: Yes.

MS FRASER: And what are some of the physical consequences other than those related directly to the mouth necessarily of poor oral health?

15 DR ZYLAN: It leads to systemic health. So we have people with disabilities that die from aspirational pneumonia, people will lose teeth and that will lead to digestion problems. So people have obesity, and, again, people with intellectual disabilities will die from something as simple as constipation.

20 MS FRASER: And you mentioned obesity. Why is obesity more common in somebody who has oral health difficulties?

DR ZYLAN: When you have difficulty with digestion and chewing, you'll have – often have an increased consumption of refined sugar. So your diet then tends towards putting on weight.

25 MS FRASER: And while many of those particular characteristics can impact on somebody whether they have a disability or not, there are particular difficulties that are faced by people with cognitive and intellectual disability as a result of poor oral health, isn't there?

30 DR ZYLAN: Yes, there is. And the – I think it's important to realise that the – it's – it's a chronic disease. So it's like when you go to the doctors for diabetes, the doctor doesn't do something that instantly cures the diabetes. So a – a dentist can pop a filling into a tooth, but that's not going to stop the decay happening in the mouth. And same from gum disease, a one-off treatment's not going to – to tackle that. So it's an ongoing systemic problem that affects quality of life for people with cognitive disability.

35 MS FRASER: And difficulties with oral health have a greater prevalence in people with disability as a result, for example, of excess saliva and difficulties with speech.

DR ZYLAN: Yes, so there's much more issues of dysphagia problems with eating. There's also more tooth-wear, erosion and just difficulties around getting the daily care. Daily oral health care is a vital component to – to – to stopping systemic inflammation. And, look, that's – there has been studies back from 1966 where
5 cessation of oral health care within 10 to 21 days will cause inflammation and gingivitis and – and gum problems in individuals.

MS FRASER: And that study would have been based on individuals without intellectual or cognitive disability?

DR ZYLAN: Yes.

10 MS FRASER: The Commission has heard thus far about some of the difficulties that people have experienced in transitioning from child or paediatric health services to adult health care. Can you talk briefly about the transition from child or paediatric dental services, if that is an appropriate term, to adult dentistry.

15 DR ZYLAN: So in private practice, people with – children with a disability might see a paediatric dentist and stay with that paediatric dentist till young adulthood, or they may transition to a special needs dentist at 18. In the public sector, the rules are much more strict. So they will see a paediatric dentist until 18 and then transition to a special needs dentist.

20 MS FRASER: And is it always the case that a person who has received special needs dentistry care as a paediatric patient will transition to a special needs dentist as an adult?

DR ZYLAN: In – in the public sector, they would need to.

25 MS FRASER: Before we move to consider some of the specific barriers that exist for people with intellectual disability in accessing oral health care, I wanted to stop briefly to consider the collection of data in this area. Data is an issue that has been the subject of much consideration already by the Commission over the course of last week. The submission that you are speaking to today acknowledges a lack of data in relation to oral health of people with intellectual disability. It's the case, isn't it, that the Australian Government conducts national oral health surveys each year?

30 DR ZYLAN: Yes. And the – the lack of data to do with people with disability is that the reason given was that it is apparently too difficult to collect.

MS FRASER: And what do you understand that to mean, that it's simply too difficult to collect?

35 DR ZYLAN: I would think that there's probably not the funding in place and there's also not the – the resources. There's also not necessarily the data being collected. In the submission, we touch on later about an oral health assessment being

included with an overall health assessment that's mandatory in residential units, for instance, and so that would be a way for data to start being collected.

5 MS FRASER: And it's the case, isn't it, that where data has been collected in the past, it hasn't necessarily been given as much weight as it may have needed, given the small datasets used - - -

DR ZYLAN: Yes, it - - -

MS FRASER: - - - in relation to oral health.

DR ZYLAN: Yes, it hasn't been given the importance that it should.

10 MS FRASER: So it's the case presently that there is no reliable data in relation to the oral health of people with disabilities in Australia?

DR ZYLAN: Yes.

MS FRASER: Nathan, moving to consider some of the barriers, could you speak to some of the barriers that exist for people with intellectual disability in relation to accessing oral health care and maintaining oral good health?

15 MR DESPOTT: Yes, I can. The perspective of the Your Dental Health project and our partners and also from, I guess, within the intellectual disability sort of research enterprise would be that the issues are less to do with, you know, physically
20 accessing the dental clinic, which is still – is still a barrier, but in our experience it's more to do with the planning and procedural gaps and the poor interface between the disability sector and the dental sector. So, for example, you would have direct support workers with minimal training and experience in how to recognise the basic signs of poor oral health such as red and bleeding gums and that kind of thing. And I
25 guess if they do have those skills, a lack of ability to connect those to gingivitis, the need to see a dentist urgently, that kind of thing. Also basic treatment planning, pre and post-planning, preparing a person to see a dentist, desensitisation, that sort of kind.

We also find that, from the dental perspective, that because of the inconsistency that many dentists have experienced when they have engaged with the disability sector or with disability support workers in the past, I think we found that there has been a bit
30 of disengagement from the dental side as well. So there's – for example, there may be a lack of trust that the support worker supporting the person to the appointment has the authority or ability or wherewithal to help make sure the dental advice walks out the door with the person, goes home and makes its way into planning documents and the schedule, for example.

35 MS FRASER: So you would - - -

COMMISSIONER SACKVILLE: Sorry, can I just ask something? Last week we heard about the general structure of the medical profession, private, public, and so on. Would you mind just explaining briefly the division between private dental services and public dental services and, in particular, what services are available to people – just leaving aside the question of disability for the moment. People who require dental services but are unable to afford going to a private dentist. What's available?

DR ZYLAN: In private practice it would be a fee for service. So it would depend on finding a practitioner that's offering the services that you need. The different states around Australia all have different priorities and funding mechanisms and how they go about providing that treatment. And so that would depend on a case-by-case basis within the public sector of what treatment was funded and the number of treatments that would be available under that funding. So it would then be how that's triaged amongst the patients that require that treatment.

COMMISSIONER SACKVILLE: But where do you get the treatment?

DR ZYLAN: So the treatment would generally be at clinical health settings or at dental hospitals.

COMMISSIONER SACKVILLE: And how many dental hospitals are there in Australia? Maybe you can take that on notice.

DR ZYLAN: I would take that on notice.

COMMISSIONER SACKVILLE: Thank you.

MS FRASER: So coming back - - -

COMMISSIONER SACKVILLE: Sorry to interrupt. Carry on.

MS FRASER: Coming back to the evidence that you've just given in relation to barriers, it's fair to say that there's barriers in existence from the perspective of the patient, from the perspective of the care worker and from the perspective of the dental health provider themselves. One of the issues that you just touched upon is the preadmission information gathering process. And that's something that our previous witness has spoken to this morning. Is it the case that something as simple as a mandatory intake form, for example, that identifies at the very first stage whether or not somebody might in fact have an intellectual or cognitive disability or other special need, would help to address this issue?

MR DESPOTT: I think that it's more than just identifying the diagnostic situation around the person. At intake it's also important to understand what are the current supports that are there for the person. If they do have an intellectual disability, what plans do exist? Does the organisation – the support organisation, the family, the informal carers, the paid support workers, for example, the guardians, the nominees,

do they have active support plans or consistent approaches, documents, or behaviour support plans? Sometimes the information that gives very specific advice on the steps of how to communicate with the person, support the person, prepare them, is already there in writing in a plan that is quite intelligible to the average dentist. It's often just a matter of knowing how to pass that on. So intake forms need to just not be rehashing information about the person's diagnostic situation in a vacuum. It also needs to be asking questions around the connection with other plans and interdisciplinary environment.

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10 MS FRASER: So something along the lines of a detailed intake form, along with a checklist of sorts. So are there additional documents that you can provide? Drawing on the evidence of the witness earlier, is there a familiar cup that you can bring to the dental appointment to assist in the provision of that care? That the checklist and the form, working together, would improve the experience in the first instance. Is that a fair statement?

15 MR DESPOTT: I think that would be a fair statement. That would be one solution. Obviously, there's more nuance than just that.

MS FRASER: Absolutely, but as a starting point.

MR DESPOTT: Absolutely.

MS FRASER: Some of the other barriers that we have heard evidence about this morning are some of the physical barriers that exist within a dental environment. So things such as loud music and – or loud speaking, a lot of those sensory challenges that might exist for people with intellectual disability or autism. Rich, as a private – Richard, sorry, as a private dental provider, how simple is it, in your experience, to actually put into place some of these changes that would assist the experience of a person with intellectual disability or autism?

20
25 DR ZYLAN: I think a lot of those changes are common sense, so they would be quite easy to put in place. It's actually just making everyone aware of – and communicating with the patients coming in and that's something that could quite easily be embedded within undergraduate training and also with continuing professional development for dentists to assist with how they interact with patients with a disability and their family. Obviously, other measures such as specialist sensory rooms, they would need to be put in place at health settings or hospitals and if private practices were to access those, there would need to be collaborative set-up in that instance.

30
35 MS FRASER: But it's about giving the best personalised care to each one of your patients, as you would whether they had a disability or not, isn't it?

DR ZYLAN: Yes, it is. And it's putting yourself in their shoes.

MS FRASER: So for a patient like AAL, who we heard about this morning, it might be as simple of asking his mother, “What would a song be that he might like to hear when he first arrives at the dentist?”

5 DR ZYLAN: Absolutely, and if you knew that you could have the correct music or if there was a particular favourite toy, or a cup, or do they need noise cancelling headphones, or even something as simple as a weighted blanket. So they’re all very easy items to provide in treatment.

10 MS FRASER: Nathan, it’s the case, isn’t it, that your dental project has actually developed a number of online resources to assist carers, persons with intellectual disability, and dentists to maintain good oral health and to assist in that interaction with a dentist. I would like to just put up on the website now – sorry, put up on the screen the website now that actually profiles some of those particular resources. So on some of the screens in the room we can see the Inclusion Designlab website. If we actually scroll down slowly on that page, we can actually see that a number of resources had been developed by Inclusion Designlab website in consultation with

15 other parties. If we move towards the bottom of the page, we will actually see a number of videos.

20 So, for example, dentistry and disability is approximately a seven minute video that actually speaks to the process of going to the dentist and identifies some of the aspects of what could be expected to occur at the dentist, and it’s that sort of a tool that our previous witness was speaking to this morning. It’s about making those resources known to people who may actually benefit from them. If we scroll further down that screen we will actually see a number of different videos, but moving to the bottom – and I would say that they’re all extremely useful in dental care for people with disabilities. But at the bottom of that screen we can see some videos that are effectively cartoon videos about the process of cleaning and flossing one’s teeth. That’s something that would no doubt be useful to many of us, particularly those

25 with children, but equally, it has application to disability settings, and it may in fact be the case that it’s as simple as reminding disability health care workers and family members about these processes. Can you tell me, Nathan, what is the reach – so what is the awareness amongst – to your knowledge, amongst disability care providers and persons with disabilities about these sorts of resources?

30 MR DESPOTT: I should just point out that these resources are based on a few principles, and that explains my answer for reach. They’re designed for adults with intellectual disability, so despite the fact that there are animations there, they are designed for the needs of adults. We also focus on people with mild and moderate intellectual disability, and people who do have, you know, behaviours of concern and might have a behaviour support plan, but for whom planning before the appointment may actually decrease the need for some of those different devices and interventions

35 during treatment. So while we do advocate for those techniques to be used in treatment, I guess the thesis behind our project is good planning and preparation and

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desensitisation and addressing anxiety and understanding behaviours can often mean it's smoother even within the appointment.

These materials have been endorsed – the dual read guide, sorry, the guide in easy language near the top of the webpage has been endorsed by the ADA. So that's
5 available to all ADA members. We've had significant inquiries for these resources. Thousands of views and downloads and are regularly asked to send out boxes of 50 or 60 copies of the document. At the moment, our work is to – we're seeking
10 funding for communities of practice, but funding in this space to develop unique interdisciplinary resources that can turn into professional development resources for dentists. Very hard to fund because the work needs to include that inclusive research phase as well. So organisations or philanthropics that just want to fund the systems will need to also fund a bit of the research work as well because we don't have the evidence base.

15 MS FRASER: How well equipped, in your experience, are most carers or support workers in maintaining a person with intellectual disability's oral health?

MR DESPOTT: I think the issue there is that there are some wonderful shining lights, support workers, support professionals, support organisations who do demonstrate incredible practice in this space. The issue is that there's inconsistency. And when you have inconsistency it's hard to build trust from the other sectors that
20 connect with the disability sector. I would say, certainly, it would be rare to find a support organisation whose workers are experienced in planning for appointments regularly and making sure they then continue to happen for years to come. It's rare to find workers with experience in desensitisation, support with diet, communicating support needs to a dentist or the reception staff at a dental clinic, rare
25 to find support workers that would understand the role of the planning documents they have and how they could benefit the dentists. And also, it's quite rare to find support workers that will be able – be able to look out for the basic signs of poor oral health and gingivitis and press the red button, as it were, and say, "Right, we need some dental treatment here". So having all of those areas of practice in the one
30 organisation and in the one worker, personally, I don't feel that's too much to ask, and our project team also doesn't feel that's too much to ask but it is very rare to see that in any support organisation.

MS FRASER: And when you mention the warning sign for something like gingivitis, a warning sign is something as obvious as red gums, possibly, isn't it.

35 MR DESPOTT: I would almost go so far to say there seems to be a sense of mythology that some of these poor oral health phenomena are comorbid or automatically something you would find in groups of people with intellectual disability but in fact they're not. They're actually a sign of poor maintenance, preventative care and home care.

MS FRASER: And we have heard evidence in the Commission about that already, a tendency to miss diagnose on account of the existence of a disability and say that's simply part of the disability. It's about the care worker being vigilant, isn't it, and thinking for a moment about the fact that this may have nothing to do with the disability and may in fact be the sign of an underlying health condition?

MR DESPOTT: I would say 100 per cent of the time. I'm not aware of any situation where having an intellectual disability diagnosis leads to gingivitis. That's ridiculous, yes.

MS FRASER: Does a support worker who undertakes training in order to complete their carers' qualification, do they, in your experience or knowledge, undertake any particular study in oral health?

MR DESPOTT: Our team recently completed a mapping and review of the six or seven units in VET training relating to oral care for individualised support disability and aged care, so Certificates III, IV and the diploma, and we found that there is incredible amount of information, a huge volume of various techniques in those units. We would prefer to see one single unit that contains some of the basic practice content I've just described to you. And that doesn't exist. But I also say that it's very rare to find support staff who have completed any of those units as it is. I would also find that we don't just need to have average – the average support worker doing this training. We need to make sure that people who are responsible for operating in the role of house supervisor, for example, or accommodation services manager in support organisations have this training because they need to set the tone at the top, as it were.

MS FRASER: Yes. So while there may be some components of the training that does address oral health, they are not compulsory components; is that correct?

MR DESPOTT: Correct.

DR ZYLAN: Counsel, I think they should be compulsory. I will just recount a story where I went to a shared accommodation house one time and there was a young adult with an intellectual disability, and he was having behavioural issues, acting out, hitting his face. And dentally I noticed he had very few teeth. And the comment from one support worker to another was that, "Well, we might have to up his meds tonight". And so it hadn't occurred that it may actually be a dental issue causing that pain.

MS FRASER: And that's certainly something that we've heard about through the Commission already.

DR ZYLAN: Yes.

MS FRASER: About those sorts of associated behaviours. It's the case, isn't it, that dental visits themselves are not funded by the NDIS?

MR DESPOTT: So obviously dentistry is seen as a service that any person would pay for. What is available from the NDIS is the wraparound support. So, for example, support workers, in some cases transport, a limited range of consumables such as, you know, devices and dental health products. There's also, obviously, 5 funding for behaviour support and the creation of behaviour support plans. Consultation with occupational therapists and speech pathologists. And also, there's actually funding for training for carers, carers being quite a broad term. You think of informal family carers who are not under the same legislative framework as paid support workers working for NDIS-registered providers, but there is training for that. 10 But generally speaking, what we find is regardless of all those supports, it's still quite expensive for people with intellectual disability, people living on a pension, for example, to be able to access the local dental clinic, particularly if they don't have private health insurance, which is quite common. There are some fantastic community health organisations such as Carrington Health and Monash Health, 15 where they have community clinics that are publicly funded. But generally speaking, we would actually argue that there is some scope, some need for funding of services such as oral health therapists to visit people's homes and to do the basic check-up and clean that's needed for preventative care. And I know this is obviously not part of the original scope of the NDIS, but we feel that that would be an appropriate 20 solution or some equivalent.

COMMISSIONER SACKVILLE: Can I just ask whether there is a fundamental problem here. You're attempting to craft some very worthwhile initiatives on a profession that operates basically on fee for service. Now, unless there are public facilities broadly available around the country, how is this going to work? How are 25 you going to achieve the goals you want to achieve within a system that requires people to pay for the service – and I assume that if you are a dentist and if someone comes – has an intellectual disability and it's going to take more time, presumably more expensive in terms of the time involved, who pays and how is it going to work?

MR DESPOTT: As I was saying, I think it's entirely appropriate for those 30 wraparound supports, which is where we see the biggest need in the disability sector to be covered by the NDIS. But in terms of dental services themselves needing to be managed differently, so that people can access them, then I entirely agree with your sentiment there.

COMMISSIONER SACKVILLE: Yes, but what's the answer to my question? 35 How are we going to get there?

DR ZYLAN: So the National Disability Council in America last year had it mandated that there would be special needs training embedded in the undergraduate courses, and I think that one of the answers would be embedding that in the courses in Australia, because as a dental student you get very little exposure to people with a 40 disability. And in reality, from a dental perspective, the actual work that you do is not any more complex than what you do on any other patient. It's just having understanding and time.

For instance, I've had a patient come to me where I said, you know, "Why are you here", and the parents have said, "We're here just for you to organise a general anaesthetic to have some teeth taken out". And with a little bit of time and effort, that particular patient had two fillings done in the chair. So I think it's about raising
5 awareness and helping people with a disability have work done that can be done in the general setting, which would then alleviate waiting lists in the public health sector, so you're not having people who have more systemic disease while waiting for dental treatment.

10 COMMISSIONER SACKVILLE: It of course is notorious that lawyers are extraordinarily generous, perform lots of pro bono work. Is there any pro bono type schemes within the dental profession?

MR DESPOTT: I think, actually, this system does require a lot of really good general dentists to give of their – of their time over and above what the rate would be.

15 COMMISSIONER SACKVILLE: How does the system do that?

MR DESPOTT: Sorry?

COMMISSIONER SACKVILLE: How does the system do that?

MR DESPOTT: They do it outside of the system, is what I'm saying.

COMMISSIONER SACKVILLE: Okay.

20 COMMISSIONER BENNETT: Just continuing on from the theme raised by the Chair, is it your view that people with intellectual disability, that the consequences of not having access to good dental care exposes them at a higher rate to other health issues, is the first question. And so does that then create a case that says if you deal with this, over the long term, other health costs could be reduced that may manifest
25 themselves because you didn't – because they didn't get access early and systemically to good health care? So trying, in a sense, to understand, is there an economic model that puts an exceptional case for a cohort in our community that might need additional assistance or access because over the period of time you could actually reduce the health costs that manifest themselves from poor dental care?
30 Does that question make sense? I'm trying to understand if there's any research or whether you believe this is the case.

DR ZYLAN: I think there would be a clear case that the cost of preventative dental treatment would be far reduced, as compared to multiple hospitalisations that would be required if someone developed systemic disease later on. I think it's also about all
35 allied health professionals being aware. So if you've got someone that has had red bleeding gums and they've had multiple other allied health visits but haven't been referred to the dentist or someone else hasn't noted they need treatment, then that's adding to the load of the systemic disease down the track.

COMMISSIONER BENNETT: Are you aware of any studies that have been conducted in Australia, sort of health economic modelling that has been conducted in Australia or overseas, that sort of can show us that possible impact and cost reduction of an earlier intervention?

5 MR DESPOTT: We have referenced some of the studies in our submission, but provided more detail about the content of that research in the Oral Health and Intellectual Disability Guide. That's one of the items we've submitted. The short answer to your larger question is yes, absolutely. There is an incredible link between the lack of preventative oral health support and severe chronic disease in people with
10 intellectual disability. However, we don't have enough clear information of the specifics of that because we haven't collected enough data. On top of that, I would say it's also – to add to the question that was asked before, it's difficult to gather that kind of data when so many people with intellectual disability living in supported accommodation live in environments where the staff and the people working there
15 are not able to understand or recognise the signs of good or poor oral health in the people they're supporting.

MS FRASER: You acknowledged earlier in answer to a question that I asked that the NDIS does not fund services that people would ordinarily have to pay for if they didn't have a disability. To come back to one of the issues that the Chair has just
20 raised, it's the fact, isn't it, that some people with disability have to or would benefit from attending a dentist more regularly than somebody without a disability as a result of their disability? Is that a fair thing to say? Their oral – sorry, not more regularly, but their visits may be longer, that they may require familiarisation visits and so forth, and that is something that could not be said to exist in a non-disabled
25 population, if I could call it that.

MR DESPOTT: So the example that you often hear in training when we usually run workshops or observe workshops for people going into the NDIS when it comes to what is reasonable and necessary is examples such as, you know, all of us are responsible for buying our own car, that the NDIS might be able to pay for
30 modifications to that car if you need that. I feel that that very basic reduced concept doesn't apply to people with intellectual disability seeing the dentist and maintaining the oral health as your question is implying. So essentially, it is reasonable to expect that a person with intellectual disability, with behavioural issues, sensory issues, and a lack of good support around them will end up needing to see the dentist more than
35 the average person. Yes.

MS FRASER: So that would be a modification that would be needed in terms of the delivery of oral health as a result of that person's disability. The more regular appointments or the familiarisation visits, that's a modification.

MR DESPOTT: I would – yes, I would say essentially yes. Obviously, these –
40 these words in your question have got a lot of policy loading in the – in the NDIS space. But on just the plain face value of what you asked, I would agree with that, yes.

MS FRASER: So it may well be that there's a case for further government funding to subsidise or pay for additional visits to the dentist for a person with a disability, for example, to familiarise themselves.

DR ZYLAN: Absolutely, that would be wonderful.

5 COMMISSIONER SACKVILLE: Is your assumption that anybody with an intellectual disability would be on the NDIS?

MR DESPOTT: They would be my assumption, yes. A significant proportion of - - -

COMMISSIONER SACKVILLE: Is it supported by the facts, as far as you know?

10 MR DESPOTT: As far as I know, yes. A significant proportion of Australians with intellectual disability would be eligible for NDIS services. Whether they've been able to access the NDIS or been supported to access the NDIS is another issue altogether.

COMMISSIONER SACKVILLE: The gap between eligibility and obtaining the
15 entitlement?

MR DESPOTT: Correct.

COMMISSIONER SACKVILLE: Thank you.

MS FRASER: Can you provide for the Commission a brief summary of what is the NDIS practice standards.

20 MR DESPOTT: Yes. The NDIS practice standards maintained by the NDIS Quality and Safeguards Commission are the standards by which NDIS registered service providers are audited regularly. The NDIS practice standards cover core modules and then specialist modules for registered providers who are registered for those specific groups. The NDIS practice standards do not specifically cover oral
25 health. However, more importantly, from our perspective it's not just about auditors asking questions about oral health, it's also about understanding and inquiring into the way practice works in support organisations.

As you've heard already from what we've been saying in the submission, maintaining oral health is not just about checking for bleeding gums alone and
30 helping people brush their teeth, it's about planning, observation and interdisciplinary communication. And there are some organisations that will be able to demonstrate that and some that won't. And the NDIS practice standards I feel are an important tool, but we do feel there has to be something a little more pointed in them relating to oral health and the way that organisations engage with these
35 interdisciplinary matters.

MS FRASER: So it would be a recommendation that you may well make to the Commission that at a bare minimum, the NDIS practice standards would, in fact, identify oral health as particular subject/topic, and provide accountability measures for disability service providers around oral health?

5 MR DESPOTT: I think that's an important matter for consideration by the NDIS Commission, yes.

MS FRASER: Coming back to the Your Dental Project, one of the resources that was developed or has been developed by the project that is available through the website that we showed earlier is the dual read guide. And, Commissioners, we find
10 that at tender bundle volume D, tab 185. Nathan, you mentioned the dual read guide earlier in the evidence that you gave. Can you explain to me briefly, what is the guide and how is it used?

MR DESPOTT: The dual read guide Your Dental Health is a publication designed for people with intellectual disability and for their supporters. Each double-page
15 spread is divided up so that plain language devoted – or targeted at the supporter is on the left-hand side, and easy language and pictures/images for the person with intellectual disability on the right side. The guide runs through an introduction to oral health. It then runs through home care and self-care, and then goes into a summary of the private and public systems.

20 MS FRASER: And in your experience, what is the take-up of that guide? So how far reaching is it?

MR DESPOTT: Well, firstly, it's been endorsed by the Australian Dental Association. It's - - -

MS FRASER: What does that mean? So - - -

25 MR DESPOTT: Yes.

MS FRASER: - - - I appreciate what that means, but what does that mean in terms of the take-up of the guide?

MR DESPOTT: So it means that it's on the Australian Dental Association website and that is known through the Australian Dental Association's various federal, state
30 and territory magazines so that registered dentists in Australia have access to it. It's also regularly sought in hard copy by those that – that want it. However, I must note that disseminating it, running communications campaign, printing it, logistics, is all paid for by Inclusion Melbourne and by a small number of grants that we've received over the years. It's very hard to seek funding to push out and disseminate and
35 communicate a lot of the content that we're talking about today and the content in these publications.

MS FRASER: One of the other resources developed by the project is the Oral Health and Intellectual Disability Guide. And, Commissioners, that's at tender bundle volume D, tab 186. That guide is specifically designed to assist dental practitioners to provide services to people with intellectual disability, and that guide
5 has been distributed, on the basis of the evidence in the submission, to every dentist in Victoria and Western Australia. Can you tell me why it hasn't been distributed to other States?

MR DESPOTT: So it's been distributed in hard copy to every dentist in WA and Victoria, and then there has been articles and links to the online version of the guide
10 to all the other States and territories in Australia. But that is again simply down to the fact that the ADA has not had the funds to pay for that dissemination. So our partnership, the Your Dental Health team and the Disability/Oral Health collaboration, has sought small philanthropic grants from outside disability and health funding to – to disseminate those resources. So it is actually an issue of
15 funding, primarily.

MS FRASER: In terms of special needs dentistry specifically, there are 17 special needs dentistry providers in Australia. Eight of those are in Victoria, four are in Queensland, three are in New South Wales, one is in Tasmania, and one is in Western Australia. The Commission has heard some evidence already today in
20 relation to some of the services provided by special needs dentistry. Richard, can you tell me, what are people – what causes a person to be referred to a special needs dentist?

DR ZYLAN: So referral to a special needs dentist is made by a general dentist. And to – to speak with what happens with a special needs dentist is that from a – the
25 time that a referral is made, it may be 12/18 months to see a general dentist – a special needs dentist. If they were to need a general anaesthetic, that waiting list could be 18 months to – to two years. A lot of the special needs dentists now in the time between seeing them and assessing for general anaesthetic will have
30 familiarisation visits where someone's coming – coming in and they may just be sitting on the chair becoming familiar, they're working with the – the family on helping break down barriers and ensuring that the oral health care is as good as possible until being able to be seen under general anaesthetic.

MS FRASER: And special needs dentists who work in special needs dentistry providers have undertaken additional training, haven't they?

DR ZYLAN: Yes, they have. So it's a post-graduate course. So – and when they graduate, they're – they also spend a lot of the time working in institutions and teaching and doing education. So you haven't got 17 special needs dentists just in
35 the clinic the entire time.

MS FRASER: How many universities across Australia currently provide the post-graduate course in special - - -
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DR ZYLAN: There's four.

MS FRASER: Four. And where are those universities located?

DR ZYLAN: So Adelaide, Melbourne, Sydney and Brisbane.

MS FRASER: The cost of a post-graduate course in special needs dentistry is
5 approximately \$130,000.

DR ZYLAN: That's correct. And there's – there's no scholarships. And so people
undertaking those courses are often at a time when they've got other life costs, and
often can't work in order to undertake those studies. So from a needs point of view,
there – there's often not a great incentive beyond passion in actually pursuing those
10 studies.

MS FRASER: So while there is that additional study available, there's significant
barriers to a person actually wanting to and ultimately undertaking that study.

DR ZYLAN: Yes, there is.

MS FRASER: Such that one of the recommendations that has been touched on
15 already would be to embed more of those special needs dentistry components into an
undergraduate dentistry course.

DR ZYLAN: Yes, because that would then come back to making general dentists
probably more comfortable and happier to undertake that – that treatment. And also,
having that exposure as an undergraduate, it allows you to actually be exposed and –
20 and see the rewarding nature of that work.

MS FRASER: To what extent, if any, are needs of intellectually disabled and
people living with autism already addressed undergraduate dentistry programs?

DR ZYLAN: It's been a while since I was there, but when I was there it was not –
not great. I know in Melbourne, for instance, that Dr Jane Tracy from the CDDHB
25 goes in and – and – and runs some familiarisation with treating people with a
disability, and that's the type of thing that needs to occur far greater.

MS FRASER: When you say she runs some courses or some - - -

DR ZYLAN: She comes in and does training around dealing with people with a
disability.

MS FRASER: How long would that training ordinarily last for? Are we talking
30 about one hour in an undergraduate course, or are we talking about a subject, or - - -

DR ZYLAN: No, look, it would probably be a day or two.

MS FRASER: Right.

DR ZYLAN: So it's not significant.

COMMISSIONER GALBALLY: Can I ask a question there. Do people with an intellectual disability deliver some of the training?

5 DR ZYLAN: Yes, they do. So she has someone who will come in and speak to the students. And I think that's probably really important. So I think that a lot of people are siloed at universities. They may not have the exposure to – to working with people with a disability, and so there's that mystique. So I think breaking down, treating and – and finding out that it's not particularly complex and it's just learning
10 how – how to – to use different techniques to deal with those people would be really important.

COMMISSIONER GALBALLY: Yes, so they're regarded as established trainers alongside Jane.

DR ZYLAN: That's how she would - - -

15 COMMISSIONER GALBALLY: Thank you.

DR ZYLAN: - - - treat them, yes.

MS FRASER: Do dentists undertake a form of continuing professional development - - -

DR ZYLAN: Yes, they do. They - - -

20 MS FRASER: - - - yearly requirements?

DR ZYLAN: So that's 60 points over a three-year cycle. With continuing professional development there are compulsory components. And so certainly if you're wanting to embed some special needs training into the CPD, yes, there's the precedence of having a compulsory component.

25 MS FRASER: And is there currently, to your knowledge, any component even whether it's compulsory or not compulsory in the CPD program that addresses the needs of people with intellectual disability?

DR ZYLAN: No, there's not, and I think that's something that Inclusion Melbourne and the Oral Health collaboration are looking at doing. Again, it comes down to – to
30 an issue of funding.

MS FRASER: But if it was part of the continuing professional development and it was compulsory, then it would be a matter that everybody would need to address?

DR ZYLAN: Yes, it would, and that would be a really quick, simple, easy recommendation to actually get some change happening very quickly.

MR DESPOTT: Can I add a comment to that based on Commissioner Galbally's comment before, that the work we do in developing these resources and also the CPD materials that we're looking to develop through a community of practice, all of this is based on working very closely in a participatory action research format with people with intellectual disability, which is why it takes time and it's not simply a matter of getting behind the computer and dumping our knowledge into documents and resources. So I think that's really an important issue to remember when we're talking about creating resources and training.

MS FRASER: One of the issues that's identified in the submission is poor communication that currently exists between dentists and patients, or dentists and supported living environments, support care workers and dentists and the GP. The Oral Health and Intellectual Disability Guide that we've referred to earlier contains two forms that are designed to address these issues. If we could bring those forms up on the screen. There is what I'm going to helpfully refer to as the orange form and the pink form. If they could be brought up on the screen. So we see here – and I appreciate the text may be small on the screen – we see here on the Oral Health Assessment pink form, this is a form that would be used in terms of recording the outcomes of a dental visit and providing the outcomes of that dental visit to a person's GP. Is that a fair summary of the form?

DR ZYLAN: Yes, because I think with a lot of places that there's a mandatory annual health check-up. So by embedding an oral health check-up, it allows the GP to also monitor what's happening dentally. And typically, someone might visit the GP 14 to 20 times per one visit to the dentist. So it's a way of actually allowing oral health needs to be monitored and for a GP to work in collaboration with the dentist, especially with, as I've spoken earlier, oral health is linked to overall health.

MS FRASER: So this is a form that already exists that's contained in the Oral Health and Intellectual Disability Guide and, if used properly, would allow the dentist to communicate the specific oral health needs to a person's GP. But in practice, how often, in your experience, is this form actually used?

DR ZYLAN: It's not.

MS FRASER: It's not. So would it be the case that if there was a recommendation made that such a form such as this be mandated for people who presented at the dentist and identified as having a disability or special need, for that form to be provided every time they go to the dentist to their GP? That would be a positive recommendation.

DR ZYLAN: I think that would be a really positive recommendation. And part of the work when we did that was based on an incident where I was speaking with a mother of a young lady with an intellectual disability, and I had asked her how she

was going and she said she was quite weary because she had had nearly, you know, 40 to 50 visits to the general practitioner already that year, and that was maybe September of the year, and her daughter had big red flaming gums. When I asked the mother just, "I'm curious, has there been any mention about her gums", she said

5 no.

MS FRASER: If we move to look at the pink form, that's entitled the Home Oral Care Plan. And that's a form that is designed for a dentist to complete and provide to a person to either take to the home where they may live with their family or to their supported care accommodation. And we see on the second page of that form, under

10 the heading For Support Professionals, who may include family members, categories and warning signs. So we see something as simple as daily oral care regime, is it regularly refused or not completed, with a tick box. Lips, are they dry or chaffed. So those are the sorts of check boxes or triggers that you would say, if a person providing care to a person with a disability turned their mind to these things on a

15 daily basis, that would assist in the provision of good oral health care?

DR ZYLAN: Yes, it would. And it's also just some really simple red flags that can then be discussed with the appropriate practitioner later.

MS FRASER: So, again, this form exists. It's contained in the Oral Health and Intellectual Disability Guide but it's not, in your experience, being regularly used.

20 DR ZYLAN: No, it's not, and it would be great to see that embedded with the health paperwork that follows people with a disability from accommodation units around to all their medical appointments.

MS FRASER: And these forms are endorsed by the ADA?

DR ZYLAN: Yes.

25 MS FRASER: But they've not been endorsed by the AMA, the Australian Medical Association; is that correct?

DR ZYLAN: No, they haven't.

MS FRASER: What's the impact of that on their rollout, if any? Is the fact that the AMA hasn't endorsed the form, does that bear upon the rollout of the format all?

30 That might be something you would like to take on notice.

MR DESPOTT: Yes, I might take that on notice.

DR ZYLAN: But there's a very good precedence here to look at embedding oral health with overall health. So it's something that could certainly be brought to the attention of the AMA by the Commissioners.

MS FRASER: I'm conscious of the time. We've only got a few more minutes. So your submission also speaks to the use of restrictive practices. And accepting that the – that your submission is currently before the Commission, is there anything in particular, in a short-form sense, that you would like to say about the use of

5 restrictive practices in a dental health setting for people with intellectual disability?

MR DESPOTT: Yes. I mean, obviously, as you say, the submission runs through the, I guess, lack of mutual intelligibility of provisions relating to restrictive practices and restraint in the disability sector and in the dentistry sector. And what is prescribed through the NDIS positive behaviour support capability framework practice standards, the NDIS Act, and so forth, and the fact that dentists have very different permissions of what they're allowed to do in dental treatment, I guess what I would like to say from a broader perspective is that while I would like to see more special needs dentists with understanding of some of these techniques in Australia, we would also like to make sure that the people who are seeing special needs dentists are the people who really need to see them. Like the story we heard earlier. And some of the people that are, perhaps, over-referred to special needs dentists by the general dentists or people that are over-referred to general anaesthetic treatment, for example, that may actually be treated quite well and sufficiently in the general dental setting, that that outcome would be able to occur rather than seeing the special needs dentistry world sort of clogged with people who probably don't need to be there. We also feel that that requires general dentists to have a better understanding of positive behaviour support, supported decision-making and the planning, the techniques that already exist and the practices that already exist in the disability sector.

25 MS FRASER: So by making some of those modifications that we've already touched on today, we may, in fact, address the issue of over-referral, what you've just described as over-referral to a special needs dentist, which would then free up those services for those who really need them.

MR DESPOTT: Correct. Yes.

30 MS FRASER: The Australian National Oral Health Plan 2015 to 2024 – and, Commissioners, this is at tab D – sorry, tender bundle D, tab 184 – interestingly, makes specific reference to what is called Priority Population 4 people with additional and/or special needs – specialised needs, and that is addressed on pages 63 through to 68 of that oral health plan. In terms of the recommendations that are made in that plan, they are as follows:

35 *Collect national baseline and ongoing data to more accurately identify the number of people with additional and/or specialised health care needs; (2) improve the oral health literacy of care workers and the carers of people with additional and/or specialised needs to incorporate oral health in their existing assessment, care planning and care processes; (3) build workforce capacity and competency in the oral health sector to effectively address the needs of*

40

people with additional and/or specialised health care needs; and (4) improve physical access to dental treatment facilities.

So what we can see there is in the National Oral Health Plan that has been in existence for five years, the four key recommendations that relate to people in
5 Priority Population 4, being people with additional and/or specialised health care needs, are exactly the sorts of things that you have addressed with us today. But in your firsthand experiences of the operation of people in Priority Population 4 in a dental setting, there is still much more work to be done to put into place these recommendations. Is that a fair summary?

10 DR ZYLAN: There's a lot of work and probably a lot of funding to be found for all those criteria to be met in the terms of that plan.

MS FRASER: And appreciating that we are very nearly at an end, I would like to thank you very much for coming and giving your evidence today. Is there – your submission addresses a number of other recommendations, many of which we've
15 touched on today, but is there anything in closing that you would like to say to the Commission?

DR ZYLAN: I just think that there's preventative measures in place to help develop overall health and oral health for people with cognitive disabilities, and that we should really view that every tooth that's extracted where preventative measures
20 were not taken should be considered as neglect and, as Commissioner Sackville said, an injustice.

MR DESPOTT: I guess I would say that overall, the impression that our project team has developed is that this is not so much an issue of manifest incompetence but actually an issue of gaps, of a lack of interdisciplinary communication and of an
25 inconsistency of practice. And that many of the practices that we need to fill some of these gaps already do exist, and that it's about sharing that information and making sure these two formerly separate sectors have a better connection between them. Of course, underneath that, though, I refer to the Chair's comment before of the fact we do need to ask a deeper question around how we fund dental care in this country.

30 MS FRASER: Thank you very much.

COMMISSIONER SACKVILLE: Mr Despott, Dr Zylan, thank you very much indeed for your submission. Thank you also to your colleagues who have participated in that very detailed submission, which we have read very carefully and which contains some very important recommendations. Thank you also for coming
35 along today and sharing your views and experience with us. Thank you.

DR ZYLAN: Thank you.

MR DESPOTT: Thank you.

<THE WITNESSES WITHDREW

[1.00 pm]

COMMISSIONER SACKVILLE: Now, Ms Eastman, should we now take the luncheon adjournment till 2 o'clock, is that convenient?

5 MS EASTMAN: Yes.

COMMISSIONER SACKVILLE: Yes, we will adjourn till 2.

ADJOURNED

[1.00 pm]

RESUMED

[1.59 pm]

10

COMMISSIONER SACKVILLE: Yes, Ms Eastman.

15 MS EASTMAN: Commissioners, the next witness is Narelle Reynolds. And before she comes to give her evidence, can I acknowledge and pay my respects to all First Nations people following this afternoon's proceeding, both in the room and also watching the broadcast. The matters that we're going to talk about this afternoon involve First Nations people, and the approach that we wish to take as counsel assisting is that we have a lot to learn from our First Nations people, and I will be very much guided from Ms Reynolds and Dr Avery, who will give evidence after Ms Reynolds, as to the appropriate way in terms of addressing people from First Nations communities, and also ensuring that I take a culturally sensitive approach as I work through the material. If I make a mistake, I'm sure that Ms Reynolds will be able to assist me as we go along. So I call Ms Reynolds.

20 COMMISSIONER SACKVILLE: Thank you, Ms Reynolds. If you wouldn't mind coming forward. Thank you very much. And please sit down. Thank you. You can sit down, thank you. That's fine.

25

<NARELLE REYNOLDS, SWORN

[2.01 pm]

<EXAMINATION BY MS EASTMAN

30

COMMISSIONER SACKVILLE: Thank you very much for coming to the Commission today. Ms Eastman will now ask you some questions.

MS EASTMAN: So you are Narelle Reynolds?

MS REYNOLDS: Yes.

MS EASTMAN: And you've made a statement for the Royal Commission, dated 10 February this year?

MS REYNOLDS: Yes.

MS EASTMAN: You've got a copy of your statement?

5 MS REYNOLDS: Yes.

MS EASTMAN: Do you want to take that out? And, Commissioners, just while Ms Reynolds is doing that, you will find a copy of the statement in part A of the tender bundle behind tab 35. And this will become exhibit 4.17.

COMMISSIONER SACKVILLE: Thank you.

10 MS EASTMAN: So you've got a copy of your statement there, and the contents of the statement are true and correct to the best of your knowledge and belief?

MS REYNOLDS: Yes.

MS EASTMAN: All right. So let's start. You've come to the Royal Commission because you want to tell us about the experience of accessing health care, particularly
15 for your two sons who are now adults; is that right?

MS REYNOLDS: That's right.

MS EASTMAN: And both of your sons have Fragile X syndrome.

MS REYNOLDS: Yes.

MS EASTMAN: And they're both – they both live with you.

20 MS REYNOLDS: Yes.

MS EASTMAN: Is that right? And you're currently living in Coffs Harbour.

MS REYNOLDS: Yes.

MS EASTMAN: All right. So before we get to your sons, can I ask you some questions about yourself.

25 MS REYNOLDS: Yes.

MS EASTMAN: You are a First Nations Wiradjuri woman?

MS REYNOLDS: Yes, that's correct.

MS EASTMAN: And you were born on an Aboriginal mission in Condobolin in New South Wales.

MS REYNOLDS: I wasn't born on the mission, but I – that's where I grew up, yes.

MS EASTMAN: You grew up on the mission.

5 MS REYNOLDS: Yes.

MS EASTMAN: And you lived there with your mother, father and six younger siblings.

MS REYNOLDS: Yes.

MS EASTMAN: And over the time that you lived at the mission, you attended the local school; is that right?

10 MS REYNOLDS: Yes.

MS EASTMAN: But you had to leave school when you were 13 years old.

MS REYNOLDS: That's right.

MS EASTMAN: And when you left school, your job was picking up sticks to earn extra money for your parents; is that right?

15 MS REYNOLDS: Yes, that's right.

MS EASTMAN: Can you tell me a little bit about what that involved?

MS REYNOLDS: It involves walking paddocks, clearing paddocks, basically, clearing – you know, people would put – farmers would pull down the trees, and we used to walk behind them and burn off – gather all the sticks up in one place and burn them.

20 MS EASTMAN: Okay.

MS REYNOLDS: It's called stick-picking.

MS EASTMAN: Right. So that's a job that you did for a few years, but your grandmother was a fairly wise woman, wasn't she?

25 MS REYNOLDS: She was.

MS EASTMAN: And she knew that you wanted to be a nurse.

MS REYNOLDS: That's right.

MS EASTMAN: And so your grandmother took some steps to make sure that you could start a process of becoming a nurse; is that right?

MS REYNOLDS: Yes, she encouraged me.

MS EASTMAN: So she told you first of all you needed to learn to type.

5 MS REYNOLDS: Yes.

MS EASTMAN: And she said – one day there was a representative from the TAFE who came to the mission, the TAFE was offering some training in receptions and typing. And that was at Dubbo.

MS REYNOLDS: Yes.

10 MS EASTMAN: And your grandmother encouraged you to go.

MS REYNOLDS: Yes, she pushed me to go. Yes.

MS EASTMAN: She pushed you. You weren't too keen on that initially, were you?

MS REYNOLDS: No.

15 MS EASTMAN: But you agreed to go.

MS REYNOLDS: Yes.

MS EASTMAN: And that was a big step for you, leaving your parents and siblings.

MS REYNOLDS: Yes, it was.

MS EASTMAN: But you travelled to Dubbo for one year, and you lived in a hostel

20 in Dubbo; is that right?

MS REYNOLDS: Yes.

MS EASTMAN: But you completed the reception and typing course.

MS REYNOLDS: Yes.

MS EASTMAN: But you went back to Condobolin on the weekends.

25 MS REYNOLDS: I did.

- MS EASTMAN: Once you'd finished working – once you'd finished completing the course in Dubbo, you got a job as a laboratory assistant at the agriculture station at Condobolin. And you were about 17 years old then.
- MS REYNOLDS: I was 16.
- 5 MS EASTMAN: 16. So that was your first job. And what did that job involve?
- MS REYNOLDS: Basically, looking after animals, checking what they ate, research into lucerne hay, what sort of good things are for everyone to eat, animals.
- MS EASTMAN: Did you expect you would have a job like that at age 16?
- MS REYNOLDS: No.
- 10 MS EASTMAN: But your nan knew you still really had your heart set on becoming a nurse; is that right?
- MS REYNOLDS: Well, she encouraged me to do it because it was – it was still about learning about biology and – yes.
- MS EASTMAN: She thought it would be a good introduction.
- 15 MS REYNOLDS: Yes, to learn. Yes.
- MS EASTMAN: So in terms of becoming a nurse, which you did, it came about because your nan said to you, “You need to go and talk to the matron at the local hospital”, and to ask her if you can start to do some on the job training; is that right?
- MS REYNOLDS: That's right.
- 20 MS EASTMAN: And so the training in those days was that you didn't attend a college or university, but you did on-the-job - - -
- MS REYNOLDS: On-the-job.
- MS EASTMAN: - - - training.
- MS REYNOLDS: Yes.
- 25 MS EASTMAN: So you worked at the local hospital ; is that right?
- MS REYNOLDS: Yes.
- MS EASTMAN: For about two years.
- MS REYNOLDS: Yes.

- MS EASTMAN: And that was your initial training to become an enrolled nurse.
MS REYNOLDS: Yes.
MS EASTMAN: And then after that, you did work in nursing for a further eight years.
- 5 MS REYNOLDS: Yes. For a while, yes.
MS EASTMAN: And in terms of your experience working in nursing and the health sector, you've worked in a range of jobs and you've got – if you want to have a look, you've got them set out at paragraph 11 of the statement. So that's on page 2.
MS REYNOLDS: Two?
- 10 MS EASTMAN: Page 2, number 11.
MS REYNOLDS: Yes.
MS EASTMAN: Okay. So I'm just interested to ask you about a few of these jobs from your perspective as a nurse and working in both health care and disability. So the Royal Commission this morning has heard a little bit about dental care. And one
15 of the jobs that you had was coordinating services for young Aboriginal children access dental care. What did that involve?
MS REYNOLDS: Going to families, speaking to the families, organise their children to visit dentists and to educate their parents, educate the dentist. And I also worked as a – I trained as a therapist – dental therapist.
- 20 MS EASTMAN: You trained – you didn't tell – you haven't told me that. So you trained as a dental therapist.
MS REYNOLDS: I forgot. Yes, so I actually was – helped, went with them to the dentist, took the children.
MS EASTMAN: How did – was that to help the children be familiar with what
25 happens at the dentist?
MS REYNOLDS: Yes, well – and treatment. And treatment, yes.
MS EASTMAN: Okay. So you've had lots of different jobs over the course of your life, haven't you?
MS REYNOLDS: Yes, I have.
- 30 MS EASTMAN: And many of them have been in health.

MS REYNOLDS: Yes.
MS EASTMAN: In disability sector services and in child care; is that right?
MS REYNOLDS: That's right.
MS EASTMAN: All right. Can I ask you some questions now about your family
5 and, in particular, your children.
MS REYNOLDS: Yes.
MS EASTMAN: So you have your eldest daughter, Tamie, she's now 41 years old.
MS REYNOLDS: That's right.
MS EASTMAN: And she has one son, Ryan, who's 11 years old.
10 MS REYNOLDS: That's correct.
MS EASTMAN: And then after Tamie, about two years later, you had Justin.
MS REYNOLDS: Yes.
MS EASTMAN: And he's now 38 years old. And then following Justin was Luke,
and he's now 33 years old. You might have to say - - -
15 MS REYNOLDS: Yes, sorry.
MS EASTMAN: - - - yes, rather than nod.
MS REYNOLDS: Sorry.
MS EASTMAN: Okay. And then your youngest child is Casey, and she's 32 years
old.
20 MS REYNOLDS: Yes.
MS EASTMAN: Okay. And your family has moved around various parts of
Australia - - -
MS REYNOLDS: Yes.
MS EASTMAN: - - - over the course of your life and the children's life. Is that
25 right?
MS REYNOLDS: Yes.

MS EASTMAN: So you've lived for some of the time in Condobolin. You've also lived in South Australia.

MS REYNOLDS: Yes.

5 MS EASTMAN: And you've lived in Dubbo. And you currently live in Coffs Harbour.

MS REYNOLDS: That's correct.

MS EASTMAN: And what other places have I missed along the way?

MS REYNOLDS: Port Augusta, Eden, Orange, yes.

10 MS EASTMAN: So you've moved around quite a lot. Okay. So can I now ask you some questions about your children and their various health conditions.

MS REYNOLDS: Yes.

MS EASTMAN: Is that okay? So can we start with Tamie.

MS REYNOLDS: Yes.

15 MS EASTMAN: And in your statement, paragraph 17, you tell the Royal Commission that in 2012 she was diagnosed with leukaemia, and that meant spending a lot of time with her at Westmead Hospital.

MS REYNOLDS: It did.

MS EASTMAN: And she received treatments, and she's now in remission.

MS REYNOLDS: Yes, that's correct.

20 MS EASTMAN: And her son, Ryan, has the Fragile X condition.

MS REYNOLDS: So does Tamie.

MS EASTMAN: And Tamie does as well.

MS REYNOLDS: Yes.

25 MS EASTMAN: But in terms of Tamie's Fragile X condition, it's not as severe as the Fragile X condition for your two sons, Justin and Luke.

MS REYNOLDS: That's correct.

MS EASTMAN: Is that right? And I will come – we will come in a moment to explaining to the Royal Commission what Fragile X is. Okay. Now, for Luke, he's your third child and your second son. In 2015 he got very sick, didn't he?

MS REYNOLDS: He did.

5 MS EASTMAN: So he had a lot of headaches, vomiting, he lost his appetite. And he's had some fairly serious health problems - - -

MS REYNOLDS: Yes.

MS EASTMAN: - - - that we're going to talk about.

MS REYNOLDS: Yes.

10 MS EASTMAN: All right. So we've mentioned Fragile X. And in your statement you point out that when both Justin and Luke – and I assume Tamie as well – when they were born, you didn't know about Fragile X.

MS REYNOLDS: No, I didn't.

MS EASTMAN: And in terms of explaining to the Royal Commission what Fragile X is, you say in the statement it's not a disease. But do you want to tell the Royal Commission what Fragile X is and your experience of Fragile X in terms of your family? What would you like to tell the Royal Commission?

15 MS REYNOLDS: Fragile X is an inherited condition and it's in the chromosomes. So they're – you know, we have X and the Y chromosomes, and the X in Fragile X people is degraded and it causes intellectual disabilities. There's a whole range of things that it causes, yes.

MS EASTMAN: So someone with Fragile X might have quite distinct physical features.

MS REYNOLDS: Yes, they do.

25 MS EASTMAN: Is that right?

MS REYNOLDS: Yes, they do.

MS EASTMAN: And what are the physical features.

MS REYNOLDS: My – my sons have large ears and large foreheads, and a lot of Fragile X clients do have that. And I can usually pick them when I – when I meet
30 people. And they have a lot of characteristics of autism, with the hand flapping and the hand biting. A lot of – originally it was diagnosed as autistic, yes.

MS EASTMAN: And there's an association called the Fragile X Association. Is that something that you're involved with?

MS REYNOLDS: I ring them for advice, yes. They've been helpful, especially when I get blocked in where to go, how to manoeuvre around something to achieve an outcome for my sons. They're good for advice.

5 MS EASTMAN: Okay.

MS REYNOLDS: Yes.

MS EASTMAN: So can I ask you now a little bit about how you came to learn that Justin and Luke had Fragile X, and some of the associated physical characteristics, but also the impact on them from an intellectual perspective. Can I ask you some questions - - -

10 MS REYNOLDS: Yes.

MS EASTMAN: - - - about that. So when - - -

MS REYNOLDS: Justin - yes.

15 MS EASTMAN: When Justin was about six months old, you recall now that he started to show signs of Fragile X; is that right?

MS REYNOLDS: He did.

MS EASTMAN: And the signs that he showed was that he had no muscle tone in his hands.

20 MS REYNOLDS: He did.

MS EASTMAN: And he was unable to sit up or grasp things.

MS REYNOLDS: Yes.

MS EASTMAN: And so when Justin was quite a young baby, you did talk to the general practitioners about this.

25 MS REYNOLDS: Yes.

MS EASTMAN: Did you take Justin to see them?

MS REYNOLDS: I did. And a paediatrician.

MS EASTMAN: And you said you knew something wasn't right.

MS REYNOLDS: Yes.

MS EASTMAN: And you felt like the GPs were dismissing your concerns and not listening. Can you remember – and if you want to say anything or tell the Royal Commission anything about just that initial time in Justin’s life when you knew
5 something was not right, but just that difficulty that you recall of getting people to listen to you and take you seriously.

MS REYNOLDS: When I went to the local GP, he referred me to the paediatrician, which was in another town two hours’ drive from where I lived. And I went there. And I explained to him what was wrong, and he said, “Basically, it seems to me that
10 he’s autistic. So basically, you have – I – you have an option if you like. You could put him in a – a group home, or home, if you don’t want to raise him-type thing.” I wasn’t impressed with that, but – so I left. Yes. I - - -

MS EASTMAN: Did anyone raise with you at this very early stage as to whether there needed to be any genetic testing at all?

15 MS REYNOLDS: No. No. Basically, at that time I was told there was nothing they could do anyway.

MS EASTMAN: So from when Justin was just a little fella, you believed that, based on what you had been told, that he had a diagnosis of autism.

MS REYNOLDS: Yes.

20 MS EASTMAN: Is that right?

MS REYNOLDS: That’s correct.

MS EASTMAN: And were you provided with any information or resources about what someone with autism might need?

MS REYNOLDS: I wasn’t given any information at the time, no.

25 MS EASTMAN: So what did you do, just work it out yourself?

MS REYNOLDS: Yes, I did some research of my own, and I had a lot of friends with nursing, so I asked when I went home to Condo and I learnt that way.

MS EASTMAN: So it was important for you, wasn’t it, that all your children went to school and you wanted them all to finish to HSC, to year 12; is that right?

30 MS REYNOLDS: That’s right.

MS EASTMAN: And Justin went to the local primary school?

MS REYNOLDS: Justin did, but not at first. Because there was no special ed class in Condo, because it's only a small community, that's why we moved to Orange, to the special school, so he could attend that.

MS EASTMAN: Okay. So he started primary school at Orange; is that right?

5 MS REYNOLDS: Yes.

MS EASTMAN: And then something happened when he was at primary school.

MS REYNOLDS: Yes.

MS EASTMAN: There was a Professor - - -

MS REYNOLDS: Yes.

10 MS EASTMAN: - - - who was doing some research. And the Professor was interested in genetic issues, and you say this is Professor Gillian Turner. And she was working at Newcastle University.

MS REYNOLDS: Yes.

MS EASTMAN: Is that right? And she had asked permission through the school

15 whether or not the kids could be tested. And you agreed to Justin being tested.

MS REYNOLDS: I did.

MS EASTMAN: And that meant taking a blood test.

MS REYNOLDS: Yes.

MS EASTMAN: And through that process, you discovered that Justin had Fragile

20 X.

MS REYNOLDS: Exactly.

MS EASTMAN: And was that the first time that anybody had talked about Fragile X, or that you ever became aware of it?

MS REYNOLDS: Yes, that was the first time.

25 MS EASTMAN: And what did that mean for you? What was – so first of all there's Justin being tested. So you found out for Justin. What happened after that and what did that mean for you?

MS REYNOLDS: My whole family was tested because it's genetic. But it only proved that myself as a carrier, and with Dr Turner, Professor Turner, she brought a

genetic counsellor with her, and so she explained to me how it all worked and how there was more that I could do. Justin – the boys could learn. Autistic is different to Fragile X. And I found that they have learnt more. There's a lot of tools that you can use with Fragile X to help them, yes.

5 MS EASTMAN: So in terms of the whole family being tested, that – you agreed then to have yourself tested.

MS REYNOLDS: Yes.

MS EASTMAN: And also all of the other children.

MS REYNOLDS: Yes.

10 MS EASTMAN: And what about your broader family? This is a pretty sensitive issue, isn't it, in First Nations families about testing of any kind. And so was that a very difficult issue to raise with your broader family, just beyond your children?

MS REYNOLDS: It was very difficult. Very emotional.

MS EASTMAN: Yes.

15 MS REYNOLDS: And at times very hurtful, yes. It's hard.

MS EASTMAN: And so I think over time some members of your family accepted, but other members of your family have really struggled to understand Fragile X - - -

MS REYNOLDS: Yes.

MS EASTMAN: - - - as a genetic condition.

20 MS REYNOLDS: Yes.

MS EASTMAN: But it's not anybody's fault, is it.

MS REYNOLDS: No. No, it isn't. It's just what you're born with.

MS EASTMAN: Is there some shame and stigma attached to having Fragile X in some First Nations families?

25 MS REYNOLDS: Back then, before it was known, I think, about what Fragile X meant or how you could get it, I had comments such as, "Are you trying to tell me that some of my family is going to be spastic?" You know, that was just a given word back then. And that caused me to move away from all my family because it was hurtful to me and my family, yes.

MS EASTMAN: And so it was a pretty difficult time for you when you discovered that Justin and Luke had Fragile X and that had a fairly significant impact on them and their ability to do tasks, and to participate in school life, and that caused you to really worry about their future; is that right?

5 MS REYNOLDS: I did. I didn't – but with Luke, I went to the same paediatrician, who basically said I was being an irate mother because I couldn't possibly get - - -
MS EASTMAN: What was it – what did you do to warrant that?

MS REYNOLDS: Yeah, I couldn't possibly have two autistic children, but this was prior to having the blood test done, to say that it was Fragile X and not autistic.

10 MS EASTMAN: Right. And in terms of just the medical services around you, the local GPs – and I think you also used the Aboriginal Medical Service from time to time. Did anybody give you any advice about what it meant for the two boys having Fragile X in terms of their future and their opportunities in the future?

MS REYNOLDS: No, no.

15 MS EASTMAN: Nothing?

MS REYNOLDS: It was just genetic counselling, I think. Hazel Robertson, she used to come and visit me in Condo and in Orange, and talk about how to – because it's hereditary, and it was going to be a known fact that there was going to be more families and more children be born with this condition. So we actually went around
20 to the community and talked to all the families that I knew had this condition in their family. But not all the families wanted to know about it, because of their own - - -

MS EASTMAN: Their own circumstances.

MS REYNOLDS: Yes.

MS EASTMAN: So it's just been very difficult, hasn't it, to be able to share
25 information about what Fragile X means?

MS REYNOLDS: Yes.

MS EASTMAN: That it's nobody's fault.

MS REYNOLDS: Yes.

MS EASTMAN: That it's not a disease, and that there are some support services
30 available for families if the diagnosis is there.

MS REYNOLDS: Yes.

MS EASTMAN: What about genetic testing before somebody might have a child? Is that – how is that going, in terms of your observations in the First Nations communities?

5 MS REYNOLDS: It's basically non-existent. I have family – or I know most of my community. And the ones that I know have grown up, who have that hereditary Fragile X in their family, if I talk to them when I go home and I say to them, you know, “Just ask the doctor to test it”. And I see kids in the communities still now. And I've said to their mothers, “Get this child checked because they're having” – you know, they're non-verbal, they're having all these issues at school, and they're not knowing why, but it's because of, you know, they just – they need support to do it.

MS EASTMAN: So still a lot more that we can do as a community in education - - -

MS REYNOLDS: Of course.

MS EASTMAN: - - - around Fragile X.

15 MS REYNOLDS: There is, yes.

MS EASTMAN: That's - - -

MS REYNOLDS: Yes.

MS EASTMAN: I think you've told me that that's - - -

MS REYNOLDS: Yes, there is.

20 MS EASTMAN: - - - an important issue.

MS REYNOLDS: Yes.

MS EASTMAN: All right. So can I come back to Luke and Justin.

MS REYNOLDS: Yes.

MS EASTMAN: So you got them through and they finished the HSC and year 12.

25 MS REYNOLDS: Yes.

MS EASTMAN: And then you wanted them to get jobs.

MS REYNOLDS: Yes.

MS EASTMAN: And so in terms of trying to get jobs for both Luke and Justin, that you've made attempts over the years to try to find them opportunities for work. And

would it be fair to say that they've had a few attempts, and some of them have been successful and some - - -

MS REYNOLDS: Some of them not.

MS EASTMAN: - - - of them not successful.

5 MS REYNOLDS: Yes, that's true

MS EASTMAN: And you might want to talk about one example involving Justin but we will see when we get there. All right. So can we deal with Justin.

MS REYNOLDS: Yes.

MS EASTMAN: And you describe him in paragraph 28 as a gentle giant.

10 MS REYNOLDS: Yes.

MS EASTMAN: So he's a big fellow, isn't he? He's well over six foot.

MS REYNOLDS: He is.

MS EASTMAN: Okay. But he loves the Lord.

MS REYNOLDS: He does.

15 MS EASTMAN: And he loves to sing.

MS REYNOLDS: He does.

MS EASTMAN: But he needs full-time care and he cannot live independently.

And so your role now is as a full-time carer to Justin; is that right?

MS REYNOLDS: Yes.

20 MS EASTMAN: And your two daughters also help out.

MS REYNOLDS: Yes.

MS EASTMAN: Okay. So Justin's had a range of health issues over his life, following the diagnosis of Fragile X. Around that time, you also received a diagnosis that he has epilepsy.

25 MS REYNOLDS: Yes, that's correct.

MS EASTMAN: And he has experienced seizures over his life.

MS REYNOLDS: Yes.
MS EASTMAN: All right. And on one occasion he was hospitalised having had a seizure.
MS REYNOLDS: Yes.
5 MS EASTMAN: And you say while he was there he left the room and the hospital staff just lost him.
MS REYNOLDS: Yes.
MS EASTMAN: And they found him on the road crying and you took him home.
MS REYNOLDS: They didn't find him.
10 MS EASTMAN: You found him.
MS REYNOLDS: I found him.
MS EASTMAN: So just on the road, what - - -
MS REYNOLDS: Yes.
MS EASTMAN: - - - nearby the hospital.
15 MS REYNOLDS: In the middle of the road, yes.
MS EASTMAN: Crying, and you took him home.
MS REYNOLDS: Yes.
MS EASTMAN: And for many years after that he didn't have a seizure.
MS REYNOLDS: Yes, that's correct.
20 MS EASTMAN: Right. Can you remember when it was that Justin was hospitalised in relation to this seizure?
MS REYNOLDS: He was about seven.
MS EASTMAN: So he was a little fellow then?
MS REYNOLDS: Yes.
25 MS EASTMAN: And was that the part – one of the sort of starts for him about getting very nervous about going to hospital?

MS REYNOLDS: That was the first time I think I recognised the fear, anxiety in him and to going to hospitals, because that was probably the first time he has been in hospital. And I asked the staff why didn't they look for him? Nobody gave an answer.

5 MS EASTMAN: Right.

MS REYNOLDS: Take him home.

MS EASTMAN: And so Justin's had a few issues in hospital. You had to have a tooth removed in hospital; is that right?

MS REYNOLDS: That's right.

10 MS EASTMAN: And you tell the Royal Commission in your statement that when that happened – and I think you were living in Condobolin then.

MS REYNOLDS: Yes.

MS EASTMAN: So how old would Justin have been at that time?

MS REYNOLDS: About 28.

15 MS EASTMAN: All right. And you wanted the doctors to listen to you because you knew that Justin would need some medication - - -

MS REYNOLDS: Yes.

MS EASTMAN: - - - before he went into the hospital - - -

MS REYNOLDS: Yes.

20 MS EASTMAN: - - - to calm him down.

MS REYNOLDS: Yes.

MS EASTMAN: And you felt that the doctors – did they listen to you on that time?

MS REYNOLDS: No.

25 MS EASTMAN: And so when he got to hospital to have this tooth removed, he got really upset; is that right?

MS REYNOLDS: That's right.

MS EASTMAN: And you felt no one was listening to you. And something pretty bad happened, didn't it? So do you want to tell the Royal Commission about that?

MS REYNOLDS: Throughout my years with my children, I've always put in another plan. And so I brought my family to come and support me. And I said to my brother, "Please watch him because he is going to hurt me because I've put him here". And I did ask doctors to give him something to calm him down. But anyway,
5 I got thrown from one side of the room to the other. And it hurt. But – and then they wanted to give him something because then they were frightened that he would hurt them.

MS EASTMAN: And Justin didn't - - -

MS REYNOLDS: But it was only after he hurt me.

10 MS EASTMAN: Justin didn't mean to - - -

MS REYNOLDS: No.

MS EASTMAN: - - - hurt you at all.

MS REYNOLDS: No.

MS EASTMAN: This is his way of expressing that great fear - - -

15 MS REYNOLDS: Yes.

MS EASTMAN: - - - and anxiety that he had about being at hospital.

MS REYNOLDS: Yes.

MS EASTMAN: And the fear of not knowing what was going to happen to him?

MS REYNOLDS: Yes, yes.

20 MS EASTMAN: And so having the whole family there helped you, and it took all of you - - -

MS REYNOLDS: Yes.

MS EASTMAN: - - - to help calm him down.

MS REYNOLDS: It took all of us to sit on him, basically.

25 MS EASTMAN: Right. And he was able to have the procedure. But you don't really want to have to, each time you go to the hospital - - -

MS REYNOLDS: No.

MS EASTMAN: - - - have a troop of six members of your family to help you - - -

MS REYNOLDS: That's basically what I've done.
MS EASTMAN: Right. But each time you feel like surely there must be a better way - - -
MS REYNOLDS: Yes.
5 MS EASTMAN: - - - that we can ensure that Justin and Luke are able to go to hospital without - - -
MS REYNOLDS: Yes.
MS EASTMAN: - - - being so scared; is that right?
MS REYNOLDS: Yes.
10 MS EASTMAN: And that also causes you some anxiety, doesn't it? You never know what might happen, and that's a pretty scary thing for you as well.
MS REYNOLDS: Usually I'm the one that get hurt, yes.
MS EASTMAN: All right. Can I ask you now about Luke.
MS REYNOLDS: Yes.
15 MS EASTMAN: So Luke also needs full-time care, and he cannot live independently. And you're his full-time carer and also your daughters help as well.
MS REYNOLDS: Yes, yes.
MS EASTMAN: And he doesn't love the Lord in the same way that Justin does.
MS REYNOLDS: No.
20 MS EASTMAN: His Lord is rugby league; is that right? And his favourite team is the Queensland Broncos.
MS REYNOLDS: Broncos.
MS EASTMAN: And so if he has a religious bent at all it's in favour of rugby league; is that right?
25 MS REYNOLDS: That's right.
MS EASTMAN: He often wears his Broncos top and he's a very firm supporter.
MS REYNOLDS: Yes.

MS EASTMAN: So I did ask you this, how is it that a boy from Dubbo ends up following the Queensland Broncos? How did that happen?

MS REYNOLDS: He likes Indigenous players, the players for the Broncos, and there's not many Indigenous players play for New South Wales. And his uncle was a
5 follower. So, yes, and he just followed his uncle.

MS EASTMAN: All right.

COMMISSIONER ATKINSON: I can tell you as a Queenslander I'm not sure he shouldn't be following the Cowboys.

MS REYNOLDS: Well, he likes Johnathan Thurston.

10 MS EASTMAN: But for Luke, being involved in being able to go to the local rugby league games, it's been a really important thing for him.

MS REYNOLDS: Yes.

MS EASTMAN: So you can't underplay that, for him, his love of rugby league - - -

MS REYNOLDS: Yes.

15 MS EASTMAN: - - - and being able to watch the teams as he did in Dubbo was just a quiet - something that really has helped him; is that right?

MS REYNOLDS: Yes, yes.

MS EASTMAN: And I think when he turned 30, the local Dubbo team took him out for his first beer.

20 MS REYNOLDS: They did. They did.

MS EASTMAN: Did you know about that at the time?

MS REYNOLDS: Yes, no, they told me, yes.

MS EASTMAN: So Luke has had also a number of really troubling health issues that you've had to help him work through over the years; is that right?

25 MS REYNOLDS: That's right.

MS EASTMAN: And his health started to decline, in particular, in 2015. And that stopped him being able to go to the footy matches.

MS REYNOLDS: Yes.

MS EASTMAN: And he really spent a lot more time indoors.
MS REYNOLDS: That's right.
MS EASTMAN: And that was something for you. Noticing that change in Luke caused you a real concern. And you really wanted to be quite strong in getting some
5 answers as to what was going on with Luke; is that right?
MS REYNOLDS: That's right.
MS EASTMAN: And so initially, you organised for him to be seen by the GP and to get some blood tests; is that right?
MS REYNOLDS: That's right.
10 MS EASTMAN: And those blood tests showed that it was highly likely that Luke had developed a form of thyroid cancer.
MS REYNOLDS: Yes, that's correct.
MS EASTMAN: And you were told by the GP that that type of cancer was generally curable through surgery - - -
15 MS REYNOLDS: That's right.
MS EASTMAN: - - - radiation or chemotherapy.
MS REYNOLDS: Yes.
MS EASTMAN: So the GP gave you that news initially; is that right?
MS REYNOLDS: Yes.
20 MS EASTMAN: And did the GP have to tell Luke about this, or did you have to tell him?
MS REYNOLDS: No, I preferred not to. I wanted Luke to have the biopsy first to confirm it.
MS EASTMAN: So you had to explain to Luke that he might have cancer.
25 MS REYNOLDS: Yes.
MS EASTMAN: And you had to explain to him that he needed to go to hospital to have what's called a biopsy.

MS REYNOLDS: The biopsy was done in a – we have radiology – not in the hospital. Yes, that was – that would be too hard.

MS EASTMAN: Okay.

MS REYNOLDS: Yes.

5 MS EASTMAN: You had to tell him that he might have to have the cancer removed, otherwise he might die.

MS REYNOLDS: Yes. Yes.

MS EASTMAN: So that was a hard thing to tell him.

MS REYNOLDS: Yes, it was.

10 MS EASTMAN: And you knew that Luke had a very acute fear of hospitals - - -

MS REYNOLDS: Yes.

MS EASTMAN: - - - of doctors, and of medical environments.

MS REYNOLDS: Yes.

MS EASTMAN: So you knew this was going to be pretty challenging in terms of

15 managing this particular cancer diagnosis.

MS REYNOLDS: Yes.

MS EASTMAN: And you say to the Royal Commission in your statement that when Luke is in unfamiliar surroundings, he experiences significant anxiety.

MS REYNOLDS: He does.

20 MS EASTMAN: So when doctors or nurses or medical staff come close to Luke to attempt treatment, he thinks that people are trying to harm him.

MS REYNOLDS: Yes, that's right.

MS EASTMAN: And so his initial response is to resist.

MS REYNOLDS: It is.

25 MS EASTMAN: And then he will attack.

MS REYNOLDS: Yes.

MS EASTMAN: And he's a big fellow as well, isn't he?
MS REYNOLDS: Yes.
MS EASTMAN: And so when Luke feels that someone has put him or pushed him into a corner, he will attack.
5 MS REYNOLDS: Yes.
MS EASTMAN: To save himself. Is that right?
MS REYNOLDS: Yes.
MS EASTMAN: And so you knew this was going to be really difficult for anybody to undertake a physical examination of him and for the doctors to be able to really
10 look closely - - -
MS REYNOLDS: Yes.
MS EASTMAN: - - - at his cancer. But you knew that blood tests were not enough and that - - -
MS REYNOLDS: Yes.
15 MS EASTMAN: - - - Luke would need to have an invasive procedure in the form of biopsies. Now, how many attempts have there been to get the biopsy done?
MS REYNOLDS: We had eight attempts. And I – I asked the GP to just give him two Valiums at the – before the first one, and I – I basically said to him, “I will bring
20 Luke to you. If it's – if it causes a drama to give two Valiums, or any other medication to help him calm him down, I will bring him to you or you can come to him.” But he wouldn't do it. So after eight attempts, the doctor that was doing the biopsy, he had already previously done it twice and said he can't – can't – she
25 couldn't do it again. So I asked her to write a letter to the doctor and just explain why Luke needed something to calm him down. So the ninth attempt, with the medication, it got done. But every procedure with doctors, you have to – basically, I tell people you have to put – I have to put my boys on show for people to get it. Basically, he had to go through all that just to prove a point, that he did need something to calm him down.
MS EASTMAN: You got so frustrated with this - - -
30 MS REYNOLDS: Yes, I did.
MS EASTMAN: - - - in trying to get access to somebody to help you, that you actually went to NITV. That's the National Indigenous Television station, part of SBS. And you spoke to Stan Grant and asked him to run a story on your family so

that you could actually get some help. What took you to take that step to have to feel that you needed to go to the media to get some assistance?

MS REYNOLDS: It was actually – they were – they were in Dubbo for disability awareness at the time, and they came and talked to me. And I told them my story.

5 And Ella – and she said, “Narelle, you should let us do this story because it’s a good story.”

MS EASTMAN: But not all your family was that keen on you going on the telly; is that right?

MS REYNOLDS: No, my daughters weren’t.

10 MS EASTMAN: Yes.

MS REYNOLDS: But they agreed because it was for their brother to hopefully improve. I’m not about bringing anything down. I’m about trying to make things easier.

MS EASTMAN: Okay. And so you did that story. And that brought some
15 attention on your family’s needs; is that right?

MS REYNOLDS: It did. It did.

MS EASTMAN: But it also sort of caused some people to feel a little upset that you had - - -

MS REYNOLDS: Yes.

20 MS EASTMAN: - - - to go to the media.

MS REYNOLDS: Yes.

MS EASTMAN: Is that right?

MS REYNOLDS: It did, yes.

MS EASTMAN: So after about two years of fighting with the system, as you say,
25 or the doctors, Luke actually had his surgery.

MS REYNOLDS: Yes.

MS EASTMAN: And after the surgery, the surgeon patted you on the back and said, “You did a good job convincing us to do that.”

MS REYNOLDS: Yes.

MS EASTMAN: You remember those words.
MS REYNOLDS: I do.
MS EASTMAN: You say, "I'll never forget it."
MS REYNOLDS: I'll never forget it. And I wanted to punch him.
5 MS EASTMAN: I was going to say your response was, "I felt like punching him."
I assume you didn't do that.
MS REYNOLDS: He had no idea.
MS EASTMAN: Yes.
MS REYNOLDS: Everything about my sons is preparation. And it's not
10 preparation for one day. It's preparation months and months ahead. For this surgery
that – Luke's doing – procedure – next one – I started six months ago - of prep.
MS EASTMAN: Just to get him ready for some surgery.
MS REYNOLDS: Yes. Yes.
MS EASTMAN: So it takes six months to get him ready.
15 MS REYNOLDS: Sometimes it's longer, but it's all about preparation.
MS EASTMAN: And in terms of that preparation, is that about talking to him and
telling him what's going to happen? What else do you do?
MS REYNOLDS: What's going to happen. I take him to the hospital. We do a
20 walkthrough. I try to get people there to – and sometimes – some of the nurses are
really good, and they have a yarn to them, try to relax them before they go,
familiarise themselves with the environment. And sometimes it works and
sometimes it doesn't.
MS EASTMAN: Okay.
MS REYNOLDS: But it – it is worth doing that.
25 MS EASTMAN: Since Luke's surgery, you tell the Royal Commission that he has
deteriorated. So the surgery hasn't resulted in his health being better. And on many
occasions you visited doctors and asked for referrals because you want to find out
why and what's going on. Is that right? You know something doesn't add up.
MS REYNOLDS: As a parent, you know when your child's sick. You know when
30 there's something wrong. And my son kept – he kept having such pain. And it's not

about – it’s not about him just saying it. You could see it, that he was in pain. So I kept going back to the doctors. And all they did was basically up his medication, OxyContin, more painkillers. But I wanted to know why, if he’s had the cancer removed and his thyroid out, he should have – and his medication is – everything is routine, he should have been improving, like everybody else who’s had their thyroid out.

5 MS EASTMAN: Have you found - - -
MS REYNOLDS: He should have improved.
MS EASTMAN: Have you found out what’s wrong?
10 MS REYNOLDS: No. No, I still haven’t.
MS EASTMAN: So you still haven’t been able to access a medical service to be able to help you understand.
MS REYNOLDS: That’s why I moved to Coffs Harbour.
MS EASTMAN: All right. So you felt Dubbo was a dead end.
15 MS REYNOLDS: Yes.
MS EASTMAN: And because of your investigations with the NDIS, you thought that because the NDIS had a complex supports needs pathway in Coffs Harbour, that it was worth the chance of using the NDIS, relocate all of your family to Coffs Harbour, and to see if you could get access to some of the particular programs in
20 Coffs Harbour that might be able to help Luke; is that right?
MS REYNOLDS: I’ll just backtrack.
MS EASTMAN: Of course.
MS REYNOLDS: I’ve moved to Coffs Harbour because I was – I got involved with a – a friend of mine who wanted to develop a – a service that would create a
25 culturally appropriate service. And I was interested, so we moved for that, so that my boys could access something that was culturally inclusive. But still then she said there was a good doctor there as well. And then I found out about the – the complex care team in NDIS. And I – I went and seen them when I knew Luke was
having - - -
30 MS EASTMAN: Okay.
MS REYNOLDS: Yes.

MS EASTMAN: Now, the move to Coffs Harbour has also been quite challenging for you and the family, hasn't it?

MS REYNOLDS: It has.

5 MS EASTMAN: And one of the significant challenges is that, in effect, you are homeless.

MS REYNOLDS: Yes.

MS EASTMAN: And this is something that causes you deep distress. And it's a very difficult thing to talk about in the Royal Commission.

10 MS REYNOLDS: At the moment, in the last 12 months I've lived in a tent, in a shed, and a cabin. Everything has been short-term. And it is hard on my sons, because they don't like change. So everything has, like I said, preparation. And so it has been difficult. However, the goal why I'm there is to get answers. So I figured – I figured sometimes the negative – I can deal with it. It's painful, but it's – it's just the way it is.

15 MS EASTMAN: It's been very hard for you to find appropriate housing in Coffs Harbour.

MS REYNOLDS: Yes.

MS EASTMAN: And you brought your kids up to have their own space.

MS REYNOLDS: Yes.

20 MS EASTMAN: And at the present time they don't have any space.

MS REYNOLDS: No.

MS EASTMAN: It's pretty crowded. And there's seven of you living in a one bedroom cabin in a caravan park.

MS REYNOLDS: At the moment I'm living in a – in a flat with my – with my - - -

25 MS EASTMAN: So you've got a broader family support - - -

MS REYNOLDS: Yes.

MS EASTMAN: - - - round there.

MS REYNOLDS: Yes.

MS EASTMAN: Is there any prospect that the housing will improve for you?

MS REYNOLDS: Not at the moment, no.
MS EASTMAN: But you haven't been shy, have you - - -
MS REYNOLDS: No.
MS EASTMAN: - - - in asking for the relevant services and making inquiries
5 and - - -
MS REYNOLDS: Yes.
MS EASTMAN: - - - knocking on doors - - -
MS REYNOLDS: Yes.
MS EASTMAN: - - - and talking to various people.
10 MS REYNOLDS: Been to a lot of viewers – viewings, applied for a lot of housings.
MS EASTMAN: What about housing that's appropriate for the people with the type
of disabilities that both your sons have? What's the situation in Coffs Harbour for
housing that would support them and their needs?
MS REYNOLDS: Very limited.
15 MS EASTMAN: At the same time, you say in paragraph 57 that last year the NDIS
funding tripled for Justin and for Luke.
MS REYNOLDS: That's correct.
MS EASTMAN: And notwithstanding the increase in NDIS funding, there are no
services that allow you to find appropriate housing.
20 MS REYNOLDS: No, that's correct.
MS EASTMAN: And for you, having safe and secure housing is really important to
your health and to the health of your sons; is that right?
MS REYNOLDS: That's right.
MS EASTMAN: And so while the housing situation remains a little bit in limbo,
25 you're concerned about what impact this is going to have on the long-term health of
everybody in the family; is that right?
MS REYNOLDS: My – my sons are traumatised by me making them move. And I
see that trauma all the time, but there's not much I can do about it.

MS EASTMAN: Now, you don't want people to feel sorry for you.
MS REYNOLDS: No, I don't.
MS EASTMAN: You're not that type of person.
MS REYNOLDS: No.
5 MS EASTMAN: But you want people to know and understand about just the layers that you, as a First Nations person, has experienced where you get a connection between housing, employment, access to health services, and - - -
MS REYNOLDS: That's correct.
MS EASTMAN: - - - disability services. And that's why you're happy to share this
10 story.
MS REYNOLDS: Yes.
MS EASTMAN: But you don't want people feeling sorry for you, do you?
MS REYNOLDS: No.
MS EASTMAN: You're a very strong woman in your advocacy, aren't you?
15 MS REYNOLDS: Yes, I am.
MS EASTMAN: And while you advocate very strongly for your family, you're the person other people come to - - -
MS REYNOLDS: Yes.
MS EASTMAN: - - - and ask you, "Auntie, can you help us with this? Where
20 should we go, and what should we do?"
MS REYNOLDS: That's just the way it is.
MS EASTMAN: Can you tell the Royal Commission a little bit about all of the other people that you help in terms of your advocacy and your knowledge?
MS REYNOLDS: I live in Coffs Harbour, but I regularly sort problems out in my
25 community in Condo. I do that all the time. That's just – that's the way we all work. And I have – whilst in Coffs Harbour, I've had other Aboriginal people who have disabilities or have mental health problems come and talk to me. Their – their workers have brought them to me to ask what is it they can do. And it was only last week that I wrote – I got so frustrated with them, with the doctors. This one client,
30 I've known her for now for over eight months, but she had been to the doctors for a

lot of years and never had one health assessment. And that frustrated me. So I wrote a list. And I said please – I gave it to the worker. I said, “Please, when you take her to the doctors, I want you to tell the doctor to have all this done”. But she gave the doctor the list and anyway, it’s getting it done – just simple things. She’s got really bad teeth. She’s never been to the optometrist, never had any cognitive assessments done. Nothing. Nothing. And I find that so irritating.

5 MS EASTMAN: And one thing you talk about in your statement is the absence of culturally inclusive practices in health care and services.

MS REYNOLDS: Yes.

10 MS EASTMAN: And from your experience, a lot of health services do not know how to deal with people and help people with disability who are also First Nations people; is that right?

MS REYNOLDS: That’s right.

MS EASTMAN: And for you, you say being Aboriginal, on top of being the mother of children with intellectual disability, is what you describe as the double whammy.

15 MS REYNOLDS: Well, it is.

MS EASTMAN: This is paragraph 61.

MS REYNOLDS: It is.

MS EASTMAN: And you say:

20 *Being black and fighting through the health system is one thing, but fighting for sons with intellectual disability is another.*

And you say:

I don’t know if anyone can understand that.

25 Can you help us try to have an understanding as to why this is such a fight for you all the time?

MS REYNOLDS: It’s – Aboriginal people have long years running – I grew up on a mission – and my mother always advocate most of the people who lived on the mission lived in tin shacks. So Mum used to fight for just decent living conditions. So I grew up with that advocacy. And then when I had my sons, just trying to get doctors to – and any – whether it’s health, housing, education, well, they’re dismissive because I’m black, “What do you know?” And because they’re the professional and they know better than me. And I find that really condescending. So I generally work around trying to help – I will rather help you understand so that my

sons can get better access. Rather than jump up and down and make a noise, I will work with the services. And I do that. I work – I will offer my services free to help them understand what it means to be Aboriginal, and what it means for my sons to have a disability. And my role as a carer, as a mother who know my sons, can do so much, but they're not given an opportunity to display their talents. They've just got a disability. That's all they've got. They're more than that.

5 MS EASTMAN: You say this – and if you want to read this or you want me to read it's in paragraph 62 of your statement.

MS REYNOLDS: I need glasses. Sorry.

10 MS EASTMAN: Paragraph 62, these are your words.

MS REYNOLDS: What page?

MS EASTMAN: Page 9, paragraph 62.

MS REYNOLDS:

The majority of First Nations people are oppressed.

15 And I've always believed that we are oppressed. I grew up, like I said, on the mission, and it was – we were told to stay in that environment. We weren't allowed to trust white people. We had to comply with what mission managers and whoever. If they were white, we had to comply with what they said. We weren't allowed to have our own ideas and our own way of doing things. It wasn't good enough, I suppose. It wasn't – it was their way or the highway, type thing. So you tend to not even express that maybe it could be a better thing if you do it this way.

20

MS EASTMAN: So this is why you say:

Blackfellas always have to comply with white rules.

MS REYNOLDS: Yes.

25 MS EASTMAN: And:

We have to ensure that our place in the world, that is rightfully ours, is safe.

MS REYNOLDS: Yes.

MS EASTMAN: And:

We have to show white people our own value.

30 And you say:

That's just the way it is.

MS REYNOLDS: It is. I was brought up to value who I am as a Wiradjuri woman, as an Aboriginal woman, and I do. I will always be who I am, and I teach my kids to be proud of who they are, their culture, and to share it to those that want to learn.

5 MS EASTMAN: While it's not in your nature, you continue to fight.

MS REYNOLDS: Yes.

MS EASTMAN: And you will do so for all your children.

MS REYNOLDS: Yes.

MS EASTMAN: But particularly your two sons; is that right?

10 MS REYNOLDS: Yes.

MS EASTMAN: Now, you've got some suggestions for improving the system. But one thing I wanted to ask you about is complaints and raising issues. So from time to time you do raise complaints and raise issues, and you ask people to help you. But it's the case, isn't it, that if they can't help you, you just want to know if they can or

15 can't.

MS REYNOLDS: That's right.

MS EASTMAN: You don't want the empty promise.

MS REYNOLDS: I don't want lingering.

MS EASTMAN: You say:

20 *I don't have time to linger. I can't wait.*

MS REYNOLDS: No.

MS EASTMAN: And so one of the issues for you is if you do ask for help or you do raise concerns, you want people to be direct with you.

MS REYNOLDS: Yes.

25 MS EASTMAN: And not make you a promise that they can't keep.

MS REYNOLDS: That's right.

MS EASTMAN: And if they can't help you, you will go to the next person - - -

MS REYNOLDS: Next one, yes.
MS EASTMAN: - - - or you will look yourself.
MS REYNOLDS: Yes.
MS EASTMAN: Or options.
5 MS REYNOLDS: Find a solution.
MS EASTMAN: So against that background, you've made some suggestions for improving the system for First Nations people generally, not just for your son.
MS REYNOLDS: Yes.
MS EASTMAN: But that's very much informed by your pretty strong view that, "If
10 you can't help me, don't waste my time".
MS REYNOLDS: Yes.
MS EASTMAN: And so the suggestions that you've made are about making sure that if people can deliver on their promises, that they should be able to deliver on their promises; is that right?
15 MS REYNOLDS: Yes.
MS EASTMAN: So the suggestions that you've made – so if you've still got your statement open, at paragraph 65, you say that:
Each hospital should have at least one trained disability worker. This could be a trained registered nurse who is educated in the fears and anxieties of people with intellectual disability.
20 MS REYNOLDS: Yes.
MS EASTMAN:
And this person could know about the different options and adjustments available in the hospital setting.
25 MS REYNOLDS: Yes.
MS EASTMAN: So if that had been available to you, that could have made a really big difference to – instead of having eight attempts at a biopsy, that you might have been able to help Luke - - -
MS REYNOLDS: Yes.

MS EASTMAN: - - - have that treatment – have that procedure done much earlier on; is that right?

MS REYNOLDS: Yes, that's correct.

MS EASTMAN: You also say that you believe the NDIS should be visiting service
5 providers.

MS REYNOLDS: Yes.

MS EASTMAN: And if something is wrong, the NDIS representative should go to the service provider in person, and they should see for themselves rather than - - -

MS REYNOLDS: Yes.

10 MS EASTMAN: - - - I think as you say, sitting on a desk and reading it on an email; is that right?

MS REYNOLDS: Yes.

MS EASTMAN: And for you, writing emails is something that actually takes a bit of effort.

15 MS REYNOLDS: It does.

MS EASTMAN: You don't have the internet connected.

MS REYNOLDS: No.

MS EASTMAN: You don't have access to these facilities. But sometimes it's a little frustrating that being able to talk to some government agencies assumes that
20 you've got access - - -

MS REYNOLDS: That's right.

MS EASTMAN: - - - to internet, email, computers - - -

MS REYNOLDS: Yes.

MS EASTMAN: - - - and the like. So that's a bit frustrating from time to time.

25 MS REYNOLDS: It is.

MS EASTMAN: You think the NDIS needs to have Aboriginal liaison officers who can work with carers and assist people with disability to access services.

MS REYNOLDS: I do. I've actually supported a few family members, and my daughter as well, with her grand – with her son, my grandson. And I found they don't have – they – I suppose everyone's different but trying to get your own perspectives to NDIS, sometimes bureaucrats, I suppose, you would say, know it all,
5 and they don't. Sometimes when you're sitting on the other side of the table, I generally get a feel if you're listening to me or not. And so I don't – Aboriginal people just shut down. We just don't talk, because what's the point of talking to you when we know you're not listening.

MS EASTMAN: Well, I think you say you're aware of a lot of Aboriginal people with disability don't remain connected with or continue to seek services from the NDIS.

MS REYNOLDS: They don't.

MS EASTMAN: And you think this is because there are no Aboriginal legal – sorry, liaison officers who could connect the service providers and clients; is that
15 right?

MS REYNOLDS: Throughout history there was, you know, ACLOs, Aboriginal liaison officers in hospitals. There's never been anything in NDIS to support access for Aboriginal people. There hasn't been an NDIS component to say can you – I mean, I know there's Aboriginal Advisory Group and all that there but they don't
20 know what the ground root's like. And so there's no one between them and the people out there. There's no connection. And most of the time they need to have a familiar face, a black face, just to feel like they're safe to talk to. And that's what I do but I know there needs to be someone employed by NDIS to help that gap. I believe there's a gap in that.

MS EASTMAN: Now, there was a few other things that I think you've been thinking about after you prepared your statement that you wanted to add by way of suggestions. So can I hand over to you, and please tell the Royal Commissioners the additional thoughts that you have.

MS REYNOLDS: Because my boys have a disability and I – my life has been how
30 do I make their life improve, what can I do as a parent to help them access, so I worked as a child care worker and I took my children to early intervention. And then I worked in the school to get them access to help the teachers, so I worked with the teachers. How can they help – how can I help them. So I've always worked on the approach that it works both ways. And if I help you, can you help me help them. So
35 it's a win-win all the way around. But not everyone thinks like that and not everyone is receptive. Especially when – because, you know, when you're a parent, you can get a little bit aggressive. I know I can, especially when I feel like they're not listening to me, and it could be a good thing, and it could work.

You just have to open your mind up to have this work, let it – just trial it. You know,
40 I've said to providers, that my son went to go to disability services, "I will come",

because there was no other Aboriginal clients there. And I said, “He likes to do all these stuff but youse don’t run these sort of programs”, I will offer – you said, I said, “I will come and show you how to introduce just some tap sticks, to have music, Aboriginal music, to be inclusive”. My son will feel much better because it’s part of
5 him there, but they’re not receptive to that. So service providers still have a long way to learn about cultural inclusion, and it doesn’t matter whether it’s health, education, it doesn’t matter. Right across the board, they still have a lot to learn about what we have to offer and what youse can gain by it.

Yes. And I think there’s communication gap. I think all workers with disabilities
10 should train in disability, you know, have a Cert IV in disability. I think they all should have some sort of qualification to work with people with disability and have ongoing training about when they get a new client, you know, providers should at least give them some support in how to work with that client. I find that I’m training the workers, and I found this from day dot, I train the teachers how to deal with my
15 sons, and I train the disability support workers, how to – the triggers, what they like and what their dislikes. Because that’s a win-win for me. Because that helps them stay longer but it also helps them know my sons.

Yes. You know, and I believe that there’s no respite. There is no respite. Even with
20 NDIS. I have – I don’t get respite. My respite is my daughters staying with my sons and I will go. There’s no – NDIS doesn’t seem to – and service providers don’t seem to look at I – if I say I need a break, most of the time they will say, “Oh, there’s this service, that service, that service”. So I say, “You come and pick him up and take him in the door”. Got to give a visual. You pick him up. You take him. See if he will go in the door, because they never do. And I can’t do it. I’ve tried. I will be
25 thrown over the fence before they walk in the door because their place is home, but there’s not a lot of thought on for carers to have a break, and I’m not here to advocate for me, but it’s all carers. We all need help. Everyone. I don’t ask – I don’t want a lot of respite. Sometimes I just – like this is my respite, coming here and sleeping on a bed. I sleep on a lounge. Two-seater lounge. So coming here and sleeping on a
30 bed was my respite, and I appreciate it. Yes.

MS EASTMAN: Ms Reynolds, thank you very much for your evidence today, and sharing so much about the personal matters in your family over many times and also at the present time. We greatly appreciate the evidence that you’ve given to the Royal Commission. If the Commissioners please.

35 MS REYNOLDS: Thank you.

COMMISSIONER SACKVILLE: Ms Reynolds, thank you too, from – on behalf of the Commissioners for coming and telling us about Luke and Justin. And we too very much appreciate the way in which you have explained to us your own experiences. Thank you very much.

40 MS REYNOLDS: I hope there’s change. That’s all. Thank you.

<THE WITNESS WITHDREW

[3.02 pm]

MS EASTMAN: Commissioners, would it be convenient if we had a 15 minute adjournment, and then Dr Avery will give his evidence.

5 COMMISSIONER SACKVILLE: Thank you. We will do that.

ADJOURNED

[3.02 pm]

RESUMED

[3.23 pm]

10

COMMISSIONER SACKVILLE: Yes, Dr Avery. Thank you. Welcome to the Commission. And if you wouldn't mind taking the oath or affirmation, as the case may be, thank you very much.

15 **<SCOTT AVERY, SWORN**

[3.23 pm]

<EXAMINATION BY MS EASTMAN

20 COMMISSIONER SACKVILLE: Thank you, Dr Avery. Ms Eastman will now ask you some questions.

DR AVERY: Might need that later.

MS EASTMAN: Commissioners, Dr Avery's statement is found at part B of the bundle, tab 10 and tab 11 and this will become exhibit 4.18.

COMMISSIONER SACKVILLE: Yes, thank you.

25 MS EASTMAN: So Commissioners, there's one typographical error we need to correct. Is that right, Dr Avery?

DR AVERY: That's correct.

MS EASTMAN: So this is paragraph 58 on page 19 of the statement.

DR AVERY: Yes.

30 MS EASTMAN: And it's in the second last line. And where you say, "systemic efficiencies", that should be, "systemic deficiencies".

DR AVERY: Deficiencies. And that's a direct quote from the coronial report, when we get to that later.

COMMISSIONER ATKINSON: Right.

5 MS EASTMAN: Other than that typographical error, the contents of the statement dated 14 February this year are true and correct?

DR AVERY: That's correct.

MS EASTMAN: Right. Now, you hold the role of Senior Lecturer, Research and Policy Director at Western Sydney University.

10 DR AVERY: So the university position's a Senior Lecturer position. So that's academic. I maintain an affiliation of the First Peoples Disability Network as strategic policy adviser. They're a non-government organisation. So two functions here.

MS EASTMAN: All right. And you've prepared a very detailed and lengthy statement for the Royal Commission addressing a number of issues.

15 DR AVERY: That's correct.

MS EASTMAN: And our focus this afternoon is going to be on the work that you have done and your research in relation to accessing the health system.

20 DR AVERY: That's correct. The research that I do is much broader, but given the focus of this Commission, I'm just really restricting to health. And when I say I'm restricting it to health, it's really the somatics that are the physical part of health. I could have another one on mental health as well, but just noting the content.

MS EASTMAN: So it is very likely we will see you a few times in the course of this Royal Commission, given the work that you've done and your research; is that right?

25 DR AVERY: I will have to get one of those coffee cards, buy one get one free things. So yes, I would imagine so.

30 MS EASTMAN: We will see what we can do. So I want to just start in your statement because in paragraph 3 you want to help us with some language and terminology. So you use "Aboriginal and Torres Strait Islander people" interchangeably with "First Peoples". Do you want to say something about the language that you use and how you've come to use that particular language and expression, both in your statement and also in your research.

DR AVERY: So just in terms of the language – and it's often contested. So the way that I have chosen to use it, a lot of government agencies that I've dealt with,

particularly the Australian Bureau of Statistics, they collect Aboriginal and Torres Strait Islander data. So in that space, I tend to use that terminology. First Peoples, that's an acknowledgement to the community that I'm affiliated with and the organisation the First Peoples Disability Network - and we use the word "First Peoples" as differentiated from First Nations because the disability community, when you're looking at disability, it's this non-spatial concept. So people with disability have a shared experience, so my nation is Worimi. I might have a shared experience with Wiradjuri. They're nations but we wanted to emphasise disability being a shared experience. So even when we talk about people overseas, such as First Nations – First Peoples in New Zealand, it has that sort of commonality. These are personal preferences I don't get hung up on too much, so that's just my – how I've used these terms in this statement.

MS EASTMAN: And you also wanted to make it clear that in the evidence that you will give today and the contents of your statement to the Royal Commission, that it may contain stories and expression of people who have died.

DR AVERY: So that's correct, yes. And we would expect that. So even people watching – Aboriginal and Torres Strait Islander people watching this through the webcast or live streaming, that disclosure, you know, just to inform people it might be traumatising in some cases, so - - -

MS EASTMAN: All right. Can I start with a little bit about you. So you are an Aboriginal man. And I think you've said you're a Worimi man. And you also have a disability. Are you happy to identify that for the Royal Commission?

DR AVERY: Yes.

MS EASTMAN: And it might also explain why I am trying to slow right down, but also that you're lip reading - - -

DR AVERY: Yes.

MS EASTMAN: - - - as I ask you the questions.

DR AVERY: Yes. So Aboriginal - my nation that I identify with is Worimi, which is – if you're driving from Sydney to Brisbane - we're river people. So you cross the river, Karuah River. Then you get to the Manning, that's my part that I identify with. I'm profoundly deaf. So I wear a cochlear implant, which is quite important to point out because sometimes I go to Aboriginal communities and they're kind of a bit standoffish. And I go, "I'm deaf" you know, "It's a cochlear implant".

MS EASTMAN: What do they think?

DR AVERY: And they go, "Oh yeah, thank God for that –".

MS EASTMAN: They think you might be - - -

DR AVERY: “I thought you were a copper”, which is – you know, we laugh but it’s actually there’s this dark undertone to it because going out, there’s a theme of my testimony, in that they’re very unfamiliar with health technologies that we would feel exposed to, but they do – they’re very familiar with this overlying oppression. So,
5 yes.
MS EASTMAN: You’ve very recently, just this month, taken up an appointment with the School of Social Sciences at Western Sydney University.
DR AVERY: That’s correct.
MS EASTMAN: That’s the role of Senior Lecturer.
10 DR AVERY: That’s correct.
MS EASTMAN: And from 2014 to 2020 you have been involved or are presently involved in a community-based research work with the First Peoples Disability Network; is that right?
DR AVERY: That’s correct.
15 MS EASTMAN: And during this period of time you’ve conducted a research program that sourced the experiences of Aboriginal and Torres Strait Islander people with disability, and that’s called “Culture is Inclusion, a Narrative of Aboriginal and Torres Strait Islander People with Disability”, and that was published in July 2018.
DR AVERY: That’s correct.
20 MS EASTMAN: And do you have a copy with you here?
DR AVERY: So this is the copy. We’ve attached it to the evidence as attachment B, I think it is. So the full copy of the book is submitted in the evidence.
COMMISSIONER SACKVILLE: And we have had a copy and we have read it.
DR AVERY: That’s wonderful. Yes, great.
25 MS EASTMAN: You have been appointed by the Australian Bureau of Statistics to a number of their expert advisory committees, including the National Aboriginal and Torres Strait Islander Social Survey.
DR AVERY: That’s correct.
MS EASTMAN: The Survey of Disability, Ageing and Carers.
30 DR AVERY: Yes.

MS EASTMAN: And Indigenous Data and Statistics Roundtable.

DR AVERY: Yes.

MS EASTMAN: Your role there is to provide advice on data collection methods, ethics and identifying how any limitations in Aboriginal and Torres Strait Islander
5 datasets may be explained by users of statistics and data.

DR AVERY: Yes.

MS EASTMAN: It sounds a bit complex.

DR AVERY: Look, that's what changes. If you're looking at – you will hear a lot
10 of stories come through, but what the statistical data – and the reason we have such
good relationship with the Australian Bureau of Statistics is we know that when
you're looking at policy and you're wanting to cost programs, you actually need
data. And what we're able to show through our relationships with the statistical data
and the stories is what you're hearing as one-off – they're not one-off stories. These
15 are issues – it could be shown to apply for the entire group of people who are
Aboriginal and disability. And the reason we have to be – in the Aboriginal dataset
and the disability dataset, you don't find it in one place. You kind of have to get
your hands dirty. So that's the reason why we – it's intersecting the two.

MS EASTMAN: And you have completed a PhD on the causes and effects of
20 health and social inequalities experienced by Aboriginal and Torres Strait Islander
people with disability, and your PhD's entitled "We Go Hunting Together – Cultural
and Community Inclusion as a Moderator of Social Inequality Experienced by
Aboriginal and Torres Strait Islander People with Disability".

DR AVERY: Yes. So that's a much longer title than Culture is Inclusion but that's
25 academics for you. But that's the academic component. This was really written for
community, our community, and we did it to get that knowledge back to the
community, so they can actually start exercising self-determination.

MS EASTMAN: And we will come shortly to the methodology that you used in the
research for your PhD, and that included taking direct testimony or direct evidence of
the experience of Aboriginal and Torres Strait Islander people.

30 DR AVERY: Yes.

MS EASTMAN: All right. So in addition to all those qualifications, you have also
had professional experience in the health sector; is that right?

DR AVERY: That's correct.

MS EASTMAN: And so some of your work has been work involving being the health programs manager, and health care analyst at a major Australian health management organisation.

DR AVERY: That's correct.

5 MS EASTMAN: And you also have a Masters degree by research in Health information and Management; is that right?

DR AVERY: That's correct.

MS EASTMAN: And that's part of the Masters of Business Law degree that you've undertaken.

10 DR AVERY: No, they're separate.

MS EASTMAN: Separate. Another one as well.

DR AVERY: One is a course degree, so actually two separate masters, one is a research degree and the second was a business law degree but I put health law in it because business law is quite boring, to be honest.

15 MS EASTMAN: For some maybe. Some of us like it. All right. So can I turn to paragraph 14. And I want you to, perhaps, explain this to the Royal Commission. So when you came to prepare your evidence one of the core issues was to address chronic failures in the health care system to deliver upon its duty of care to people with disability. And you thought very carefully about linking the evidence that you
20 give this afternoon with the Royal Commission's Terms of Reference. So this is set out in your statement. But was there anything in particular you wanted to draw to the Royal Commission's attention.

DR AVERY: No. Essentially, when I was thinking about the nature of the cases that I was coming across through the peoples' testimony, it was they had a right to
25 care, they had a need for care, but that access to care was denied to them at a critical point, and because it was denied – so it was something that wasn't given to them – that has led to quite catastrophic events, and their health and wellbeing being threatened and jeopardised. So it's the non-provision of care, more so than they did something that went wrong. That's why I have termed it in terms of neglect.

30 MS EASTMAN: All right. In your statement you set out the scope of work but I want to jump to the methodology you have used.

DR AVERY: Yes.

MS EASTMAN: You deal with this at page 5, starting at paragraph 21.

DR AVERY: Yes.

MS EASTMAN: So the primary source of evidence for this statement comes from a community-based research program. And that was hosted by First Peoples Disability Network. I think we can use FPDN. And it was research that you undertook that was subject of academic review, both in Australia and internationally. So the
5 research was conducted as the Living Our Ways program. What can you tell us about the Living Our Ways program?

DR AVERY: So it might be useful to go back to why we decided to do research. So I had spent a lot of time working – leading into this, I was with the National Congress of Australia’s First Peoples and I was working on the production of the
10 Aboriginal and Torres Strait Islander Health Plan. And at that point in time, I’m doing – I’m going, “Where’s the voice of people with disability?” So when disability’s presented, it’s really presented as a chronic disease and really, like, epidemiology, but the voices of people with disability weren’t there. And because I’m sitting in the community organisation and I’m on the phone and what I’m
15 reading in terms of research that was there, a small amount, is coming from the service sector.

So it did not align with what I’m hearing sitting in a community organisation of Aboriginal people, in relation to health care. And that carried over when I was working with the First Peoples Disability Network, which is an Aboriginal
20 community-controlled disabled people’s organisation. So it’s different to university. It’s different to government. They are very grounded. So we’re hearing these stories. I’m going, “Where’s – I can’t see this”. So we came up and I was encouraged at that point in time by an Aboriginal academic to take on a research program and start it as a PhD to kind of say, well – and our research question was
25 quite straightforward.

We just wanted to go to Aboriginal people with disability with one research question and said, “What is your story?” So that was it. And then we would follow the story wherever it led. So I didn’t specifically ask about, “Tell us about health” or “Tell us about education”. The cases that you are hearing were volunteered by the people
30 during the – their interviews, on their terms, when they chose to. So I didn’t really - so that’s what it – that’s what it was designed to do. So that’s the testimony part of it from Aboriginal people and the voices. Then we kind of went, “Well” – we were kind of concerned that if we just came with all these stories, they would be positioned as, well, they’re one-off or one-off cases.

35 So this was the need to have statistics. And even now, there are very few acknowledgements in government about the statistical profile of Aboriginal people with disability. So you won’t get places like the NDIS, for example, acknowledging even something as straightforward as how many people with disability are Aboriginal. You can’t get that. The exception is some reports in the Australian
40 Bureau of Statistics. So we did that work. We kind of had to get the statistical profile, and we coupled it with the personal. So you have the – and they validated each other. So the testimony was giving the human impact, and the statistical data was saying, “This is the whole group of people, a whole population that’s affected”.

MS EASTMAN: So on page 9 of your statement – and it’s diagram number 2 – you’ve put in a diagram from this exercise. Shall we put that slide up, if that’s available. Right. I’ve found, when you were explaining your evidence to me, this very – this is very helpful.

5 DR AVERY: Yes. So - - -

MS EASTMAN: Just tell the Royal Commissioners what the diagram depicts and how that helps us understand the research methodology.

DR AVERY: So this explains the various – so we would call it a mixed methods approach in that there’s people’s stories or qualitative data, and there’s numbers, so statistics and stories coming together. So the red bar is the statistical data, and that comes from the Australian Bureau of Statistics. So it’s not data that we’ve collected. We’ve used existing data from Australia’s recognised statistical collection agency. So it’s not us, it’s their data.

MS EASTMAN: Can I ask you to slow down just a little bit.

15 DR AVERY: Yes.

MS EASTMAN: Thank you.

DR AVERY: And so the – and so that’s – we used those datas. And we had to pool together various pieces of the data. So some of it exists in the disability data and some of it exists in the Aboriginal data. And we had to pool those together for those group of people who were Aboriginal and have disabilities. So it’s not in one place. So we did that work. The second part was the testimony. And I interviewed 47 Aboriginal and Torres Strait Islander people with disability using that “What is your story” approach. And we also had an elders’ forum. So that was more talking around the issues more generally.

25 The third part of it, because when you analyse data in terms of – so systems are designed by theme. So there’s the health sector and the health faculty, and education and – education faculty. There’s justice. That’s how systems are organised. People don’t live their life like that. And so what we also produced were things called yarnings pieces. So yarnings in Aboriginal culture, it’s more than just story telling. It’s how people locate themselves in their sense of place. So it’s a bit more than just, “I’m going to tell you a story.” So it’s used that Aboriginal methodology as part of a research. And what that enabled us to do is you’re not just seeing people’s lives at one part. So when you’re hearing these stories about what happens with people in the health sector, they’ve got all these other things happening in their life. It’s education, “How do I get transport”, and that. So I’ve just focused on that part.

35 MS EASTMAN: In paragraph 31, you say that:

The Aboriginal and Torres Strait Islander people with disability who participated were invited to tell their story in as much or as little detail as they felt comfortable with.

And:

5 *Importantly, the research did not seek to guide responses from people participating in the interviews through direct questions on their experience.*

So the approach was a far more open-ended exercise - - -

DR AVERY: Correct.

10 MS EASTMAN: - - - of giving the Aboriginal and Torres Strait Islander people the opportunity to tell you what they wanted to tell you, rather than you structuring the questions in a way to obtain the information that you thought you wanted to hear.

DR AVERY: Correct.

MS EASTMAN: Is that a summary of - - -

DR AVERY: Yes, so - - -

15 MS EASTMAN: - - - the path of process?

DR AVERY: Yes.

MS EASTMAN: And all of the interviews that were undertaken were transcribed, and then de-identified in terms of the participants; is that right?

DR AVERY: That's correct.

20 MS EASTMAN: Okay. Now, I'm up to another part that you wanted to explain to the Royal Commission about some introductory comments on disempowerment, and accessing health care and what you've called intersectionality. So this is at paragraph 33 and following. So the Royal Commission has heard the word "intersectionality" in the work that we've had to date, and also during our hearing in Melbourne in December. But you want to say something about intersectionality as it touches upon the research work that you've undertaken. What would you like to tell the Royal Commission about what intersectionality means - - -

DR AVERY: Yes.

MS EASTMAN: - - - in the context of your research?

30 DR AVERY: So intersectionality is more than just saying, "I'm Aboriginal and I happen to have a disability." So what intersectionality – and it's really given our

community a vocabulary to speak to their experience. So Aboriginal people with disability, it's not enough for them to say, "Look, I'm Aboriginal", and you can carry that experience of being an Aboriginal person with a disability or you're part of a disability community and you happen to be Aboriginal. So it's not a thing that's just
5 part of their identity. What it really is about intersectionality, you need to see it in terms of a power and where people sit in the social hierarchies of power. So if you're Aboriginal – and this is shown in some of the data – it's – it's not enough to – so if you're an Aboriginal person and you have experienced health inequalities, or a person with disability you experience health inequalities, if you
10 bring those two things together, the inequalities that you experience are greater than either of those two larger groups if you traverse those two population groups. And it comes down to, if you like, how you're – and an elder of ours was speaking about this as far back as 1991. It's this notion of being double-disadvantaged. So you can experience racism, you can experience ableism, but there are some times when those
15 two come together.

So an example that I give in the research is there's an Aboriginal man living not far from here. He has a cognitive impairment. And his public presentation of his disability, coupled with the negative stereotypes about Aboriginal people and drinking, he gets passed off as drunk. So he can't go shopping. He can't catch
20 public transport. Now, one of those things mightn't be enough. But you put those two things together, his – his life is basically taken away from him. He's unable to participate. And he's actually disempowered by those two things coming together. So some of the stories that you will hear are disability stories, and if you add the Aboriginal component, it's just like turning the volume switch right up. But in some
25 cases, you actually need – you can only explain it when you bring those two things together.

MS EASTMAN: All right. So I want to turn to the key themes that emerged from your research, and you've set this out page 12, at the top of the page there are four key themes. The first is:

30 *Barriers faced by Aboriginal and Torres Strait Islander people obtaining a disability diagnosis.*

Secondly:

The presumption within health systems that people with disability (of all types) lack capacity to participate in their health care decision-making.

35 Thirdly:

Diagnostic overshadowing and the intersection with institutional racism in health

And finally:

The disproportionate impact upon people with disability in the rationing of health care resources.

So those were the four key themes.

5 DR AVERY: Yes.

MS EASTMAN: And you've dealt with them in some detail in the statement. And I'm keen that we get to the examples of the testimony. So we might just deal with each of these themes - - -

DR AVERY: Yes.

10 MS EASTMAN: - - - briefly. So the first being barriers to obtaining a disability diagnosis. And your research found that diagnosis in practice was an important trigger to obtaining support for the particular disability. And the failure to get a diagnosis meant that people might fall between the cracks.

DR AVERY: That's correct.

15 MS EASTMAN: There are a number of factors that you found that contributed to not being able to obtain a disability diagnosis, and those factors are set out at paragraph 39 in your statement.

DR AVERY: Correct, yes.

20 MS EASTMAN: And they included cultural expressions that Aboriginal and Torres Strait Islander people use to refer to disability that are different compared to the language that is used in the health and medical system. And I just wanted to ask you what does that mean, and can you briefly explain to us how that works in practice?

DR AVERY: Yes. So you might hear language around various models of disability. So there's one model of disability called the medical model of disability, and that describes the nature of the impairment so it really kind of locates it in the person, and it sort of - that's where the diagnosis comes in. And it's really looking at what the person - in terms of an impairment. There's also a social model which really looks at the environment in which a person lives. So a room like this, "Is it accessible? Can I get around? Can I hear?" That's social factors.

25 and that describes the nature of the impairment so it really kind of locates it in the person, and it sort of - that's where the diagnosis comes in. And it's really looking at what the person - in terms of an impairment. There's also a social model which really looks at the environment in which a person lives. So a room like this, "Is it accessible? Can I get around? Can I hear?" That's social factors.

30 The third one - and this is where our research is touching on new things - is this cultural model of disability. And that's about a belief system. So if you think about the medical system, the medical model and the social model, they locate - they're deficit-based. So it's dis. The big dis part. The medical model/location of the person. So the person can't do X, Y, Z and needs to be fixed or cured. And that's

35 pretty much where the health system starts and ends. The social model is, "How do I

live?”, and then, you know, “What are my social relationships?” So things around a stigma, stigmatisation, “Can I get round?”, those are important in the social model. And the second – and the third one is, “Do I actually see disability?” So in Indigenous cultures, we don’t see – the – the social model – the notion of disability is actually imported in colonisation. So in traditional Indigenous cultures, our culture and other Indigenous cultures, we don’t see that, it’s a cultural inclusion. So we don’t see the deficit as much. So it’s quite complex and complicated having to navigate, though, through.

So the example I give is fetal alcohol spectrum disorders. So a medical model approach was, “You need to have a diagnosis.” So there’s challenges of that. If you’re getting a diagnosis and you live in a remote community, there’s a whole range of health professionals that you need to consult: a paediatrician, a child psychologist. There’s numbers. We listed that in the appendix. So that’s one. But you might have the best diagnostic tool available, but the stigmas attached to, again, drinking and blame of the mother, or how the child might get labelled by a diagnosis, that’s a social thing, and those kind of things impact on whether they will come to the system in the first place. If they’re worried that they’re going to get blamed or stigmatised, they will avoid engaging with the system.

And the cultural one, again if you’re living in remote communities and you just don’t see the disability because it’s more an inclusive culture, then – so these are all the things that interrelate. It is quite complicated, but they’re the kind of factors you need to think about. There’s no one kind of fix in this. You really need to understand – and different things will apply for different people in different places.

MS EASTMAN: Right. The next one you refer to is this presumption that people with disability lack capacity to participate in health care and decision-making. And in terms of that feature for Aboriginal and Torres Strait Islander people, it’s the clinicians making assessments and assumptions about capacity. And what you found is that this is coupled with discrimination; is that right?

DR AVERY: Yes. So the example I give – and I know this hearing was focusing on cognitive impairment – I said the – the notion that it’s almost this underlying presumption that health care practitioners – that people can’t look after their affairs. And it’s not just in the health setting, I saw it in the education setting and employment services. It’s like, “You have a disability, you don’t have personal agency.” That’s a presumption.

So the example I give was a person who’s a quadriplegic. And he was – the nature of quadriplegia, he went to a health care practitioner, and he said, “I’ve got pain in my leg.” And he was basically going, “Well, you can’t have pain in your leg, you’re a quadriplegic.” And so it was dismissed. And in some cases, it was – it was like, “Well, we don’t believe you.” And that was kind of, in itself, some of the disempowerment that people faced. And we saw opposite as well. There were a few cases in the testimony where people sort of said, “Oh, the doctor really talked to me”,

but it was almost like they were surprised that that happened. And – but – they – they expressed a sense of empowerment in having been part of that.

MS EASTMAN: The next one is diagnostic overshadowing and the intersection with institutional racism in health. And you’ve dealt with this in paragraph 50 and following in your statement. And I think you give the example in paragraph 51 of people who may have health conditions, but the assumption will be made that the person is drunk or faking it. Is that what you mean by “diagnostic overshadowing”?

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DR AVERY: Yes. So I know it’s come up – diagnostic overshadowing has come up during this hearing, and I’ve been following it. And, again, understanding it from a medical model and social model will help. I’ve got a bit of latitude. It might be worthwhile – I was introduced to this term, “diagnostic overshadowing”, back in 2015 from a number of esteemed disability rights researchers in the United Kingdom who were talking about this kind of issue and said, “You need to get your head around diagnostic overshadowing.” So the reason I want to mention that, it’s the reason we’re having a discussion about diagnostic overshadowing now, it’s because of disability rights scholarship, not the health services or clinical research. So that’s the first thing.

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So I – if you have a – go back through the testimony – and I hope I got this correct – the – the people who spoke about it were saying, “To my mind, diagnostic overshadowing is – is primarily for clinical use and it’s used to aid in the communication difficulties between the doctor and the patient.” So that’s very much a medical model interpretation. What we’ve applied is a social model interpretation. So if you look at the examples that I give, it was an Aboriginal person with disability, and the – the case that I give here was a quadriplegic, his body started shutting down due to hyperthermia, caught out on a hot day, had gone to a bottle-o because he’s quite resourceful and gone, “Well, that’s where they have ice and water to cool the body down.” When the ambulance turned up, he was passed off as being drunk. And it wasn’t until sometime down the track, you know, some – when he actually made it to the emergency ward at the hospital that they kind of started backtracking. So that presumption is – you get passed off. So they took diagnostic overshadowing, they took shortcuts, and it’s based on prejudice.

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Now, the difference between my testimony and what you’ve heard to date is that’s not a communication problem. That’s prejudice. And the problem is if you see diagnostic overshadowing exclusively as a communication issue, this is how the system will respond, they will hire some consultants, and make up a nice brochure or do a website, but they won’t get to the core of the institutional prejudice that sits within the health care system in which highly qualified health care practitioners can just pass people off with need as being drunk or faking it.

MS EASTMAN: Commissioners, I’m just conscious of the time, and there’s still a few more matters that I want to address with Dr Avery. So if those watching the

broadcast and the Commissioners can bear with me and Dr Avery for another 10 to 15 minutes or so, we will be able to complete the evidence.

COMMISSIONER SACKVILLE: Yes, certainly.

MS EASTMAN: All right. So the next issue that you raise, just following through
5 those four core themes, was the disproportionate impact on what you describe as
rationing of health care resources. So this is paragraph 53 and following. And one
of the barriers that you think needs require further interrogation is the
disproportionate impact of rationing health care resources, that that has upon people
with disability. And this is an area of particular concern reflecting systemic
10 disempowerment for Aboriginal and Torres Strait Islander people with disability.
And you gave the example in your statement at paragraph 54 of an elderly
Aboriginal man who was interviewed in a remote location. And partway through the
interview, he lifted his trousers and showed you a wound on his knee that covered a
pin. And he said he had had a knee operation at a regional centre and had been in
15 hospital for about two weeks, and that was about 500 kilometres away from his
home. But when he was discharged from the hospital, he had to make his way home
from the hospital on a bus by himself. And when you asked where he was staying,
he said that he was sleeping rough. And so this was something that came to you in
the testimonies, that – issues around rehabilitation, access to simple things such as
20 transport to assist people in post-surgery recovery be able to return to their homes,
are these the examples of a disproportionate rationing of health care services? Is that
what you wanted to highlight?

DR AVERY: Well, I suppose I just wanted – the most confronting thing for me that
an Australian health care system would discharge an elderly Aboriginal man after a
25 major knee operation straight into homelessness, where he told me later that he had
to walk 800 metres with a bucket to get fresh water back into homelessness. And
I'm just kind of thinking – now, it's very speculative of me. I don't understand what
happened in the hospital and how these decisions – but I can imagine it.

You might have to free up a bed for a very busy regional hospital and you've got
30 three people. "Well, I won't discharge you because someone will kick up a fuss. I
won't discharge you because you'll kick up a fuss." No one will find out about this
Aboriginal man. And that's the nature of why I think, you know, Aboriginal people
with disability when it comes to rationing, when it comes to budgeting, the nature of
their disempowerment that they're hidden away, it kind of loses in that debate. So
35 that's kind of what I was getting at.

MS EASTMAN: Now, in the work that you've done, Culture is Inclusion, at page
113 there's diagram 4, and we've got a copy of that to put up on the screen. And we
might need you to explain this graph, because I think it identifies fairly clearly all of
the points that you have been making about the double disadvantage, as you call it.
40 So can you just explain to us this graph and what the findings reveal?

DR AVERY: So this is the statistical data. And this data comes from the National Aboriginal and Torres Strait Islander Social Survey which is collected by the Australian Bureau of Statistics. And the question was: do you have problems accessing health care. So it was a self-reported questionnaire. So what we've – what
5 we did – and we did this together with the Australian Bureau of Statistics, was disaggregate the data by if you were Aboriginal or disability, Aboriginal and disability, Aboriginal with severe and profound disability. So if you can imagine that there's this kind of gradient. So this is actual statistical data here. So if you look at the sort of far left as I'm looking is the general population without disability.
10 So they don't have as – they're low on the scale. People living with disability but not Aboriginal, or Aboriginal without disability, their barriers, their self-reported barriers to accessing go up one level. The next category, we've added Aboriginal and Torres Strait Islander people with disability but it's not severe and profound. So we've put the two together. And their barriers go up again. And we've called that
15 intersectional inequality. And the final graph was we had a look at Aboriginal people and we added severity of disability. So the kind of fourth column is any disability, the last one is by severity. And you will see that there's this almost perfect line going up. And I should say that I had this checked by about three or four different departments in the Australian Bureau of Statistics because you see that and
20 it's almost too good to be true, that data, as a researcher.

MS EASTMAN: Maybe not too good to be true, as the case may be.

DR AVERY: But there's no intervention. So no one has done anything about it. It's not on anyone's radar. So it's actually quite understandable that it would gravitate to that – the theory and the testimony and the statistical data all lined up.

25 MS EASTMAN: All right. Now, there is a significant part of your statement where you also raise for the Royal Commission issues about deaths in custody. And what I might do is assure you that that is part of your evidence for the Royal Commission, and the Commissioners have read that part. But I'm keen to get to the systems-wide failing, but specifically your recommendations, based on your research, as to what
30 needs to change and what the Commission should do. So do you want to say something briefly about the systems-wide failing. So you've dealt with this at paragraph 61 on page 20.

DR AVERY: So a lot of the examples and case studies that I've spoken to and the testimony, it's like what's happened at the point of service, and they're particularly
35 almost manoeuvred into vulnerability, particularly the first point of contact. So things like the emergency departments, and ambulance, when there's acute need for health care but that has been denied. So that's the examples. But that doesn't sit in isolation. So you need to then look at what is happening at the policy level. So when they're writing health policy frameworks, is it Aboriginal health policy
40 frameworks, national health frameworks or disability health frameworks, what's covered there. You need to walk down into the clinical governance system.

So this is what happens in New South Wales Departments of Health, what are their quality assurances, if there are adverse events, how does that feed back in. Then it goes to the front line service. Then it also goes into how are they trained. So what are they teaching in the medical schools, the colleges of general practice. And then
5 what are the accountability mechanisms, both within the system, but even reaching into the coronial system. And all the way through, wherever you look at, it's a case of what disability people would call othering. So there's this disacknowledgement that these – like these issues don't exist. They get othered. It's almost like they're
10 hiding behind this cloak of deniability. "If I don't engage I don't have to do anything about it".

And I think this is the nature of complexity, is they just haven't been able to deal with it. So some of their cases that I've gone and some of the policy network – policy engagements I've had, it's one system – one part of the system, they spit out responsibility to another part of the system. And that part of the system spits it out to
15 another one. So when you have complicated complex health needs, you really need everyone to kind of buy in and take responsibility, but you have a situation where actually no one's taking responsibility for this. So that's the nature of why you need to take a whole of system approach to this.

MS EASTMAN: I think you say in paragraph 66 that:

20 *Aboriginal and Torres Strait Islander people with disability are in need of a sophisticated approach to address their health needs in which all parts of a health care system come together collaboratively in accepting joint and several responsibility for attaining improvements in the health outcomes.*

But that doesn't happen and you say:

25 *We are met with a policy merry-go-round in which no one accepts responsibility.*

DR AVERY: Yes, so I sit in Aboriginal and the disability. It's like watching a game of tennis watching them flip between one to the other. So the one example I gave – and I traced this example of the Aboriginal health policy, which we were
30 involved with. So the Aboriginal Health Plan says, "We will improve the health of Aboriginal people with disability through the National Disability Strategy". So you go to the National Disability Strategy and it says, "We will delegate responsibility for the health of Aboriginal people to the Australian Government for improving health outcomes for Aboriginal people with disability".

35 So you go to that document, and it says, "We will improve the health of Aboriginal people with disability through Close the Gap and the health plan". So you've actually got this complete circular reference of avoidance going round. And it's so siloed that they can't see that. And I think the frustration in our advocacy and research is that they will refuse to acknowledge, either – any of those departments

will refuse to acknowledge what we're seeing as quite – it would be quite comical if people weren't dying, so - - -

MS EASTMAN: You identify three particular areas where you think the Royal Commission might focus its attention. And so these are some of your

5 recommendations and suggestions. The first, on page 24, just above paragraph 69, is you say there is a need to:

Pierce the culture of avoidance towards the health of people with disability by placing health care systems on notice.

So this is about accountability; is that right?

10 DR AVERY: Correct.

MS EASTMAN: So what is your suggestion as to what this “piercing the culture of avoidance” should involve?

DR AVERY: Again, the nature of disempowerment is such that we've operated from a relatively small non-government organisation, and government agencies that we've dealt with, whether through Close the Gap, the NDIS, have been able to sort of say, “No, no, no, we're not – we don't need to acknowledge your work”. We just think the Royal Commission here, we're looking to the Royal Commission saying, “Well, if they're not dealing with us, will they address levels of accountability in this forum”. We're kind of thinking, well, if they're not going to come here where will they come to?

20 So I think it's about bringing people here into a room like this, so policy architects who write these health plans and asking them, if a six person Aboriginal NGO can find data on health and social inequalities, how plausible is it that the resource of health system can't, and asking them those direct questions, asking them questions such as to the directors of clinical services how – do you have evidence, are you collecting data on this, on people with disability and Aboriginal people with disability, what their adverse events are, and how does that feed back in to your training of people, getting deans of medical schools in going, “Show me your curriculum”.

30 I suspect that will be more of what you don't see than what you do. And then even the coronial system, and the examples that I gave in the other part around deaths in custody, where it's almost like you heard the testimony of people saying, “The health care providers said I was drunk”. It's almost as if the accountability mechanisms are such that, “Well, I thought they were drunk”, as a possible defence to this. So there's real problems in a general lack of accountability here.

35 MS EASTMAN: The final two recommendations that you make are actually recommendations for this Royal Commission. First of all, you say:

This Commission must check its own bias and disposition towards institutionalised ways of knowing and doing, and

5 *The Royal Commission should be in a position where the disability knowledge sector, as an active contributor, contributes to the creation of better models of health care that address the specific circumstances of people with disability within the disability community.*

So I put them together. I think some of the themes that you raise in both overlap. But what would you like to say about the approach this Royal Commission takes, particularly when we look at issues around First Nations people?

10 DR AVERY: Well, I suppose part of my reasoning for putting that particular thing if – is if the Commission is going to look at holding others to account on issues around institutional ableism and/or racism, then it needs to have the capacity to do the same. And my thinking around this was when I picked up the Issues Paper and I went, “That’s - - -”

15 MS EASTMAN: Let’s pause there. So this is the Issues Paper that the Royal Commission released specifically on health.

DR AVERY: Correct.

MS EASTMAN: Right, that - - -

20 DR AVERY: So this is the Issues Paper, yes. And I had a look at the issues in there and I thought, “Well, as an advocate, that’s fantastic”. I saw the diagnostic overshadowing and I thought it grasped the issues. And then – again, this is an example – but then I looked at it, well, who do you rate as – recognise as authorities on these issues. And I saw that, you know, quite respectable well-known academics, I saw the United Nations, I saw a couple of psychologists cited. What I didn’t see was our voices and our faces. And I thought, again, the reason we’re having a discussion on diagnostic overshadowing, it has come from the disability rights sector, not the health services system.

30 So if you give that back to the people who are kind of complicit in the problem, what that does, it removes our community, our disability community from being part of the solution. We’re othered again. So my recommendation to you is just say our name. It’s First Peoples Disability Network, it’s People With Disabilities Australia, it’s the Disability Leadership Institute. These are the holders of knowledge that can help be part of the solution. So that’s the point of that. And there are other examples but we will get to that another day.

35 MS EASTMAN: Well, Dr Avery, thank you for preparing such a comprehensive statement, and to take us just really to the tip of the iceberg, so to speak, on the

extensive research that you've done. And also sharing with us the importance of the methodology and the work that this Royal Commission should be looking at in the future. I'm sure this will not be the last time that we will see you giving evidence in the Royal Commission. So thank you very much for your assistance today. If the
5 Commissioners please.

DR AVERY: Thank you.

COMMISSIONER SACKVILLE: I add our thanks to you, not only for your appearance today, but I know that you've been involved in the workshops that have been conducted, and some of the community engagements, and you have made some
10 very important contributions to those engagements, and we have, of course, taken very careful note of the research work you have done. So thank you for your contributions that you have made and the contributions I am sure you will make to the work of the Commission. So thank you, Dr Avery.

DR AVERY: Thank you very much.

15 COMMISSIONER SACKVILLE: Thank you.

MS EASTMAN: Commissioners, that completes the evidence for today. Can I just deal with some administrative matters to make sure I've covered all the tenders and the marking of exhibits.

COMMISSIONER SACKVILLE: Yes.

20 MS EASTMAN: I understand Sabrina Monaghan's statement, when she gave evidence you will recall this morning, is now adjusted to deal with the non-publication orders in relation to her children. So if that could now be marked exhibit 4.15.

25 **EXHIBIT #4-15 STATEMENT OF SABRINA MONAGHAN DATED 12/02/2020 (STAT.0052.0001.0001)**

MS EASTMAN: For Ms Reynolds' statement if that could be marked now 4.17.

EXHIBIT #4-17 STATEMENT OF NARELLE REYNOLDS DATED 10/02/2020 (STAT.0043.0001.0001)

30 MS EASTMAN: And for Dr Avery's statement, that would be marked exhibit 4.18. And that includes a copy of his CV, which is at tab 11 of the bundle. I think we've been calling that 4.18.1.

EXHIBIT #4-18 STATEMENT OF DR SCOTT AVERY DATED 14/02/2020 (STAT.0065.0001.0001)

MS EASTMAN: I hope that's addressed all of the administrative matters and otherwise we would ask the Commission to adjourn this afternoon until 10 am tomorrow.

5 COMMISSIONER SACKVILLE: Thank you very much. We shall. We will adjourn until 10 am tomorrow. Thank you again, Dr Avery.

DR AVERY: Thank you.

<THE WITNESS WITHDREW

10 **MATTER ADJOURNED at 4.15 pm UNTIL TUESDAY, 25 FEBRUARY 2020**

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