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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**

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

**SYDNEY**

**10.00 AM, FRIDAY, 28 FEBRUARY 2020**  
**Continued from 27.2.20**

**DAY 9**

**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**

COMMISSIONER SACKVILLE: Good morning. And welcome to everybody in the hearing room and who might be following the proceedings on the webcast. This is the final day of the hearing which has been investigating the provision of health care and health services for people with cognitive disability. We commence today  
5 by acknowledging and paying our respects to the traditional custodians of the land upon which we are meeting today, the Wann-gal people. We also pay our respects to First Nations elders, past, present and emerging, as well as to any First Nations people who are present today. Yes. Ms Eastman.

10 MS EASTMAN: Good morning, Commissioners. Good morning to everyone in the room and those following the broadcast. This is our final day of public hearing for this Royal Commission, and we will make some closing remarks at the end of the evidence today. For those watching, we certainly encourage anybody who also wishes to share their experience to do so with the Royal Commission, and we will talk at the end of the day about the manner in which that could be done.

15 So, Commissioners, our first witness today is going – and you will see she’s here. She’s going to give some evidence about a topic which is sensitive and extremely difficult. We are very grateful for her presence today and her willingness to talk about matters that have had a profound impact on her and her family. Some aspects of the evidence today will involve talking about suicide and suicide attempts. It will  
20 need to be done in a sensitive and appropriate way. We will endeavour to do this. We’re also wishing to alert anyone who may feel that hearing this evidence is distressing to perhaps take the opportunity to take a break from listening to the evidence during the course of the morning. And I’m about to put up some telephone numbers on the screen.

25 COMMISSIONER SACKVILLE: Yes. Thank you.

MS EASTMAN: So we have a number of telephone numbers. And for those who may not be able to watch the broadcast but are listening in, there is the Lifeline number, and that telephone number is 13 11 14. There is also the Kids Helpline, which is 1800 551 800. And Blue Knot, which is 1800 421 468. If the  
30 Commissioners please. I would just ask that Ms Abi be sworn.

**<GIUSEPPINA CINZIA PORTE, AFFIRMED**

**[10.03 am]**

**<EXAMINATION BY MS EASTMAN**

35

COMMISSIONER SACKVILLE: Ms Abi, thank you very much - - -

MS ABI: Thank you.

COMMISSIONER SACKVILLE: - - - for coming to the Commission and thank you very much for your statement, which, of course, we have read. Yes. Ms Eastman.

MS EASTMAN: So your name is Giuseppina Cinzia Porte, yes?

5 MS ABI: Pretty much.

MS EASTMAN: Pretty much. But everybody knows you as Jo Abi.

MS ABI: Mmm.

MS EASTMAN: When you say “mmm”, I might need you to say “yes”.

MS ABI: Yes.

10 MS EASTMAN: And for the purpose of giving your evidence today, I will call you Ms Abi. Is that convenient?

MS ABI: Perfect. Thank you.

MS EASTMAN: You’ve prepared a statement for the Royal Commission?

MS ABI: Yes. I have.

15 MS EASTMAN: And you’ve read the statement?

MS ABI: Yes. I have.

MS EASTMAN: And the statement is made on 26 February this year.

MS ABI: Yes.

20 MS EASTMAN: And its contents are true and correct, to the best of your knowledge and belief.

MS ABI: They are.

MS EASTMAN: Commissioners, you will find a copy of the statement in the tender bundle, part A, behind tab 22. And so I don’t forget, if the statement could be accepted into the Commission’s evidence and tendered, and marked exhibit 4-7.

25 COMMISSIONER SACKVILLE: Yes. Thank you.

**EXHIBIT #4-7 STATEMENT OF GIUSEPPINA CINZIA PORTE (JO ABI)  
DATED 26/02/2020 (STAT.0058.0001.0001)**

MS EASTMAN: So, Ms Abi, you've heard me say at the beginning that we're going to touch on some sensitive and difficult matters. So if at any stage you need a break, just let me know.

MS ABI: Thank you.

5 MS EASTMAN: So you've come to talk about the experiences that you have had in accessing and receiving mental health care for one of your sons.

MS ABI: Mmm.

MS EASTMAN: But also health care generally for both of your sons. And both sons live with autism; is that right?

10 MS ABI: Yes. That's correct.

MS EASTMAN: And you've had some significant challenges along the way, in terms of accessing appropriate care for your sons.

MS ABI: Very much so.

MS EASTMAN: And that's what you want to talk about today.

15 MS ABI: Yes, that's it.

MS EASTMAN: So because we're talking about them, shall we start by learning a little bit about them? So you have three children.

MS ABI: I do.

MS EASTMAN: Your eldest is Philip?

20 MS ABI: Yes. Philip is turning 16 and wants to get his driver's licence as soon as possible.

MS EASTMAN: Okay. So we'll come back to Philip in a moment. There's Giovanni?

MS ABI: Yes. And he has just turned 12.

25 MS EASTMAN: And your little daughter; is that right?

MS ABI: Yes. Caterina, who's 10.

MS EASTMAN: All right. And tell us a little bit about Philip. So he has just turned 16; is that right?

- MS ABI: Yes.
- MS EASTMAN: Okay.
- MS ABI: He's about to turn 16 - - -
- MS EASTMAN: 16.
- 5 MS ABI: - - - in April. He wants to get his driver's licence, which is terrifying. Yes, he's amazing. His favourite thing to do at the moment is virtual reality on his Oculus Quest. And, yes, he's very anxious to start school this year. And he's just a beautiful, beautiful boy.
- MS EASTMAN: He's a big fan of Elon Musk, isn't he?
- 10 MS ABI: Very. Yes, he just – he's on YouTube all the time, just watching anything on cosmology or astrophysics and – yes, he's just – his brain's incredible. It's just fun to watch him learn.
- MS EASTMAN: All right. Now, your other son, Giovanni - - -
- MS ABI: Yes.
- 15 MS EASTMAN: So he's just turned 12; is that right?
- MS ABI: Yes. He has.
- MS EASTMAN: So we probably just need to make an amendment to paragraph 8 of the statement.
- MS ABI: Yes.
- 20 MS EASTMAN: I'm sorry I didn't do that before. I think he was 11 when you started to prepared the statement.
- MS ABI: Yes, he was.
- MS EASTMAN: He's now 12. So he's very different to his brother, isn't he? So tell us a little bit about him.
- 25 MS ABI: Yes. He's more of an underactive version of autism, in thought and in action. He needs a lot more support to, sort of, you know, do anything and be challenged. He likes his safe places and he very much loves online gaming, but, in particular, the element where he gets to speak to other people in a safe zone. That's, sort of, his way of having friendships.

MS EASTMAN: And Caterina, who is not the subject of this particular hearing today – but you describe her as very cute. But she is the youngest in the family. And you've got some perspectives on her experience as a sibling of two brothers who live with autism. What did you want to tell the Royal Commission about her?

5 MS ABI: I suppose she's an accidental carer. I was really concerned at one stage, when I was very focused on the boys, especially when Philip became sick, that it was damaging her. And I found this great research that really, sort of, laid my fears to rest. That said that the siblings of kids with special needs are so compassionate. And she was actually asked by my brother what she wants to be when she grows up  
10 and she said special needs teacher. So, yes, she and I very much are carers, but I do make sure that she gets to carve her time out so that she has a life of her own, because I think that's really important for siblings of kids with special needs.

MS EASTMAN: All right. And you parent the three children as a single parent; is that right?

15 MS ABI: Yes. I do.

MS EASTMAN: And you have support from your family?

MS ABI: Yes. Especially my mum.

MS EASTMAN: And also support from your former husband; is that right?

MS ABI: Yes. Yes.

20 MS EASTMAN: So let's move to Giovanni.

MS ABI: Mmm.

MS EASTMAN: And you say in your statement before you had children you were aware of what autism was.

MS ABI: Mmm.

25 MS EASTMAN: And you knew people who had children with autism. But you didn't have any particular expertise or any special interest in autism; is that right?

MS ABI: No. I mean, I found it fascinating because it was in the family and my friendship circles. I don't think I thought it would happen to my family, but no one ever does.

30 MS EASTMAN: All right. And so when Giovanni was a toddler, you suspected that he might have autism. But you weren't too worried at that time, until people started to say to you, "I think Giovanni might be on the spectrum."

MS ABI: Mmm.

MS EASTMAN: And so you listened to these comments and you found that the reactions were negative.

MS ABI: Mmm.

5 MS EASTMAN: And you – well, you were initially dismissive. You said, “Don’t be silly.”

MS ABI: Not me. So what happened was I strongly suspected he had autism from the age of 18 months. I pretty much knew that he did. And when I would suggest it to doctors and teachers and members of the family, they would tell me that I was  
10 being silly. So especially when it came to, you know, our local GP and his preschool teachers, when they would say to me, “No, he’s fine,” I thought I was just being paranoid. But I really strongly felt that he did.

MS EASTMAN: All right. But you, sort of, took it upon yourself to say, “Well, I need to find out a little bit more.” And you say in your statement that you googled a  
15 lot.

MS ABI: Yes, a lot of googling.

MS EASTMAN: And you filled out an online “Does your child have autism?” survey. Were they helpful to you?

MS ABI: They were. I mean, some of them are silly. But if you are careful where  
20 you go, you can get some really good, comprehensive ones. And, of course, they all came back as yes. And I think I was just starting to build up my bravery when it came to saying to those people that asked, you know, “We’ve really got to do something about this,” because I had read that the earlier you get help, the easier their lives will be.

MS EASTMAN: And so initially had a discussion with Giovanni’s GP?

MS ABI: Mmm.

MS EASTMAN: And you asked the GP, “Do you think I should get him assessed for autism?” And the GP said, “Look, I think it’s fine.”

MS ABI: Yes. I kept hearing this word “fine”. And they would say things like,  
30 “No, he makes eye contact, he tells you he loves you, so he can’t be on the spectrum.” They just, sort of, have this idea of one form of autism, and I don’t think they had the training or understanding to know just how subtle and different it can be. And the thing that was really annoying was that they weren’t taking me seriously. I was concerned. So I wish they had just said, “Well, you’re concerned so  
35 let’s investigate this.”

MS EASTMAN: And so when he was still young, you did turn your mind to whether or not you would need to take him to a paediatrician.

MS ABI: Mmm.

5 MS EASTMAN: But the cost of having a private paediatric assessment was an impediment; is that right?

MS ABI: Very much so. We had suffered bankruptcy in the financial crisis and, you know, we had two, almost three children at that stage, and the area in which I lived, if you can find – I could not find a paediatrician who would bulk bill. And they were all like, you know, 2 to 3 hundred dollars for an initial consultation, which

10 was our grocery money for the week, if not more.

MS EASTMAN: So someone might say to you, “Well, why didn’t you go to the public system?”

MS ABI: Because the waiting lists are crazy and they’re so far away. And, you know, we were trying to work and raise the kids. And I suppose I just kept – I mean, it’s not that I was trying to avoid it or delay it. I know it was urgent, but there’s only so much you can cope with in a day. I was still trying to care for Giovanni and for Philip, and, you know, be a mum and work. So the convenience factor of health care, the affordability, it’s all so important, because, you know, easy access means having it be close by and affordable, without a three-month waiting list, and I just

15 couldn’t find it.

20

MS EASTMAN: Okay. So Giovanni started kindergarten – started school in 2014.

MS ABI: Yes.

MS EASTMAN: And you say in your statement everything went wrong.

MS ABI: Exactly. He just didn’t cope.

25 MS EASTMAN: And so he was becoming quieter and more insular when he was at school.

MS ABI: Mmm.

MS EASTMAN: And you felt that the teachers were not recognising signs of autism. So at this point you hadn’t got any diagnosis but you, in your own sense, had

30 a sense he must – this must be it.

MS ABI: Yes.

MS EASTMAN: And one of the teachers did raise with you whether he had special needs and thought that he might have a hearing impairment; is that right?



MS ABI: She didn't think he was special needs. I had asked her, because she was the special needs teacher at the school. I said, "I just think he might be on the spectrum. Like, should we investigate this?" And she said, "No. You know, I think he is hearing-impaired." I'm like, "Why do you say that?" And she said, "Well, we

5 did an exercise in, you know, this special needs class," where she said, "Everyone close their eyes and tell me what they can hear." And when she asked him, he said "nothing". So she suggested I get something called an audiogram. So we - - -

MS EASTMAN: And you did that?

MS ABI: Yes.

10 MS EASTMAN: And the hearing was fine.

MS ABI: \$90, and it was fine.

MS EASTMAN: All right.

MS ABI: And even after that, she didn't take seriously my suggestion that he might have autism. And I suppose, looking back, I didn't really need anybody's support,

15 but these were teachers and doctors. They know more than me – or at that – that is at least how I felt at the time.

MS EASTMAN: All right. So he managed to just hang in there throughout kindergarten.

MS ABI: Mmm.

20 MS EASTMAN: And you eventually did get an assessment in 2015. So he was about seven years old at this time?

MS ABI: Yes. He was.

MS EASTMAN: And you set out in your statement about the process of obtaining an assessment. And the assessment came through seeing a psychologist; is that

25 right?

MS ABI: Yes. So I just – we saved the money up, to have it done as soon as we could in 2015, without a – I can't remember if I had a referral, if I got a referral discount or not, but it was still over \$2000 to have it done, and time off work and time out of school. Yes. And then we got the assessment.

30 MS EASTMAN: And were you actively involved in the assessment process?

MS ABI: Yes. The – the assessment process is really intensive. It involves teachers and parents and carers, me in particular, Giovanni, and takes a few days.

And then a few weeks for them to come up with a report that will let you know what's going on.

MS EASTMAN: And so I think it's the case that you were told the report was ready but you had to pay for the report, and that was a little bit of a stressful situation.

5 MS ABI: Yes.

MS EASTMAN: But you eventually got the report; is that right?

MS ABI: I did eventually. It was a painful process, though.

MS EASTMAN: And you had a – and received by email.

MS ABI: Mmm.

10 MS EASTMAN: And you had a quick read of the report in the car, on the phone.

MS ABI: Yes. I was just flicking through, because I just wanted to see what the answer was. And it was on the very last page or one of the last pages.

MS EASTMAN: And you saw that the answer was a diagnosis of autism.

MS ABI: Mmm.

15 MS EASTMAN: And the report was quite long.

MS ABI: Mmm.

MS EASTMAN: And once you got that confirmation, you just put the report to – aside for a few months.

MS ABI: Yes.

20 MS EASTMAN: Because you just felt you needed to process that diagnosis before you then turned your mind to, "What are we going to do?"

MS ABI: Yes.

MS EASTMAN: Is that right?

MS ABI: Yes.

25 MS EASTMAN: Okay.

MS ABI: Because it was just so painful. No one had listened or believed me. And I didn't want to say, "I told you so." I just felt so misunderstood and just, sort of, so

sad for my son. You know, an autism diagnosis isn't the end of the world. I just wish that one person had said, "Just get an assessment." So having the assessment was amazing. I wish I had done it earlier.

5 MS EASTMAN: So you then had to turn your mind to what would be appropriate form of treatment and management for Giovanni in relation to his autism.

MS ABI: Mmm.

10 MS EASTMAN: And, again, you deal with this in your statement. So this is paragraph 30 and following. So you immediately informed his school about the results. And did you talk to the school about what might happen? I think you say in your statement you kept thinking that the autism fairies at the school would fly in and fix everything for him, but that didn't happen. So as you know, the focus of this hearing is on health - - -

MS ABI: Yes.

15 MS EASTMAN: - - - and access to health care. But you wanted to say something briefly about your experience in telling the school about the health diagnosis. So what – again, we will be brief on this topic, but what would you like to tell the Royal Commission about how the school responded when you told the school, the relevant teachers, and, I assume, the principal about the diagnosis? What happened?

20 MS ABI: They didn't have any procedures in place. And I was told, on the special needs Facebook groups I had joined, to get the diagnosis, give it to them, they would be able to access some funding, Giovanni could access the school psychologist, someone who could specialise in teaching him. None of that happened. I think I thought the diagnosis would be, sort of, the turning point for Giovanni. But aside from just affirming what I had known for years, it didn't make anything easier at all  
25 on us.

MS EASTMAN: And in terms of, then, the health side of things, you thought that a paediatrician and/or the psychologist would help you coordinate what the options might be for managing; is that right?

MS ABI: Yes.

30 MS EASTMAN: And that didn't really happen to your satisfaction; is that right?

35 MS ABI: No, because the diagnosis I received just had this long list of suggestions for what I do for Giovanni, and it was probably 15 or 16. I had never heard of an occupational therapist before, speech pathology, psychology for anxiety, all these things, and it was so overwhelming. And then when I started making phone calls to access the services, there's waiting lists or they're not near to your home or they cost hundreds of dollars. And I just didn't even know where to begin. So turned to

Facebook once again. And they suggested, you know, occupational therapy, but make sure it's a good one. But in my mind I'm like - - -

MS EASTMAN: You also tried speech therapy, didn't you?

5 MS ABI: We did a bit of speech therapy. But it's all just hundreds of dollars and you don't know what's going to work and what's not going to work. For Giovanni to even benefit from it, he has to trust the person. So you can't just get any available person who's affordable to do it. It has to be this amazing person you trust with your child, who he trusts, who you can afford, who doesn't have a three-month waiting list, who can start working with your child.

10 MS EASTMAN: All right. And so for him, in terms of attending school, while you were trying to explore different options to support him, school became quite difficult for him and you took him out of the – what you describe in the statement as the mainstream school; is that right?

MS ABI: Mainstream schooling, yes.

15 MS EASTMAN: All right.

MS ABI: We were with the Catholic system. I'd heard public was better, but that's where we were. But I realised, through starting to work with an occupational therapist, he might need a more focused and intensive setting when it comes to education.

20 MS EASTMAN: And so I'm going to ask you a little bit about some of the other health care experiences that you've had with him. But just bring us up to date in terms of Giovanni now. How is he travelling now and what's the situation in terms of school and his opportunities at school?

25 MS ABI: He's not in a school at the moment. He was at an excellent school last year. They just loved him. He loved them. It was a public school. But they didn't have specialists when it came to autism, and our attempts to get funding for him all failed. Even after we got his anxiety diagnosis. So we applied to go to a support unit. We got a place locally. He lasted one day. He told me he had been manhandled by a couple of people there, and he was very upset. So I pulled him out.  
30 And we're on the waiting list now for another support unit, or I might do some distance for a little while until we figure out what to do.

MS EASTMAN: Okay. Now, you wanted to talk about some of the experiences in – for Giovanni accessing health care generally. So these are some of the matters that start at paragraph 40 of your statement. So when you go to the GP for anything with  
35 Giovanni, you say to the doctors, "Giovanni has autism, so you're going to have to explain everything as you're doing it - - -"

MS ABI: Yes.

MS EASTMAN: “- - - so that he understands what’s going on.”

MS ABI: Mmm.

MS EASTMAN: And so you feel that you are almost like his intermediary; is that right? That you have to explain to the person giving him the health service, “This is  
5 what his condition is. This is how you will need to speak to him.”

MS ABI: Mmm.

MS EASTMAN: How have you learnt to do that?

MS ABI: Just through trial and error. I mean, I don’t mind that someone doesn’t  
10 automatically recognise that he has autism, but as soon as I say it they’re either  
brilliant or they’ve just got no understanding of how to communicate with him. And  
it makes you so grateful when you find somebody who communicates with him  
properly. But I just wish that it was always consistent for him. Because in my head  
and the head of all special needs parents isn’t what’s happening now – that I’m in  
15 control of his life. It’s, like, in 15 years’ time, when he’s an adult and goes to the  
doctor, will they talk to him, listen to him, communicate with him properly?  
I mean, I can be the Giovanni whisperer now, but when he’s older he needs to be  
listened to and heard. So I just wish everybody was up to speed on how to  
communicate, because he’s fascinated with the doctor, he’s fascinated with the  
20 processes. Just because he’s not looking at the doctor doesn’t mean he’s not  
listening. But, yes, we – he had to get an X-ray on his toe recently. And I said to the  
sonographer, I said, “He has autism, so just explain everything as you go.” And she  
did and he loved it. He was so fascinated by it. Yes, it’s just so hit and miss. And,  
as I said, I just want his experiences in the future to be consistent.

MS EASTMAN: All right. Anything else you want to say about your experience in  
25 accessing health care, both through mainstream medicine but all of the Allied Health  
services that you’ve used, that you want to say to the Royal Commission? And then  
we will start with Philip.

MS ABI: Yes. With Philip?

MS EASTMAN: No, we will start with Philip in a moment.

30 MS ABI: Okay. Sorry.

MS EASTMAN: I want to make sure I’ve covered everything that - - -

MS ABI: For Giovanni?

MS EASTMAN: - - - you wanted to talk to the Royal Commission about.

MS ABI: Yes. I think I just want to say that, you know, when you've got special needs children it's – life is so hard. Like, every day is hard. You know, trying to figure out, you know, what he will eat for breakfast is hard. It's so limited. His anxiety, his – you know, anything else that's going on. So you're already very busy.

5 And then you have occupational therapy, other children. So when you go to find help for your child and it's hard to access or you can't afford it, or it's an hour's drive away or there's a three-month waiting list, it feels impossible and you just feel like – you just – I'm just trying to raise my child so he can have access to health care and education and a life. And I just feel like there's – it's just so hard. It's really,

10 really, really hard. And I'm worried about his future because I can fight for him now when, you know – when I can, but, yes, I don't know how he's going to fight for that when I'm no longer here.

MS EASTMAN: Can we turn to Philip?

MS ABI: Yes.

15 MS EASTMAN: You're okay for that?

MS ABI: Yes.

MS EASTMAN: All right. And you've got a picture in front of you.

MS ABI: Yes.

MS EASTMAN: And that's going to help you talk about Philip. And at some point

20 in time you're going to tell me if you want to share that picture that you've got.

MS ABI: I'm happy to share that. Yes, he's quite proud of that.

MS EASTMAN: All right.

MS ABI: Art is, sort of, his therapy.

MS EASTMAN: Let's talk a little bit about what happened with Philip before we

25 put the picture up.

MS ABI: Okay.

MS EASTMAN: So he's your first child.

MS ABI: Yes.

MS EASTMAN: And while all of these things are happening with Giovanni, it

30 didn't occur to you to suspect that he might also have autism; is that right?

MS ABI: Not for a second did I suspect he had autism. I was so shocked when it was suggested to me by one of his psychiatrists in hospital. I was like, “What?” But then, when I thought about it, it just started to make sense.

5 MS EASTMAN: Okay. And the way in which you came to Philip’s diagnosis of autism was very different to Giovanni.

MS ABI: Yes.

MS EASTMAN: And we’re going to talk about that now.

MS ABI: Yes, the worst ever.

MS EASTMAN: All right. Okay. So Philip went to mainstream primary school; is that right?

10 MS ABI: Mmm.

MS EASTMAN: And things were going really well for him until about year 5.

MS ABI: Mmm.

MS EASTMAN: And you say that a little black cloud started to hover over him when he was in year 5 at school.

15 MS ABI: Yes. He just seemed so sad all the time. He just wasn’t my little boy. He had always been very close to me and he’d had separation anxiety and things like that, but he was my first. But, yes, it just was different.

MS EASTMAN: Okay.

20 MS ABI: I just, sort of, felt on alert.

MS EASTMAN: Now, you asked him what was going on.

MS ABI: Mmm.

MS EASTMAN: And you thought, in your family, that – were going to deal with any potential mental health issues in exactly the same way you would deal with any physical health issues.

25 MS ABI: Yes. Exactly. With no shame, no stigma. I needed him to talk to me.

MS EASTMAN: So for Philip, you thought, “Look, he’s not happy. I’m not comfortable with how he’s travelling, in terms of this sadness over him.” And you organised for him to see a psychologist when he was in year 5; is that right?

MS ABI: Yes.  
MS EASTMAN: You wanted to be a proactive parent.  
MS ABI: Mmm.  
MS EASTMAN: And you were not going to be anti anything and you didn't want it  
5 to be a big problem; is that right?  
MS ABI: Yes. True. I thought – as I learned with Giovanni, the earlier you  
organise intervention the better. So I didn't want to make the same mistake I'd made  
with Giovanni, by delaying it for years, with Philip. So I thought I will just get him  
in, let's figure this out and, hopefully, we can, you know, get my happy little boy  
10 back.  
MS EASTMAN: So you found a local psychologist and you started some treatment.  
MS ABI: Mmm.  
MS EASTMAN: And that partly involved a psychologist seeing both you and  
Philip at the same time on occasions, but on other occasions just the psychologist and  
15 Philip alone; is that right?  
MS ABI: Yes. Correct.  
MS EASTMAN: And on one occasion, the psychologist said to you, "Philip is very  
dark. He's very sad. I don't know what's going on, and he's starting year 6." And  
you were quite - - -  
20 MS ABI: That was me.  
MS EASTMAN: Was that saying you saying it? All right.  
MS ABI: Yes. I said that.  
MS EASTMAN: Okay. All right. So you said that.  
MS ABI: Yes. I said to her - - -  
25 MS EASTMAN: Okay.  
MS ABI: Because she was – she's – she was lovely. But she would focus very  
much on what he said the problem was. He would always think it was because he  
wasn't on this sporting team or because this person left school. But I said, "No,  
there's something else going on." Like, he's - - -  
30 MS EASTMAN: Okay.



MS ABI: You know, these are just problems that we fix.

MS EASTMAN: All right.

MS ABI: Yes. So I said to her – I said, “Please delve deeper. Let’s try to figure out what’s going on.”

5 MS EASTMAN: What’s going on. All right. And so Philip then moves into year 6.

MS ABI: Mmm.

MS EASTMAN: And you try to talk to him a lot.

MS ABI: Mmm.

MS EASTMAN: And your sense was that year 6 was just a little bit boring for him.

10 And he said to you, “I just need high school to start. I’m so bored at school.” And you thought, “Well, let’s get through year 6 and high school would be a fresh start.”

MS ABI: Mmm.

MS EASTMAN: And that he started high school the following year. Everybody was quite hopeful. You were looking forward to it. He was very excited about

15 starting high school, wasn’t he?

MS ABI: He was. And so was I. We just thought that was the problem. We kept trying to figure out what the problem was, we’d try to solve the problem. But then,

you know, it would land on something else and that would be the problem. And I think Philip and I both realised, I think, when he went to year 7 and he just became

20 sicker than ever, that it was a bigger issue than just school, high school, friendship groups, that there was something else going on.

MS EASTMAN: Something else going on. I think you say that your sister took Philip and your niece; is that right?

MS ABI: My niece. Yes.

25 MS EASTMAN: They were going to the same school. And she took a photo of them - - -

MS ABI: On the first day.

MS EASTMAN: - - - on the first day of school and then sent that to you.

MS ABI: Mmm.

MS EASTMAN: But there was something about that photo that you say made your stomach drop.

5 MS ABI: Yes. He just – there was no joy in his face. It was like he was just stretching his mouth. And I just could tell that he was having some sort of realisation about feeling bad that day and I just – I just could tell that something was off. It was just – his eyes were glassy. It was awful. I just – I really, really felt deeply that something was going on, and we hadn't even started to figure it out yet. And I felt, sort of, more urgency that we had to figure it out, because he was in high school now, he had lost some of his friends and it was a huge life change. So I really  
10 wanted to figure out what was going on at that stage.

MS EASTMAN: All right. I'm going to have to ask you to slow down.

MS ABI: I know. I'm sorry.

MS EASTMAN: Otherwise I won't keep up with you myself.

MS ABI: Yes.

15 MS EASTMAN: Okay. So you've seen the psychologist for almost two years.

MS ABI: Mmm.

MS EASTMAN: And you said to the psychologist, "He's not my little boy. I've been coming here for almost two years and you keep telling me he's fine. He's not. Please help me."

20 MS ABI: Mmm.

MS EASTMAN: And after you had that conversation, a psychologist had had a session just with Philip; is that right?

MS ABI: Yes.

MS EASTMAN: And then she asked – it was she, wasn't it?

25 MS ABI: I beg your pardon?

MS EASTMAN: That psychologist was a woman; is that right?

MS ABI: Yes. Yes.

MS EASTMAN: Okay. Sorry, I'm just making sure I've got the order right. She asked to speak to you alone after that session. So I will just give everybody a  
30 warning at this point in time. The psychologist told you that Philip had told her that he had tried to take his own life. And you did - - -

MS ABI: Several times.

MS EASTMAN: And you reacted as exactly as you just did now. You went, "Mmm," and nodded.

MS ABI: Yes.

5 MS EASTMAN: And in - - -

MS ABI: It just, yes, made sense.

MS ABI: Yes, it just made sense.

MS EASTMAN: In your heart, you say you knew something was going on.

10 MS ABI: Yes. And without going into the details of that, there was stuff going on at home and in his room that I couldn't figure out, that he had a reasonable explanation for, and then when she told me what he told her, I sort of – I actually was – I realised how lucky I was that he was still here.

MS EASTMAN: Okay.

15 MS ABI: Because I knew it. I knew something was going on. And he got so close, and, yes, I – the fact he's still here, I'm so happy.

MS EASTMAN: After this first conversation, the response was not to take him to hospital.

MS ABI: Mmm.

20 MS EASTMAN: It was not to seek immediate or acute psychiatric care. The advice was just watch and the psychologist said that she felt that he hadn't made a real attempt. It was a cry for help.

MS ABI: Whatever that is.

MS EASTMAN: Okay.

25 MS ABI: I mean, yes.

MS EASTMAN: So – but you followed that advice; is that right?

MS ABI: Because she's the expert. What do I know?

MS EASTMAN: And Philip continued to be under the psychologist's care.

MS ABI: Mmm.

MS EASTMAN: But sometime after – and is it fair to say, Ms Abi, that you were on sort of pretty close watch of Philip.

MS ABI: Yes. I think I was - - -

5 MS EASTMAN: Not intrusive, but you were very - - -

MS ABI: - - - subconsciously on suicide watch, I feel, looking back. I just was – yes, he was never on his own ever. Yes. We were just keeping a very careful eye on him.

MS EASTMAN: All right. So then there’s another occasion.

10 MS ABI: Mmm.

MS EASTMAN: And on this occasion you said to Philip, “Get in the car”, and you drove to the Children’s Hospital into the emergency room, and you were in the triage.

MS ABI: Mmm.

15 MS EASTMAN: You spoke to the triage nurse and you told her what had happened. And she organised for Philip to be seen urgently. So there was immediate response.

MS ABI: Mmm.

MS EASTMAN: And he was asked about whether he had hurt himself? Did he feel

20 safe? And so that immediate engagement with the triage nurse you said was amazing.

MS ABI: Mmm.

MS EASTMAN: But then you and Philip were left in a room for 12 hours waiting to see somebody; is that right?

25 MS ABI: Yes, at least. It was crazy.

MS EASTMAN: Then a psychiatrist came to see you and asked lots of questions. And you answered all of those questions. And you were – you were asked whether or not you wanted Philip to be admitted to the hospital. And you said, “No” because you didn’t know what that would mean.

30 MS ABI: Well, his psychologist had suggested next time he tries to take his own life, to take him to the hospital, to call his bluff. She said that he was doing it as an

expression of some sort of dissatisfaction, but she didn't think that he was seriously trying to hurt himself. And so I went through those steps, still thinking that she probably was right. We didn't – it was a very long wait. We didn't get admitted. We went home. I told her what had happened. Philip and I started talking more

5 about it. Not to the extent we do today, but we were starting to come up with some language to discuss what was going on with him. But I still just thought that it would be okay. I had done all the right things: found a psychologist, taken him to the hospital, was watching him carefully. And I had no idea how bad it was going to get.

10 MS EASTMAN: So he wasn't admitted to the hospital on that occasion, but the associate psychiatrist you describe here, but the psychiatrist who you saw at the hospital gave you a referral to see a psychiatrist; is that right?

MS ABI: Yes.

MS EASTMAN: And so that was the start of Philip then seeing one of the staff psychiatrists at the hospital. So you had some sessions with the psychiatrist; is that

15 right?

MS ABI: We had one session with an off-site psychiatrist. I had gotten the referral. And he took issue with the fact that Philip wasn't regularly attending school at that stage. And he wasn't regularly attending school, because I'd met with the school about Philip's emotional issues and asked for support. And they didn't have a child

20 psychologist at that point. So a couple of the teachers were left to manage us, and they treated it like Philip had a behavioural issue. And I later spoke to the organisation that runs that school and they said it's so unusual we didn't have a child psychologist at that time. And I didn't feel Philip was safe there and I couldn't

25 watch him? So he was home at that stage, very sick, very thin, and, yes, still, I was hoping the psychiatrist would give me some tools to use to get him some real help, but he just seemed to just make out like I was a bad parent because I had pulled Philip out of school for a little bit.

MS EASTMAN: Things came to a very serious point in January 2018. And you

30 came home from work early.

MS ABI: Early.

MS EASTMAN: And you saw that Philip was asleep.

MS ABI: Mmm.

MS EASTMAN: He's 14 years old at this stage.

35 MS ABI: Mmm.

MS EASTMAN: And when you tried to rouse him, he was very groggy and you immediately knew something was not right.

MS ABI: Mmm.

MS EASTMAN: So you took him immediately to the hospital.

5 MS ABI: Mmm.

MS EASTMAN: And this was an occasion when he was then admitted - - -

MS ABI: Yes.

MS EASTMAN: - - - to the adolescent psychiatric ward; is that right?

MS ABI: Yes. And, without going into detail - - -

10 MS EASTMAN: Yes.

MS ABI: - - - I knew it was serious, because there was remnants of stuff in his room that I have just picked up and stared at and my brain just wouldn't go there. And was, like, he's groggy. I'm holding this. He's groggy. I'm holding this. And, yes, that's the closest he has ever gotten.

15 MS EASTMAN: Yes. So that - - -

MS ABI: That was a horrible, horrible day.

MS EASTMAN: So that resulted in an admission into hospital.

MS ABI: Yes. Well, he needed emergency treatment - - -

MS EASTMAN: Okay.

20 MS ABI: - - - at first in the local kid's emergency ward. And, yes, that was when they suggested that they admit him.

MS EASTMAN: Right. And I know that you've told me that that experience is very traumatic. So I'm not going to ask you to talk about that in your evidence this morning. All right.

25 MS ABI: Okay. I'm happy to, though, because people don't realise how horrible it can be.

MS EASTMAN: All right. If you want to talk about that.

MS ABI: Yes.

MS EASTMAN: But briefly.

MS ABI: Of course.

MS EASTMAN: But I know how traumatic it is and I'm conscious of how traumatic it is for Philip as well.

5 MS ABI: Yes.

MS EASTMAN: But do you want to say something briefly about what your observation was - - -

MS ABI: Yes.

10 MS EASTMAN: - - - about the nature of Philip going into the adolescent psychiatric ward. And I think this is his fear that led to this drawing; is that right?

MS ABI: Yes.

MS EASTMAN: Okay. So just, very briefly, what would you like to say?

15 MS ABI: So we were – he was treated for what he had done to himself. And then once he was out of the woods, a psychiatrist came and spoke to us about admitting him. And I had never considered it before, but we felt – and I think Philip also understood – that he wasn't safe at home. So it was necessary to keep him safe. And then we were left to wait just for hours, because you have to wait for a bed to be available. And they just were saying "ward, ward", so I didn't really understand what it would be like.

20 And so Philip and I were just sort of lying down sleeping and then they came and got us. And we start getting wheeled to this place. We have no idea what it's like. No one has told us what to expect. And we go sort of the lift down to the dungeon level and you – you go through these hallways. And Philip and I were just sort of looking at each other like, "Where are we going," and then this big doors with Dr Seuss on it and a lock. And then you go into the waiting area. And they take everything off – everything off him that can hurt himself with. I signed a bunch of forms. There was no support for me. It was night-time, so they just wanted to admit him and then I was to go home and come back the next day.

30 So my child, who has almost died, like, is going to be on the other side of a locked ward, like, you know? And I make this gesture, because that's – you know, when he broke his arm I was asleep next to him every day. You know, he was sicker than he had ever been, closer to death than he had ever been, and I was – he was being taken away from me. I wish I could have stayed with him. And, yes, it was – it was awful. And the next day when I went back, after crying all night, I went back to see him and  
35 he was on the other side of the glass and we were just looking at each other and just holding our hands up to each other. I think that the system just sort of

underestimates how much you need your person when you're that sick. And it was just the worst thing ever to be separated from him.

MS EASTMAN: So talking about that was just being in an experience and in a situation where you've never been before.

5 MS ABI: Yes.

MS EASTMAN: Is what you've learnt from that is the importance of having the right supports but also - - -

MS ABI: Any support.

10 MS EASTMAN: - - - knowing – knowing what's coming up next and what's going to happen.

MS ABI: Yes.

MS EASTMAN: So that's why you wanted to talk about that.

MS ABI: I wish that they had shown me around it beforehand - - -

MS EASTMAN: All right.

15 MS ABI: - - - and had proper conversations with us.

MS EASTMAN: All right. But as a result of this admission - - -

MS ABI: Mmm.

MS EASTMAN: - - - and some investigation in relation to Philip, the outcome was the diagnosis of autism; is that right?

20 MS ABI: Yes.

MS EASTMAN: Okay.

MS ABI: The psychiatrist suggested at a meeting in the middle of the day, because the meetings were always in the middle of the day when I was meant to be at work. And if I ever said I am at work that day I don't think I can get there till a certain  
25 time, they made me feel like a terrible mother. But Philip's problems had been going on for years at that stage. You know, there's only so much time you can take off work. And so I did my best and we're sitting there and she said she felt he might have autism. I was like, "No, he doesn't. I've got one with autism, he's nothing like that." And she's like, "No, I think he does." So we got a referral for another  
30 department in the hospital to have that assessment done. Yes. And that started to



explain a bit about his mental illness and his fixation on death as a solution to every problem that would come up - - -

MS EASTMAN: Okay.

5 MS ABI: - - - and that spiral that would happen. So it was a really useful diagnosis to get for him.

MS EASTMAN: All right. Now, one consequence of that diagnosis was then you were introduced to a psychologist at the Prevention Early Intervention and Recovery Service at Parramatta.

MS ABI: Yes. I had never heard – I did not know they existed.

10 MS EASTMAN: And that has been a very important resource to you and Philip.

MS ABI: Yes.

MS EASTMAN: And Philip has been under the care of an expert psychologist - - -

MS ABI: Yes.

MS EASTMAN: - - - in adolescent health; is that right?

15 MS ABI: Yes. A very over-worked amazing expert in child psychology.

MS EASTMAN: And she has been able to assist Philip over the past few years; is that right?

MS ABI: And support me.

MS EASTMAN: All right.

20 MS ABI: Yes. She's amazing.

MS EASTMAN: All right. So I want to, now, deal with things this way: since that first admission and the diagnosis of autism, then you and Philip have worked very hard to ensure that you've had access to the right health care and right support.

MS ABI: Mmm.

25 MS EASTMAN: So the psychologist is one part of it. But things have still been rocky, haven't they, from time to time? And over the past few years Philip has had a number of admissions. And some of them have been admissions that have gone quite well, but other admissions have also been a little bit tricky, particularly where there were some renovations, I think, to one of the wards, which resulted in him  
30 having to go to a different unit and then come back and forth. So - - -

MS ABI: Yes. That was an interesting choice to renovate that ward.  
MS EASTMAN: - - - you weren't overly happy about that. All right.  
MS ABI: Yes.  
MS EASTMAN: So I may not – we may not go into that.  
5 MS ABI: Okay.  
MS EASTMAN: But what – is this the time you want to put up the - - -  
MS ABI: Yes. Any time.  
MS EASTMAN: We'll put it up. So Philip did a drawing for you.  
MS ABI: Mmm.  
10 MS EASTMAN: And when did he do this drawing?  
MS ABI: I can't remember. He does so many drawings - - -  
MS EASTMAN: Okay.  
MS ABI: - - - and they're always so stark.  
MS EASTMAN: And – and you've got that drawing in front of you.  
15 MS ABI: In front of me.  
MS EASTMAN: Because you find that very helpful for yourself.  
MS ABI: Yes. So it's he and I in a bubble screaming and no one can hear us. And  
I remember when I saw it I was so sad, but I was so happy that he put me in the  
bubble with him. So we're both sort of, like, fighting together. Yes. So he does art  
20 as therapy. He's really cute, but we sort of feel like we're not heard. You know,  
when you're shuffled around different wards. You know, I do the right thing. He  
tries to hurt himself. I take him to the local emergency room. Then we wait for 12 to  
16 hours to see someone. He may or may not be admitted. None of the experience  
of admission have been good aside from the autism suggestion. It got to a point  
25 where he wouldn't even tell me he wasn't feeling safe anymore, because he didn't  
want to go back to a certain place. So I had to promise he wouldn't, so he would talk  
to me. So we manage it ourselves now.  
MS EASTMAN: All right. And, at one point, I think Philip wanted to come and  
talk to the Royal Commission himself.

MS ABI: He did.

MS EASTMAN: And – but you and he – and he in particular – have decided that he was happy for you to speak for him.

MS ABI: “Happy” is a strong word.

5 MS EASTMAN: Sorry.

MS ABI: He really wanted to be here - - -

MS EASTMAN: Okay.

MS ABI: But – yes, I think that – I mean, he started with food allergies. And, you know, we would talk about that openly and Giovanni’s autism a bit openly. And  
10 then, with the mental illness diagnosis, everyone is suddenly, “Shh,” you know, “don’t say anything.” But I have said to Philip, because he already – when you have a mental illness you feel shame. You feel like it’s your fault. He would say to me, “Mum, why am I so sad I have a perfect life?” And I’m like, “This isn’t you.” I  
15 said, “You have a chemical imbalance in your brain which makes you feel sad.” I said, “You’re not deciding to do this.” And everyone acts as though – they would say, “Was he bullied? Does he have a hobby.” And it’s like, “He has got a great life. He has a chemical imbalance in his brain. He has to take medication for it, like a type 1 diabetic.”

And that’s how I choose to speak about it, because the shame of it stopped him  
20 talking to me for years. The shame of it almost killed him. You know, the stigma surrounding it. So we discuss it openly like any other medical issue in our family, friendship circles everywhere, because so many people are suffering from mental illness and they don’t say it because of the shame and the stigma. And that’s why the suicide rate is so high. And I’m not going to let my son become part of that statistic.  
25 And part of that work is empowering him to tell his story, empowering me to share my experience of caring for him, all the people who email me who are in my position, because we feel that we can’t talk about it because it’s so shameful. I mean, it started this whole conversation of us just going, “This is what our kids are like. This is what they need.” And we’re all in the same fight. We’re all fighting for the  
30 same things. We want our kids to be healthy and happy and alive and, yes, we try to approach it as any other medical issue.

MS EASTMAN: All right. Can I now turn to the NDIS? And - - -

MS ABI: They try.

MS EASTMAN: And since you’ve had the diagnosis for both Giovanni and Philip  
35 of autism, then you have now accessed the NDIS to obtain some assistance and support.

MS ABI: Yes.

MS EASTMAN: And one of the challenges in the NDIS is you've found about finding a right service provider or a support worker - - -

MS ABI: Case worker.

5 MS EASTMAN: - - - who can walk with your respective sons and provide them the support they need. Do you want to say something about that - - -

MS ABI: Sure.

MS EASTMAN: - - - and then I'm going to ask you about all of your suggestions for change.

10 MS ABI: Because I know that people have had positive experiences with the NDIS. I haven't yet. It sort of feels as though they haven't even Googled what autism is before I walk in the room. They haven't read our file. I'm always starting from scratch. You have to have three goals, three goals only – no more, no less – of stuff you want to work with that they will fund. And I'm like, "Well we've only got two  
15 that we need funding for. Is that okay?" And it's not. And then they give you these amounts of money and it's – I tend to get money for stuff I don't need, but not enough for what I do need.

I actually said I just need OT money for Giovanni for this year. And they're like, "No, it needs to be three goals." So I'm – you know, came up with some other stuff.

20 And then, as a result of not spending all that money, we got less the following year. We've had about eight different case workers. The latest person tried – she said, "We will do it over the phone for both boys at once." And that was the worst outcome I've gotten. And then, even when you get the money – so I got a big lump sum of money for Philip to hire somebody to help me with him. I just wanted  
25 someone to accompany him when he does his activities or, you know, goes to the doctor or maybe gets a little job. And even to access someone qualified to do that with the right training who stays, who Philip likes, has been virtually impossible. I haven't managed it yet. So I know what Philip needs. I've got money for it, but I can't get the person to do it.

30 I mean, both of my boys have it in them to be employed, productive members of society. But they're not getting the education they need. They're not getting the care that they need. And I just can't see how they're going to get there without all of that stuff in place. I want everything for them and, for me, it's just sort of like a matter of, you know, they deserve an education. They deserve good care. They deserve a  
35 great life. And I'm so sick of acting grateful for every kindness and, you know, experience of understanding. You know, you're so grateful, because you're so misunderstood all the time and people don't listen to mums, especially in health care, that you forget, hang on, they're entitled to this. They have a right to education. They have a right to have things verbally explained to them. They have a right to

have a doctor who knows how to speak to them. You know, these are their basic rights. I'm fighting for my kids' basic rights. And it's 2020 and I don't understand what's going on.

5 MS EASTMAN: Okay. All right. In the impact and the suggestions for change you raise a number of issues.

MS ABI: Yes.

MS EASTMAN: But I just – I'm looking at paragraph 111, and you say here, "Kids with autism are often geniuses."

MS ABI: Sometimes.

10 MS EASTMAN: And the only reason your kids are "disabled", as you say - - -

MS ABI: I hate that word.

MS EASTMAN: Yes – is because – because of the society we've set up around them.

MS ABI: Yes.

15 MS EASTMAN: And you say:

*The way my kids' brains work is extraordinary. If they got everything they needed they could achieve so much. They are the ones that often think different naturally.*

MS ABI: Yes.

20 MS EASTMAN:

*And we don't do anything to support that.*

And instead you say this. You said:

*Instead, we do a lot to make them fit in and all the treatment is trying to fix our kids, not fix the world - - -*

25 MS ABI: The world.

MS EASTMAN:

*- - - so they can be whoever they are.*

MS ABI: Yes.

MS EASTMAN: So this is a very strong view you hold, isn't it, about a diagnosis of autism is not going to be something that should be looked at as fixing or curing - - -

MS ABI: Mmm.

5 MS EASTMAN: - - - but it's about adapting. And that the world around them should be able to have enough capacity to adapt, to be able to allow them to access the things that you've just talked about.

MS ABI: Exactly.

MS EASTMAN: Education, employment, and the like.

10 MS ABI: Mmm.

MS EASTMAN: All right. What other suggestions for change did you want to raise with the Royal Commission?

MS ABI: Well, I remember when my kids were four and they were about to start school and you go and have, like, that physical check before you start school, 15 vaccinations, this, this and this. In my fantasy world every kid has a cognitive test as well. You pick up any issue that they have, whether it be dyslexia or autism or mental illness. And then you just put things in place for them so they can have a successful experience at school and a successful life. And that removes the stigma. Because there's parents who don't want to acknowledge that their children have 20 autism and mental illness. But that's not their right. You know, these kids need what they need, because they exist, and they are who they are. And with autism, the actual autism is such an interesting cognitive condition. It's the comorbid issues, like mental illness and ADHD, that makes it quite problematic, which you can treat. But if you get that mandatory screening and it's just like, "This is your child. This is the 25 little cute jigsaw puzzle they are. And this is what we're going to do to make sure they can have a wonderful experience at school", that would just be a dream.

MS EASTMAN: And the other issue that you've raised is the need for support for parents and information.

MS ABI: Mmm.

30 MS EASTMAN: So, at paragraph 115, you talk about the online groups - - -

MS ABI: Yes.

MS EASTMAN: - - - of people with autism and their parents.

MS ABI: Mmm.

MS EASTMAN: And that's taught you any other - - -

MS ABI: More than any other.

MS EASTMAN: - - - health professional you say.

5 MS ABI: For sure. 100 per cent. Especially adults with autism – adults living with autism. I always say, “I want to do this for one of my boys. Is it a good idea or bad idea?” And they're like, “Don't do it,” or, “Yay.” Like, it's just they're experts at who my boys are going to become in the future.

10 MS EASTMAN: All right. And so you wanted to recognise that people, through these communities, even if they're online communities, have been a very important support structure for you and your family; is that right?

MS ABI: I would go so far as to say that I wouldn't be a functioning parent of two boys with special needs without them. We just rely on each other so much. Even in the process of participating here, we've just been talking every day, because this is just our life. So we don't want it to be hard. We just want to, you know, raise our kids. I don't want to be a doctor or a psychologist or an OT any more. I just want to  
15 be a mum and enjoy my kids. And we all just celebrate the smallest things. Like there's really funny posts. Like, the other day I said, “Giovanni ate a taco. “ And they're all like, “Yay.” Because the food issues when you have autism are massive. And it has taken three years of discussions for him to even do that. And it's just –  
20 you know, it's normal life for me and for them but, yes, there's no support. You know, you can hire a psychologist but, once again, that's time, that's money, that's someone who has room for you, that's someone who is local. I can't even access easy psychological care for myself let alone all the things the kids need.

MS EASTMAN: All right. So I'm going to ask you, just in closing your evidence –  
25 and thank you very much for coming to give your evidence today – to just read the final three paragraphs of your statement.

MS ABI: Okay.

MS EASTMAN: So that starts at page 24, paragraph 116. If you want to read the final three paragraphs.

30 MS ABI: Okay:

*So I have to be a doctor, a psychologist, a psychiatrist and a nurse to both of my boys. There aren't enough good practitioners who are affordable and available to help me with my sons. I feel like their human rights are being violated every day. They exist. We live in a society where everyone who exists  
35 should get what they need, but they don't. I'm reminded all the time that there are kids with more severe autism and severe mental illness, but you can't compare hardship. Sometimes all I can see is that my boys have no hope of*

5 *having a good life. And no matter what I do I can't make that happen, because no one's helping me. I'm an educated, media savvy woman of resources and my kids are still not okay. When I do get help it's patchy and so I don't have any trust. I don't trust the health care sector. I don't know if they're trained or not, but I'm tired of trying to figure it out. I can't fix the world. I'm too busy just trying to raise my boys.*

MS EASTMAN: All right. Ms Abi, thank you very much for giving evidence to the Royal Commission today.

MS ABI: Thank you.

10 MS EASTMAN: And sharing a lot of very difficult and distressing times in your life. We're very much grateful - - -

MS ABI: Thank you.

MS EASTMAN: - - - that you've given us the time.

MS ABI: Thanks for giving us the opportunity.

15 MS EASTMAN: Commissioners, that's the evidence of Ms Abi.

COMMISSIONER SACKVILLE: We would like to thank you too.

MS ABI: Thank you.

COMMISSIONER SACKVILLE: And apologise too for the delays in you giving your evidence.

20 MS ABI: That's fine.

COMMISSIONER SACKVILLE: Thank you for being so patient with us and thank you for the care that you've taken in preparing your statement and giving your evidence, sharing your experiences and those of Philip and Giovanni and, also, that really quite remarkable drawing.

25 MS ABI: I know. Isn't he cute?

MS EASTMAN: We might put that drawing up again - - -

COMMISSIONER SACKVILLE: It is.

MS EASTMAN: - - - when we've finished your evidence, if we can do that.

MS ABI: Yes.



COMMISSIONER SACKVILLE: It's an extraordinary drawing.

MS ABI: He's just – yes, he always draws his feelings and, if he can't tell me how he is feeling, I can see from what he is drawing. But, then, when he's sick, he will rip them all up. I once spent two hours taping them together but – yes, he's beautiful.

5

COMMISSIONER SACKVILLE: Thank you very much.

MS ABI: Thanks so much.

**<THE WITNESS WITHDREW**

**[10.56 am]**

10

COMMISSIONER SACKVILLE: Thank you.

MS EASTMAN: And, Commissioners, I will remind everybody of those telephone numbers, so they can come back up on the screen. So there's the Lifeline number, which is 13 11 14. The Kids Helpline number 1800 55 1800. And Blue Knot, which is 1800 421 468. Commissioners, if it's convenient, we might have a very early morning tea for 15 minutes or so, if that's convenient.

15

COMMISSIONER SACKVILLE: It's certainly convenient. Thank you very much.

MS EASTMAN: Thank you.

COMMISSIONER SACKVILLE: Thank you again. We will return at 11.15.

20

MS EASTMAN: Thank you.

**ADJOURNED**

**[10.56 am]**

**RESUMED**

**[11.22 am]**

25

COMMISSIONER SACKVILLE: Yes. Ms Eastman.

MS EASTMAN: Commissioners, just before we take some evidence from our two witnesses who are coming up next, we thought it might be helpful to say something about the approach that the Royal Commission wishes to take in hearings of this nature. The Royal Commission will endeavour always to take a trauma-informed approach, and we will be guided by best practice, and this includes best practice in relation to reporting of incidents of suicide or attempted suicide or suicide ideation.

30

The Royal Commission acknowledges that these are very distressing topics and have to be handled carefully and sensitively, but at the same time there will be occasions during the course of the Royal Commission's work that we need to deal with these issues.

5 So some of the material that we have found helpful from the Royal Commission's perspective in a public discussion about suicide ideation we have collected – and we thought it may be helpful to just put some of those references up on the screen. These are all publicly-available material. I think they're just coming up on the screen there. And this may be helpful to some people who may be following our  
10 proceedings. And they're all, as I said, available online.

COMMISSIONER SACKVILLE: Yes. Thank you very much.

MS EASTMAN: So, Commissioners, we started this hearing – and it may feel, for some of us, a very long time ago, but it was a relatively short period of time. And our first witness was Kylie Scott. And so we're joined by Kylie's mother, Evelyn  
15 Scott OAM today. And we concluded our evidence at the end of last week with Tara Elliffe. And we have Margot Elliffe, who is Tara's mum. And we thought this would be an opportunity to hear from the mums, but very strong women who have been strong advocates for their daughters. And we reflected on the need to talk about advocacy and the impact on family. So we have invited – is it all right if we do  
20 Margot and Evelyn, rather than the formalities?

MS SCOTT: Yes. That's fine.

MS EASTMAN: We've invited Margot and Evelyn – I will just check Commissioner Atkinson's okay.

COMMISSIONER ATKINSON: Yes. I'm fine.

25 MS EASTMAN: All right. So we'll just deal with the oaths and affirmations.

**<EVELYN MARGARET SCOTT, SWORN [11.25 am]**

**<MARGOT ELLIFFE, SWORN [11.25 am]**

30 COMMISSIONER SACKVILLE: Thank you very much coming to give evidence. We very much appreciate it. Ms Eastman will ask you some questions.

MS EASTMAN: Evelyn, can we start with you? Your name is Evelyn Scott OAM?

MS SCOTT: Yes.

MS EASTMAN: And you're a retired public servant, a volunteer and an advocate.

MS SCOTT: Yes.

MS EASTMAN: And you've prepared a statement for the Royal Commission dated 11 February this year.

5 MS SCOTT: Yes.

MS EASTMAN: And, Commissioners, a copy of the statement can be found in part A of the tender bundle, behind tab 44.

COMMISSIONER SACKVILLE: Yes.

MS EASTMAN: So a copy – you've read the statement.

10 MS SCOTT: Yes. I have.

MS EASTMAN: And the contents of the statement are true and correct?

MS SCOTT: They are.

MS EASTMAN: So, Commissioners, perhaps if I tender the statement now, so I don't overlook that. If that could be received into the evidence of the Royal

15 Commission and marked exhibit 4-33.

COMMISSIONER SACKVILLE: Yes.

**EXHIBIT #4-33 STATEMENT OF EVELYN SCOTT OAM DATED  
11/02/2020 (STAT.0046.0001.0001)**

20

MS EASTMAN: Margot, your name is Margot Elliffe?

MS ELLIFFE: Yes.

MS EASTMAN: And you are a registered nurse, midwife and a child and family health nurse.

25 MS ELLIFFE: Yes.

MS EASTMAN: You have prepared a statement for the Royal Commission dated 13 February.

MS ELLIFFE: Yes. I have.

MS EASTMAN: And, Commissioners, a copy of Margot's statement can be found in part A of the tender bundle, behind tab 45. And you've read your statement and the contents are true and correct?

MS ELLIFFE: I have.

5 MS EASTMAN: All right. And, Commissioners, I deal with the tender of that statement. And if that can be received into the evidence of the Royal Commission and marked exhibit 4-34.

COMMISSIONER SACKVILLE: Yes.

10 **EXHIBIT #4-34 STATEMENT OF MARGOT ELLIFFE DATED 13/02/2020 (STAT.0062.0001.0001)**

COMMISSIONER SACKVILLE: And we do have both of those statements. Thank you.

15 MS EASTMAN: Thank you. So I want to start – both your daughters have given evidence – I'll just check Commissioner Atkinson's - - -

COMMISSIONER ATKINSON: Yes. I'm fine.

MS EASTMAN: Okay.

COMMISSIONER ATKINSON: I've just got a cough.

20 MS EASTMAN: All right.

COMMISSIONER SACKVILLE: She might be fine. I'm not sure about me.

COMMISSIONER ATKINSON: It's not a novel virus.

COMMISSIONER SACKVILLE: Yes. I wonder if Commissioner Atkinson could turn towards Commissioner Galbally.

25 MS EASTMAN: I think it's getting to that stage of the proceeding. Margot and Evelyn, both your daughters came and gave evidence last week and you both supported them to give evidence; is that right?

MS SCOTT: Yes.

MS ELLIFFE: Yes.

MS EASTMAN: But for both your daughters, it was very important that they gave their own evidence.

MS SCOTT: Yes.

MS ELLIFFE: Yes.

5 MS EASTMAN: And neither of them wanted anybody to speak on their behalf or for them; is that right?

MS SCOTT: That's right.

MS ELLIFFE: Yes.

10 MS EASTMAN: And so the capacity in which you're giving evidence is that you may speak about your daughters but you're not speaking for them; is that right?

MS ELLIFFE: That's correct.

MS EASTMAN: Okay. So there are a number of topics that I thought might be helpful to just draw together some of the themes that the Royal Commission has heard over the course of the past two weeks. And I will touch upon this in each of  
15 your statements, but I hope that we can open this up more as a discussion. So for both of you, the birth of your daughters was not met with how wonderful this is, congratulations. For both of you – Kylie was born in Melbourne.

MS SCOTT: Yes.

MS EASTMAN: And Tara was born in Sydney.

20 MS ELLIFFE: Sydney. That's right.

MS EASTMAN: What was the initial response to the birth of your respective daughters?

MS SCOTT: In my case, it was silence.

MS ELLIFFE: Yes.

25 MS SCOTT: And a delay in my husband being told. He was very worried because he thought something must have happened to me and, in a funny way, he felt a sense of relief when he was told that I was okay and that there was a suspicion that Kylie might have Down syndrome.

MS EASTMAN: Okay. Margot?

MS ELLIFFE: Yes. I think silence was the giveaway for me. Tara was my fourth child. So, you know, I knew what happened in labour ward and I had been a midwife. So, yes, it was that you could have dropped a pin. It was so quiet. I wasn't prepared to ask anything at that point, because I really didn't – I needed to have some time to get my head around whatever it was – they were going to give me, but I – it was some hours before a paediatrician came and told us. And he did it in a perfect – he followed all the rules. He did it perfectly. He gave me Tara. I sat with her in my arms, he was beside me. He did it absolutely perfectly. But the minute he said Down syndrome, I didn't hear another word he said.

5

MS EASTMAN: Why was that? You were just - - -

MS ELLIFFE: It was - - -

MS EASTMAN: - - - absorbing that?

MS ELLIFFE: It was just, I suppose, the shock. I've always described it as walking into a brick wall, and you're just dazed. I didn't actually meet that paediatrician again for 20 years. And I sat and had coffee with him one day and told him – and he was, "What could I have done better?" And I went, "Nothing. You did it perfectly. But I didn't want to hear it." He hadn't realised that part – that aspect of it.

15

MS EASTMAN: And, Margot, I think you say in your statement that your first visit to a medical centre, after Tara was born, you were asked by the doctor why you had chosen to have Tara.

20

MS ELLIFFE: Mmm.

MS EASTMAN: And the doctor said to you you should have terminated your pregnancy.

MS ELLIFFE: Yes. Tara was probably two and a half months old. It's always a long weekend when you think, "This child needs to be seen." And it was a doctor I didn't know. And, yes, I was – I sat with her in my arms. And when he said, you know, "You shouldn't have had her," I just shook my head and waited until he had written the prescription and I left. I didn't say anything. I didn't argue with him. I just – it puts you back into that closed-down state, but I went home and cried.

25

MS EASTMAN: And this is a – the undercurrent of a question like that is an assumption that you knew, an assumption that you made a choice and an assumption that that choice may have been misguided.

30

MS ELLIFFE: Yes.

MS EASTMAN: And so for both of you, I think this stepping back and asking what are the attitudes and what are the current issues in terms of testing – so in terms of prenatal testing. And this is something that you both have some very strong views

35

about, and you wanted to talk a little bit about that. I think some of the evidence that we've heard during the course of the Royal Commission is this assumption that (a) you need to be tested, (b) if you are tested, then you should do something about that. And that's a topic we're interested in exploring, because you have issues around choice, but you also have issues around dignity and value of life. And whose assumption is it? And you may have heard of some of the evidence this sense that a doctor makes that choice rather than the woman making a choice. So you want to both talk about that, and I will open it up to the two of you.

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15  
MS ELLIFFE: Well, to me it's really important to understand that it's not just the doctors, it's the midwives. It's – you know, they do a lot of the work in antenatal clinics, and there is the pressure to have the testing. There is absolutely no doubt about that. And that you should, when you get a high risk, which I find – even the language – offensive, that you will automatically terminate. I think the whole medical profession, health – just does not understand. It does not matter what decision that woman or her family make, she lives with that for the rest of her life. She might terminate, but it's – it's not unusual for them to make a donation to Down Syndrome New South Wales.

It's not unusual for them to bring it up at subsequent health – you know, births. It comes back to them. And I've – I've cared for people in their 90s who still talk about their losses. So an obstetric loss, which is what this is, even though this was a decision they might have made themselves, they don't forget it. And I think that's really important. That it needs – it's not just a case of, “Well, we've terminated this pregnancy. Now you can have another one and get on with life.” It's not like that for a woman.

25 MS EASTMAN: Evelyn, did you want to talk about this?

MS SCOTT: Yes, if that's all right. I mean, I'm never going to criticise anyone who decides, you know, to terminate. They have their own reasons. My big concern is that there is not sufficient information made available to people at the time of testing so that they can go away with an informed opinion about what's the best course for them and their family. I mean, I just wanted to mention, in Kylie's evidence on Tuesday last week she said:

*The big thing these days for doctors to know about is prenatal testing or prenatal screening. They need to know how serious it is now these days. I think we should continue people with Down syndrome not being aborted.*

35 Now, I mean, I've just got a few notes here, if you don't mind me reading them. Kylie's, you know, a black and white person in a lot of ways. And it was her view, certainly on Tuesday – still, probably – last week, that there should not be any testing. We've talked about it since. And in her talks that she gives, she does touch on it, you know, and she asks the question, “How do you think I feel when I hear about mothers being told after testing that their baby's likely to have Down syndrome and that it can and even should be terminated?” In my – well, I mean, it's

something that I really quite resent, the fact that it's me who, really, has to say to her things like, "Never mind. You're alive. You're loved, sometimes but not always respected."

5 She's very aware of what happened in Hitler's death camps in World War II, and that people with disability, particularly intellectual disability, were the first to be eliminated, and what that led to. And she's able to see on Facebook discussions that are taking place, particularly in the UK at the moment, where a foetus is likely to be allowed – can be aborted – or there is discussion now around the fact that foetuses which are detected as perhaps having Down syndrome may be allowed to be aborted  
10 virtually up to birth, and she wonders how that can happen. How can people be so cruel? And she also knows that in some countries already there are no babies with Down syndrome being born.

I mean, is it my role to say that – if there is a diagnosis of Down syndrome in a pregnancy, that some parents feel, perhaps because they've never met someone with  
15 Down syndrome, that they could not cope with a child with a disability, so they have made a decision they shouldn't go ahead, and they perhaps, for the rest of their lives, might remember how it felt. When they see examples of people like our daughters these days, they must wonder what their baby would have been like, what their baby might have been able to teach the world, like our girls are trying to do. I really do  
20 resent the fact that it's up to me to justify these abortions to her, especially when we hear that Medicare is wanting to – or thinking about fully funding NIPT for a pregnant woman. And, you know, the expectation many of the detected pregnancies will be terminated.

There are medical professionals who still look upon people like Kylie as just not –  
25 I'm sorry, deficient intellectually, but medically different too because of their three copies of the 21<sup>st</sup> chromosome. They feel that the – you know, they are burdens on Education, Health and a range of other possible services. Should I be the one to explain to her that governments feel that they can make these decisions because there might be additional costs to be met from the public purse, without looking at the  
30 costs I might incur, for example, if I'm bowled over by the little electric bus running around here and end up paralysed? Should I then be put down because of the burden and the cost? I hope not. Anyway, yes, I feel strongly about it.

MS EASTMAN: So you're concerned that these still remain issues, and that, as a community, we really haven't thought through these issues?

35 MS SCOTT: I don't think the medical community is recognising the full extent of what they should be considering.

MS EASTMAN: All right. Now, Evelyn, after Kylie was born, a social worker showed you and your husband some outdated books with appalling photos of adults with Down syndrome, and the social worker advised you not to take Kylie home and  
40 suggested that she could be adopted out. And your immediate reaction was that was not going to happen.



MS SCOTT: Yes. That is correct.

MS EASTMAN: All right.

MS SCOTT: We decided that she was ours and, therefore, we would do as much we could for her as we would do for our older daughter.

5 MS EASTMAN: Now, at the time your husband was working as a lecturer and came to know Dr Graham Clunies-Ross.

MS SCOTT: Yes.

MS EASTMAN: As a result of that, you were able to get access to a number of resources - - -

10 MS SCOTT: Yes.

MS EASTMAN: - - - to help understand about Kylie's development from infancy through to being a toddler and then, as far as you knew, into the future. So you were able to obtain some resources that would assist you to help Kylie, in terms of her low muscle tone, her fine motor skills, tongue retention, speech and the like.

15 MS SCOTT: That's correct.

MS EASTMAN: And so that was very critical?

MS SCOTT: It was, because it was an exercise where not only were they working with Kylie but I was able to learn, you know, some of the exercises and things that would enable her to perhaps progress her development more evenly, in a more structured fashion.

20 MS EASTMAN: And, Margot, you say that you had the support of a community nurse in a case management capacity, and the community nurse helped you negotiate the entire health care system after Tara was born. And that continued until Tara was five.

25 MS ELLIFFE: Yes. Yes.

MS EASTMAN: And the community nurse was able to assist you in managing Tara's health care.

MS ELLIFFE: Mmm.

30 MS EASTMAN: And she was able to assist you to access relevant resources. But you say at the time, the community nurse's qualification was called a "Retard Certificate".

MS ELLIFFE: Yes.

MS EASTMAN: All right. So did you want to say something about the role of a community nurse? And given your particular role and experience in nursing, what were the aspects of the way in which the community nurse both engaged with you and Tara, but also was able to help you navigate, that made a difference? Because some might say, “Well, Margot is a nurse. She should know where to go and how to do all of this.”

MS ELLIFFE: I think the important thing was that her children actually went to school with my three boys. And so there was a community social piece to it. And I – and it made me feel as though I – it was just part of – I was part of this community. I wasn’t isolated because I had had a child with a disability. And, you know, she would see me and say, “I will be around for coffee this week, we can have a chat.” So it was a lot of the psychosocial aspect of her that was really important to me. I didn’t have any family, as such. Either side of – my husband’s family are overseas. So it was that – to be able to talk about stuff that perhaps you could talk to family if you had them there, but to be able to talk about how I really felt. And, at the end of the day, there was no judgment.

She let me waffle on as long as I liked and have as many cups of coffee. But she’d say, “Now, the list of things that we need to do, where are you along this?” And I’d go, “Well, I’ve tried to make an appointment, but, you know” – she said, “No worries. I’ll make that appointment for you.” So she took some of the burden of making those appointments and, “Can I help you get there?” “No, no. I’ll be fine.” She said, “I can get you a parking ticket.” Just little things like that that made it more accessible for me and that I didn’t – because I had three other kids that I had to chase as well. And so just those little things. Explaining, you know, perhaps we need to look at this, and I would go, “Why?” And she would say, “Well, you know, she’s got little ear canals. So perhaps we just need to have hearing checked again.” Just little things that, yes, I hadn’t thought of.

MS EASTMAN: Do you know if there’s still a position of community nurse? So somebody who performs - - -

MS ELLIFFE: No.

MS EASTMAN: - - - that function in the public - - -

MS ELLIFFE: Not in the - - -

MS EASTMAN: - - - health system?

MS ELLIFFE: No. Not in the disability field, no.

MS EASTMAN: All right.

MS ELLIFFE: But I actually do part of that role in my job.  
MS EASTMAN: All right. Okay.  
MS ELLIFFE: Yes.  
MS EASTMAN: Now, both your daughters went to school and they both - - -  
5 MS ELLIFFE: Yes.  
MS EASTMAN: - - - completed school.  
MS SCOTT: Yes.  
MS EASTMAN: And, Evelyn, I think you, in your statement, detailed quite a lot  
about Kylie's school and her background.  
10 MS SCOTT: Yes. Yes.  
MS EASTMAN: And how she went through school. And both of them have gone  
on to find employment in different capacities; is that right?  
MS ELLIFFE: Yes.  
MS SCOTT: Yes. Kylie's had a variety of employment. And because of her father  
15 deciding that he needed to leave the marriage when Kylie turned 18, Kylie suffered a  
lot of depression and anxiety. Do you want me to speak about that now - - -  
MS EASTMAN: Well, I want - - -  
MS SCOTT: - - - or would you - - -  
MS EASTMAN: So I want to just – because this hearing we're focusing on health.  
20 So I just wanted to make sure that we didn't omit something, in terms of their  
education, and the fact that you've both encouraged them and supported them to find  
employment, and they've done that. But I want to really come back to some of the  
health care issues that have arisen along the way, in terms of their general health. So  
I'm happy, Evelyn, if you want to talk about one issue that's arisen for Kylie, which  
25 is her mental health and psychological wellbeing, and being able to access resources  
to assist Kylie in those matters. Do you want to talk about that?  
MS SCOTT: Yes.  
MS EASTMAN: And then we will come and talk about GPs and other things.  
MS SCOTT: Yes. All right. Well, I mean, because of the suddenness of my former  
30 husband's decision, Kylie and I had a pretty rough time of it. Kylie just didn't know

what was happening and it was very difficult for her. She was going into year 12 at the time at – at college, or high school. And she had so much upset that there were times when she was cutting herself. Many years later, she told me – and I hadn't even thought of it – that it was to let the pain bleed out. On one occasion, I got a call  
5 at work saying she was about to jump from a second floor balcony. And it was a pretty bad year.

Kylie continued, you know, progressing through college, TAFE, and then into various jobs. It wasn't always easy. I think her depressive problems were not assisting her in the workplace. She worked at a supermarket for a while. And then  
10 one day I had a phone call – again at work – saying I had to get there now to see the manager. She was accused of putting her hand up a girl's skirt when the girl was on steps stacking shelves. We were told Kylie had the option of resigning or he would call the police. I went outside with Kylie and suggested to her it would be best to resign as things would be made very difficult for her.

She was shocked, upset, and denied it. And I believe her. And, yes, her morale absolutely plunged. And then, a couple of years later, she got the opportunity to go to the public service on a part-time basis. She was really excited. It was fantastic. She loved dressing up, getting the bus. You know, people were kind. But the public service, for better or for worse has a lot of staff changes, and, you know,  
20 departmental restructures, and no one was allocated, it seems, for a long time to take any responsibility for organising her work. Back in those days, job agencies – job – disability job support agencies had very little time that they could spend in a workplace. And, often, over the years, we came across support people in these agencies who had just graduated from university. It was their stepping-stone into the  
25 workplace – into the workforce. So they didn't really have a lot of experience and particularly not in the public service. People were kind, but she wasn't getting structured support. There were times when people accused her of harassing them, because she would ask if there was anything she could do. There were times when she was sat at a computer and facing a wall and told to play computer games.

30 MS EASTMAN: So how did that have an impact on her psychological health?

MS SCOTT: She was devastated. She would come home and say – well, for a long time she didn't tell me about a lot of these problems, but it obviously didn't help her morale. You know, she knew that it wasn't what you should be doing when you go to work.

35 MS EASTMAN: And so what resources, supports or assistance were available to assist Kylie in terms of her psychological wellbeing?

MS SCOTT: Well, we went through a never-ending series of psychologists, even psychiatrists, for a while. They suggested medication. We tried that for a while, but it was not helping and she felt she was just, yes, not herself. We had a lot of  
40 counsellors that we went to. We weren't getting through to the nub of what her

problem was, because she kept wanting to relive what had been happening to her. It certainly wasn't helping her.

MS EASTMAN: Have you found that there are specialists who have got the experience in both intellectual disability and psychological services or psychiatric services?

5

MS SCOTT: Well, I think there might have been one psychologist who had some experience, but they have a program which they work through and then you are pretty well left to go deal with it. I don't think any of the experiences she had made a significant difference to her wellbeing.

10 MS EASTMAN: All right. Can I ask you now about the general health care and if we sort of say primary health care. Both of your daughters regularly see general practitioners.

MS SCOTT: Yes.

MS EASTMAN: And Margot – Tara talked about her GP in some detail last week.

15 MS ELLIFFE: Yes.

MS EASTMAN: So we've got Tara's evidence, but you've set out in your statement your observations about the GPs engagement with Tara and the GP's management of Tara. Did you want to say something about your observations?

20 MS ELLIFFE: Well, she's a very special person. I mean, she has got an interest in disability and she works a lot with boarding house clients. So she takes time. And I think it's time and she listens. So if I do attend with Tara, I always make sure that I sit behind the GP. Tara always sits beside her. The conversation is between Tara and the GP. If I – you know, I find that very difficult, sometimes, not butting in, but I manage. And she – we pre-organise what we're going to talk about. And she, you know, she will take a script along with her and say, you know, "It's nearly finished so I need another one."

25 So she takes visuals to remind her. She has a list of things. And the GP – if there's any decisions to make about what we might want to do, medication we might want to trial, we think about it. I research it. Talk to Tara. She researches it. We all get together and look at it again. And, you know, then Tara will go, "Well, you know, if you're both saying the same thing and – yes. Let's give it a go." So that's how we sort of work it. Sometimes I'm not there, I'm not work. So she will – I get the phone call from Tara, she puts the phone on speaker phone and we will talk it out together. So she's quite comfortable. You know, Leanne sends her off for, yes, blood tests and all sorts of tests. And if she has been sent, she will do it.

35 MS EASTMAN: Okay. And Evelyn, Kylie sees a GP on a regular basis as well?

MS SCOTT: Yes, we've had a few moves over the few years, and, you know, from the very beginning, we've always made a point of going to a GP and interviewing them. We came across one once who was not attuned at all to what we were on about. We didn't go back there. But, generally, they're all willing to learn. And the most recent one that Kylie sees has been excellent. Every time we see her she says, "I'm learning so much with you two." And, you know, she is progressing a few things at the moment with Kylie which have come up unexpectedly.

MS EASTMAN: Is the key to this aspect of primary health and the support of the GP that – that the – there is continuity of care. There's a consistency in the approach and, also, that it seems, from the evidence, a real focus on preventative care?

MS ELLIFFE: Yes.

MS EASTMAN: So anticipating issues that might arise for them as women, but also as people with intellectual disability.

MS ELLIFFE: Yes.

MS SCOTT: Yes. That would be right.

MS ELLIFFE: And I think that's shown very clearly with the GPs use of the care plan. And I suppose I was a little bit shocked to realise that most of Tara's friends actually don't have care plans, but it's a Medicare-funded option. She can have it renewed every – every year apparently. And it's just all – currently, all her history, all her test results, and just little things like, you know, every two to three months we check her ears, because she tends to – her hearing goes down so we check – we check her ears. We check her skin. You know, there's so many little things that she might not remember. And if it's on the care plan, and they pull out the care plan and go through it. And I just think that care plan's invaluable, but it seems to be a Medicare secret.

MS EASTMAN: All right. And you might recall I asked both of them, when they gave their evidence, about how they made decisions for their health care. And the issue of informed consents, and how you support people with intellectual disability to make decisions themselves. And Justine O'Neill, who is here, spoke with Jack Kelly at the commencement of the hearing about the importance of these issues. Both your daughters gave some pretty clear evidence about the way in which they make decisions. And they both said trust of their practitioner was important. So if they trusted their GP and the GP suggested a particular treatment or medication, then that's helping them make their decision. So, from your perspective as their mothers, can you – can you talk about how they go about decision-making and how that sort of sits with this concept of informed consent?

MS SCOTT: In my case, once Kylie's father and I separated, I knew very early on that Kylie needed to learn decision-making. She was very vulnerable at the age of 18 and thereon up. In terms of, you know, a lot of daily activity, she had come from a

very supportive family situation and, suddenly, was sort of dropped into a very difficult life. And decision-making was something I became aware of very early. I mean, there were times when she was duped out of money. And times when she would go to the bank and, even on one occasion, when she was given the wrong  
5 money when she asked for a withdrawal. So decision-making was crucial. And she has always been taught by me that she must always, if she's uncertain, say, "I will think about that. And I will talk to somebody so I can get informed advice. I can look at options. And then I can choose an option that would help me make the right decision." It has been very valuable throughout her life and in recent years, since we  
10 moved to Sydney 10, 11 years ago, Kylie's been accessing CID programs around decision-making, about advocacy support, and all the rest of it, and it has been very valuable for her.

MS EASTMAN: All right. Margot, what's the approach that you've observed for Tara making decisions? She was quite confident when she gave evidence last week  
15 about how she went about making decisions.

MS ELLIFFE: Yes. Look, she usually talks over things, but not always. There are times when she just zips those lips and she makes those choices herself. And you've got to respect that. And if it falls over, well, just like all my kids, when they make choices that I didn't think were very good, you've got to support her. And then it's  
20 usually how could we have done that better? But generally, she makes quite – quite good decisions. She talks about it. She goes – she might gather some information herself. Sometimes I do the – the pros and cons with her, use the visuals, write it down. And that helps her make decisions. And, like Kylie, Tara goes to CID and she has learnt lots about advocacy and decision-making and – and I think that's a  
25 really important factor that people with intellectual disability need that ongoing support. We – yes, we've taught her how to make decisions, but it doesn't mean she's going to do it – in six months' time, she's going to do it the same way.

MS SCOTT: Yes.

MS ELLIFFE: So it's the constant reinforcement that she needs to help her make  
30 those decisions. So - - -

MS SCOTT: And it is often helped by very visual things. For instance, you know, if Kylie's got a major decision like when she moved into independent living and when she then subsequently moved into the house she's now in, an affordable living apartment, we did plus and minus lists of, you know, what's the right thing here?  
35 What will work for you? And what will not work for you? And is it near transport? Is it going to help you with your shopping? Will you be able to go to the shops independently? A whole list of things. So a lot of visual lists are very helpful.

MS EASTMAN: I think she gave some evidence about experimenting with the cayenne pepper - - -

40 MS SCOTT: Yes.

MS EASTMAN: - - - and things like that.

MS SCOTT: Well, you make mistakes. We all do that.

MS EASTMAN: So independent living has been a very significant step for Kylie, hasn't it?

5 MS SCOTT: It has, yes.

MS EASTMAN: And so that's brought with it the challenges that she described about the cayenne pepper and cooking.

MS SCOTT: Yes, yes.

10 MS EASTMAN: But, overall, it's been a very good outcome for Kylie to live independently.

MS SCOTT: It has because, you know, while she was so depressed for so long. She was getting independent living training when we moved to Sydney 11 years ago, and that was really good, but, of course – and then she had lived independently in Canberra some years ago, which was a bit disastrous in lots of ways. But the independent living skills she was acquiring were also frustrating her even more so, because she wanted to do things for herself. She wanted her own home. She wanted to be able to do what she wanted to do and whatever and, you know, it was pretty hard then to get the supports in that context that she specifically needed. And since the NDIS has come in, of course, the supports can be more tailored to suit exactly what her needs are.

20 MS EASTMAN: All right.

MS SCOTT: And that is helping. Not all the things are exactly meeting every need, but we've certainly gone a long way down that path.

25 MS EASTMAN: Now, Margot, Tara gave evidence last week about a situation where she had an acute abdominal pain and you went – your husband took her to see a GP, not the usual GP. And the advice was that Tara's suggestion that the pain might be six out of 10 might actually be closer to 10 out of 10.

MS ELLIFFE: Yes.

30 MS EASTMAN: And so the advice was to take her immediately to the local hospital for emergency treatment. And your husband took her to the hospital. And you were contacted by phone at this stage, but you weren't involved in that immediate - - -

MS ELLIFFE: No.



MS EASTMAN: - - - triage exercise. But, in your statement, you describe what happened at the hospital. We heard Tara's evidence last week. And the upshot of her evidence was that, even though she knows you work in a hospital, this is not a place that she really wants to go. And as she was giving her evidence, she would talk about aspects of it and then she just jumped.

MS ELLIFFE: Mmm.

MS EASTMAN: And we didn't go into it in any detail. She didn't want to do that. But you wanted to talk to the Royal Commission about what actually happened on that occasion, in terms of the hospital presentation. And this is very relevant to communication in an emergency setting, but also the importance of you to decide when and how you're going to step in and, in effect, you had to take over the situation; is that right? Do you want to - - -

MS ELLIFFE: Yes.

MS EASTMAN: - - - tell the Royal Commission what actually happened on that occasion?

MS ELLIFFE: So I had arrived at, probably, after she had been there for at least three-quarters of an hour or more. And, at this stage, she had already seen multiple doctors. And I – I didn't see at any point any doctor at any point actually physically examine her. It was always with the curtains open, the very busy A and E staff, patients everywhere. It was – it was quite busy. Nobody closed the curtain. There was no privacy. It was – reading the notes – the doctor's reading the notes or asking her questions. And they just didn't seem to understand that she wasn't answering the questions. She just was slowly, slowly withdrawing and shutting down. And, you know, Tara – I think Tara said, "Oh, mum can read me like a book." Well, it was pretty obvious to anybody, I thought, that she wasn't responding to them. So they had done a lot of tests and everything, you know, that – the senior doctor finally arrived and said, "Okay. You've got gastro. I think you better go home." And if, I suppose, for me, if I hadn't been there, she would have got up as best she could and gone home.

It was only then that I went, "Look, we really have to talk about this pain." And so I asked her to show me where her pain was. And she tapped me on the shoulder. So if you have abdominal pain and it's referred to your shoulder, it's more than gastro, in my experience of years of working in A and E myself. And the doctor went, "Oh," and then he ordered another scan. She, at that time, was still not saying anything. She was – she just was terribly, terribly uncomfortable with the pain – and had had no pain relief at that time either.

So she had an ultrasound. And I think the sonographer was just magic. She explained everything to Tara before she did anything. She apologised that this might hurt when I press on your tummy. She did – yes, she was very good. She went off to speak to somebody else because she told Tara that there was something on the scan

that she wasn't happy with and she needed to consult with, and then we went back to the ward – went back to – to the department – A and E department. And it was then that the doctor came along and read the report or looked at the scans and said, “Oh, well, I think we need to take – admit her to the ward and she will probably have her operation tomorrow.”

5 MS EASTMAN: So the issue was not gastro, but - - -  
MS ELLIFFE: No.  
MS EASTMAN: - - - but fairly infected and inflamed gallbladder; is that right?  
MS ELLIFFE: Yes, that's right.

10 MS EASTMAN: Which is an extremely painful condition.  
MS ELLIFFE: Yes, it is.  
MS EASTMAN: And so she had to have some surgery.  
MS ELLIFFE: Surgery.  
MS EASTMAN: And that resulted in hospital stay for about four days - - -

15 MS ELLIFFE: Four days.  
MS EASTMAN: - - - is that right? And your – it's the case, I think, you stayed three out of the four nights and your husband stayed one of the nights. But you didn't feel that Tara would be able to deal with a postoperative stay in hospital alone. Why was that?

20 MS ELLIFFE: Well, at no point, could I have left her. She was – there was staff in the room all the time or there was nobody. They didn't offer her pain relief. And that's routine postoperative care is to give somebody pain relief. And she wasn't offered any. She had to ask for it or I had to ask for it. She was in a single room, the furthest from the – the central desk. So she was a long way away. She felt very

25 isolated. And she had drips in her arm. She had infusions in her arm. She had – lying there in the bed, not game to move. And, yes, she depended on somebody being there. And, you know, it's another thing that I will think about: so what's going to happen when I'm not here to be with her? We have to change it, so that she isn't going to be alone and frightened, because fear is probably – exacerbates the

30 pain even more, and we need to do something about it.  
MS EASTMAN: Well, the way she talked about that when she gave her evidence last week – and she just says, “I don't like hospitals. I don't go to hospitals.” So she didn't express it as a fear of hospitals, but just in a very sort of matter-of-fact way, she just doesn't like hospitals.

MS SCOTT: Black and white.

MS ELLIFFE: She's very black and white. Yes. No, she wouldn't say it was fear. She wouldn't identify that. But she – she won't even go and visit people in hospital because she will get – she gets a flashback. It's – and the idea of the pain that she  
5 couldn't get somebody to help her with, unless, you know, I pushed it and said, "She needs pain relief now." Not being in control. I mean, I think we all have problems with not being in control.

MS EASTMAN: So I want to turn, now, to your roles. And both of you have become very strong advocates and become very involved in associations such as the  
10 Down syndrome associations. And I wanted to ask you what was it, for each of you, that really thought, "I need to do more. I need to become an advocate, not only for my own child but more generally for young people and people with Down syndrome." Why did you decide that you wanted to take on an advocacy role? I don't know who wants to go first?

MS SCOTT: In my case, I don't think it was a deliberate decision. When we  
15 moved, when Kylie was about 18 months, from Melbourne to Canberra, we had sort of asked friends there what the early intervention services were like. And they very kindly just said, "They're great. You know, there's a centre there." But, of course, when we got there, it was nothing like we had been receiving in Melbourne. So we  
20 were pretty disappointed and had to work pretty hard to get what we felt Kylie needed. And that even resulted, because we were keen to have Kylie go into the mainstream school that her sister was at, in us, yes, having to lobby to go to the meeting which decided where Kylie might end up at school. We couldn't believe it. We had to, you know, pull out the Human Rights Act and, you know, services for  
25 children with disability and all the rest of it.

MS EASTMAN: I think, Evelyn, you listened to some evidence given earlier this morning.

MS SCOTT: I did.

MS EASTMAN: And you wanted to say something about Ms Abi's experience.

MS SCOTT: Look, I was very much reminded and sympathetic for the previous  
30 witness, because if you don't sort of research and find out for yourself, you're not going to make much headway. And you make decisions to do what you feel is right for your child – your children – and, you know, it's just staggering, really, that you're not listened to as the child's parents. You know, how could we possibly  
35 know what was right educationally for our daughter? And – and, you know, anyway, we persisted and she did go into the mainstream school. She was probably the first child with Down syndrome in the ACT to go through mainstream. But that meant that we had to – we chose to pay a friend of ours, who was at home looking after her four children, who was a teacher, to go into the classroom for three years, but maybe  
40 five or six hours a week in total, so that she could, you know, give us the feedback

from what was happening in the classroom in a notebook, and, you know, support Kylie in that way – before I think we, effectively, shamed educational authorities at that point to providing assistance.

MS EASTMAN: So that was the impetus to you starting your advocacy?

5 MS SCOTT: Yes. I think that all started when we moved to Canberra and realised that there was no similar early intervention there that we had been finding was the best way for us to proceed.

MS EASTMAN: And Margot, for you?

10 MS ELLIFFE: Well, Tara's my fourth child. I knew what you would get away with if you were pushy. And the bottom line is – well, the Education Department used to tell me, "The pie is only so big," and all of that. And I said, "Well, I don't really care. Make a bigger pie."

MS SCOTT: Yes.

15 MS ELLIFFE: She needs services and you will give them to her. I – I had lots and lots of fights and arguments with them. I was known as that pushy person. "Oh my God, she's on the phone again." I'm sure the - - -

MS SCOTT: We should have had a badge made, shouldn't we, "Pushy Mother".

20 MS ELLIFFE: I'm sure the regional education office groaned when they – I told them who I was and I needed to speak to somebody. I've also paid for things. You know, I think about the speech therapist. Tara went to a speech therapist for 10 years. She learnt lots of social skills. The benefit of her being in mainstream, because life is mainstream - - -

MS SCOTT: Yes. Absolutely.

25 MS ELLIFFE: - - - interestingly. And you have to have skills to survive in the mainstream, and they are social skills, and she needed to learn those. That's – and that was my driving force, I suppose. But, you know, my other three kids weren't angels and I often had to stand behind them and advocate for them. So, you know, you get a bit of practice and you think you can do anything. And so it just became automatic. I grew up in a home where, you know, my – my parents were on hospital  
30 boards, in local government, and I – you – they were the sort of things that you did. And if you belonged to a community, then you put back into the community. So being on the board of Down Syndrome New South Wales was just sort of like an extension. And if I could change the world for Tara, then other people would benefit. And I suppose that's my driving force that, if I can change it just a little bit,  
35 because my dad taught me that one person can change the world.

MS EASTMAN: So what are your – and this is a very convenient segue into the final question, and I want to ask both of you, from your experience, but also just some of the reflections – and I know that you both followed some of the evidence. Not all of it, but some of the evidence of the last two weeks and I think some of that

5 has resonated with your experience – based on your respective experiences, what are the key things that you think the Royal Commission should think about in terms of the changes that you would like to see for your respective daughters and, more generally, for people with intellectual disability? Margot, I will start with you and then Evelyn.

10 MS ELLIFFE: Well, I think health has got a long way to go till they actually understand the needs of people with disability. I'm often - - -

MS SCOTT: And carers. And carers.

MS ELLIFFE: And carers and family. At least it's starting that, you know, there is a carers group out there supporting us, a staff in the Health Department. But I think

15 the biggest thing that I struggle with is that my colleagues actually often don't realise that their clients or patients do actually have an intellectual disability and they need to present information differently. And visual is just the way to go. I mean, I'm a visual learner, so I suppose that's my focus. I think putting material simply and visual pictures for them is just a no-brainer; that's how it's got to be. I would love

20 to see the hospitals all have a virtual tour. They have it at the Children's Hospital. So you can go online and have a look at the ward you're going to go to, the theatre you're going to, all those sorts of things, for elective surgery. Why don't we have it for everybody else? If you're not health-literate or English isn't your first language, it would be of huge benefit to know where you're going, procedures, you know,

25 having blood and ECGs and just everything that you could possibly think of. Why can't you just get a little YouTube of it? It would make life so much easier.

MS EASTMAN: We were just – we were told yesterday that New South Wales Health has a range of policies. And one of the guiding principles was person-centred care. What would be an example of person-centred care in a hospital setting?

30 MS ELLIFFE: I've yet to see it. Person-centred care means that the individual that – and in Tara's case it would be Tara – is the centre of the care and everything is explained to her, everything is about what would benefit her. It's great policy. I don't know that it's practised.

MS EASTMAN: What would it mean? In practical terms, what would that look

35 like for Tara coming to a hospital?

MS ELLIFFE: Well, visuals, the virtual tour. People would stop and listen to her. She – I'm sure she said it to you when she was here, that she wants to be listened to and heard. Sitting with her in the moment is – yes. And nobody has time for that. Health is chaotic. Nobody has the time to sit and listen. And it is the most important

40 thing that you can give anybody is your time and to listen to them.

Just practical things. Have the time to teach her how to care for herself. You know, even having a shower, it's all rush, rush, rush. If they had said to her, before she went into the shower – because I ended up taking over and explaining – this is what we're going to do, this is how we're going to do it, and then assisting her as needed.

5 I mean, I thought that would be fairly simple, but it's not done because they don't have the time. They – the client load, short-staffed, too many tasks to do in an allocated time. So, yes, person-centred care, great policy.

MS EASTMAN: Evelyn, any reflections in terms of things that you think would be matters that might make a difference?

10 MS SCOTT: Well – excuse me – like the previous witness, I was very well reminded of the difficulties I had getting the right sort of support for Kylie with her mental health issues over many, many years. And, in the end, she was, you know, medically retired from the public service after suffering yet again through lack of real knowledge as to what her needs were. And it was a fortunate step in the sense that it  
15 gave us time to reflect on how we could get her on a better footing. I mean, I knew I had to get her confidence back. I knew I had to turn her into the person she wanted to be, whatever that meant. And it wasn't easy. She was, you know, very sad, angry. It was a very difficult time.

20 So we knew that, in the past, she had sort of done some public speaking. And did she want to do more of that? Yes. So we set about taking her to NIDA programs and getting her to a speech pathologist who could help develop her speaking skills. And slowly the confidence came back again, because she felt she was being the person she wanted to be. It – it was a long haul and it wasn't easy. And then, you know, that melded in with the independent living, because then her confidence was  
25 restored.

I just think, you know, the pathways through the mental health process for people with intellectual disability are not very clearly defined by the mental health profession. Yes. Again, it's a matter of understanding. You might be wanting to talk about aspects of behaviour, aspects of thinking, but the concrete suggestions or  
30 programs to work on, it's all about getting that confidence back again. And, you know, it can be done. I mean, I did it. I don't know how I did it, but I can do it. The profession should be able to make more of an input into that. And, as you saw the other day, Kylie is, you know, quite an extraordinary person and able, now, to talk about her feelings much more and that gives her the confidence to contribute to the  
35 community at large.

MS EASTMAN: I think that's a very good note to end on. Thank you both for sharing your experiences and giving us a window into what was behind the evidence given by both Tara and Kylie last week and – so thank you very much. We're very grateful for your evidence today. Commissioners.

40 MS SCOTT: Can I just make one short - - -

COMMISSIONER SACKVILLE: I'm sorry. Yes, please go ahead.

MS SCOTT: One short statement?

MS EASTMAN: Of course.

5 MS SCOTT: I think our experiences, though we have become very strong  
advocates, have not been necessarily supported by family members. There have  
been penalties to pay. And that's not always good. But, I mean, looking back, I  
wouldn't have changed what – what has happened, by any stretch of the imagination.  
And I think it's also important that I say I'm in awe of all that both my daughters  
have achieved and I'm very proud of them both.

10 MS EASTMAN: Thank you, Evelyn.

COMMISSIONER SACKVILLE: Thank you very much, both of you, for your  
statements, for giving evidence. I think that it's pretty clear that you've been very  
powerful advocates. Thank you so much for coming to the - - -

MS SCOTT: Thank you.

15 COMMISSIONER SACKVILLE: - - - Commission and contributing to our work.

MS SCOTT: Thanks to the Commission for giving us the opportunity to speak.

COMMISSIONER SACKVILLE: Thank you.

MS ELLIFFE: Thank you.

20 <THE WITNESSES WITHDREW [12.22 pm]

MS EASTMAN: Commissioners, we will have a very short adjournment, just so  
that we can reconstitute both the bar table and the witness table. And if you could  
give us, perhaps, three to five minutes, and then we will be with our final witnesses  
25 of the hearing.

COMMISSIONER SACKVILLE: Yes. We will adjourn for five minutes. Thank  
you.

30 ADJOURNED [12.22 pm]

RESUMED [12.30 pm]

COMMISSIONER SACKVILLE: Yes.

MS FRASER: Commissioners, we have with us our final witnesses for this particular hearing of the Commission. We have with us now Robert Strike and Justine O'Neill. Justine has previously given evidence, so it will only be Robert taking the oath.

5

COMMISSIONER SACKVILLE: Thank you.

**<ROBERT STRIKE, SWORN**

**[12.31 pm]**

10 **<JUSTINE O'NEILL, ON FORMER AFFIRMATION**

**[12.31 pm]**

COMMISSIONER SACKVILLE: Thank you, Robert.

MR STRIKE: No worries.

COMMISSIONER SACKVILLE: Ms Fraser will now ask you some questions.

15

MR STRIKE: Okay.

MS FRASER: Robert, your full name is Robert Strike?

MR STRIKE: Yes.

MS FRASER: And you're happy for me to call you Robert?

MR STRIKE: Yes.

20

MS FRASER: Now, Robert, it would be accurate, wouldn't it – I'd be correct if I described you as a trailblazer for people with disability?

MR STRIKE: Yes.

MS FRASER: And that's a word people often associate with you, isn't?

MR STRIKE: Yes.

25

MS FRASER: The Commission has heard a great deal, over the last two weeks, about some of the difficulties that people with intellectual disability have in communicating and in advocating for themselves.

MR STRIKE: Mmm.



MS FRASER: And that's something that you've got a lot of experience in, isn't it?  
MR STRIKE: Yes.  
MS FRASER: You, in fact, have been working very hard in this area for quite some time, haven't you?  
5 MR STRIKE: Yes.  
MS FRASER: In fact, 34 years ago you established – or you co-founded Self Advocacy Sydney, didn't you?  
MR STRIKE: Yes.  
MS FRASER: So 34 years ago, this is something that you and a group of other  
10 people like you, with similar goals and experiences, came together to address?  
MR STRIKE: That's right.  
MS FRASER: Now, can you tell me why was it that you and this other group of people thought that that was a good idea at the time?  
MR STRIKE: Because people were listening to their peers – like child, you know.  
15 So I thought we need something to teach people with intellectual disability to speak up for themselves and advocate on their own behalf.  
MS FRASER: You didn't think it was right, did you - - -  
MR STRIKE: No.  
MS FRASER: - - - that other people would speak for them?  
20 MR STRIKE: No.  
MS FRASER: And what sort of – the sort of work that Self Advocacy Sydney does, to this day, is that you teach people with an intellectual disability to advocate for themselves.  
MR STRIKE: Julie does training people with intellectual disability and Arthur is  
25 the executive officer.  
MS FRASER: And you provide supports to people with intellectual - - -  
MR STRIKE: Yes.  
MS FRASER: - - - disability on an ongoing basis.

MR STRIKE: We try to get people to do it for themselves. That's the aim. The aim is not do it for them, to show them how to go about it.

MS FRASER: That's right. But a really important part of that is also about educating the rest of the community, isn't it?

5 MR STRIKE: Yes.

MS FRASER: So a big part of the work of Self Advocacy Sydney is educating other people.

MR STRIKE: Yes.

10 MS FRASER: You give presentations and education sessions to all sorts of bodies, don't you?

MR STRIKE: Yes.

MS FRASER: Government bodies, businesses, those sorts of things.

MR STRIKE: Parents and people with disability.

MS FRASER: So the whole range - - -

15 MR STRIKE: Yes.

MS FRASER: - - - you address.

MR STRIKE: Yes.

MS FRASER: It's the case, isn't it, that you remain on the board of Self Advocacy Sydney.

20 MR STRIKE: Yes. Yes. I am.

MS FRASER: And there's seven board members, isn't there?

MR STRIKE: Yes. That's right.

MS FRASER: And Self Advocacy Sydney, it's not just about saying that it does the right thing for people with intellectual disability, it does that, doesn't it?

25 MR STRIKE: Yes.

MS FRASER: So, in fact, of those seven board members, five of those people have intellectual disability, don't they?

MR STRIKE: That's correct.  
MS FRASER: Because you would say they're the best people to lead their organisation.  
MR STRIKE: That's right.  
5 MS FRASER: That's right. It's the case also that there are staff at Self Advocacy Sydney with intellectual disability?  
MR STRIKE: Three staff.  
MS FRASER: And they work with people without intellectual disability, together - - -  
10 MR STRIKE: They do, but we – both.  
MS FRASER: Together in the one office.  
MR STRIKE: Yes.  
MS FRASER: It's quite remarkable, Robert, that in 2017 and 2018 you attended the United Nations in New York - - -  
15 MR STRIKE: Yes.  
MS FRASER: - - - where you spoke at the Conference of State Parties – now, this is a long – and several words I'm going to put together here, but it's important that people know this. You spoke at the Conference of State Parties to the Convention of Rights of Persons with Disabilities, didn't you?  
20 MR STRIKE: Yes.  
MS FRASER: And you spoke specifically about the Easy Read system that we've heard so much about.  
MR STRIKE: Yes.  
MS FRASER: I'm just going to show a brief video now of Robert speaking at the  
25 United Nations.  
MR STRIKE: Okay.  
MS FRASER: It's going to start playing on the screen at any moment.  
COMMISSIONER SACKVILLE: We remain confident.

**VIDEO SHOWN**

*SPEAKER: So Robert, you're a bit of an expert in inclusion of people with intellectual disability. What are the main points that you would like to share?*

5 *MR STRIKE: Main point is to help people to speak up for themselves, and encourage people to do things for themselves.*

*SPEAKER: So what are some ways that people can, I guess, teach people to speak up?*

10 *MR STRIKE: Do Easy Read. I want for people to try and show in different ways by using pictures and words together. Speak to the person when they have a support person with them. Don't speak to the support person, speak to the person with disability. People like using big words. I don't like big words.*

MR STRIKE: Straight to the point.

15 MS FRASER: And, Robert, that's something that even in my discussions with you this week - - -

MR STRIKE: Yes.

MS FRASER: I've reminded myself to not use big words all the time. And thank you - - -

MR STRIKE: No worries.

20 MS FRASER: - - - for taking me on that journey.

MR STRIKE: You're welcome.

MS FRASER: I think it's really exceptional that we've just seen that video – and there I am with my big words. I think it's great that we've just seen that video, because I suspect, Robert, that you might be the only person in this room who has spoken at the United Nations.

25 MR STRIKE: All right.

MS FRASER: And that just goes to show that it doesn't matter what your disability or your experiences in life might be, you can do amazing things. And you're certainly an example of that. And that was – you were awarded an Order of Australia medal - - -

30 MR STRIKE: Yes.

MS FRASER: - - - in 2017, weren't you?

MR STRIKE: Yes. I was.

MS FRASER: And you were awarded that for your services to people with disabilities.

35 MR STRIKE: That's correct.

MS FRASER: And that's a wonderful achievement. And you're, in fact, wearing your badge - - -

MR STRIKE: Yes.

MS FRASER: - - - today. And I said to you that that's the first time I have ever seen one of those badges in real life. So thank you for that.

MR STRIKE: You're welcome.

MS FRASER: I would like to hand you over now to Justine - - -

5 MR STRIKE: Yes.

MS FRASER: - - - who is going to ask you a few questions, so we can get another perspective or another understanding of how to communicate with a person with an intellectual disability.

MR STRIKE: Okay.

10 MS O'NEILL: Hi, Robert. So we've prepared some questions and answers together. And we thought this morning, when we were talking, that we might first comment on what it's like to be in this space, and how that – when we're talking about accessibility, it's the physical space as well.

MR STRIKE: Yes.

15 MS O'NEILL: And this space has bright lights and screens and terrifying people.

MR STRIKE: Too many screens.

MS O'NEILL: But it can be – you used the word “daunting” - - -

MR STRIKE: Yes.

MS O'NEILL: - - - to describe the experience.

20 MR STRIKE: That's right.

MS O'NEILL: And so we thought we might just say some – well, you might just say some of the things that have made it possible for you to be here and to participate. What has helped?

MR STRIKE: To help me, I – I like working with people and I like trying to show

25 people that if I can do it, they can do it, you know. Some people say people with disability can't do it and that's a load of rubbish. I'm not swearing today. I'm making certain of that.

MS O'NEILL: You said you had been encouraged by other advocates - - -

MR STRIKE: Yes.

MS O'NEILL: - - - in the past.

MR STRIKE: I had an advocate and he helped me get over my problems and my – because I was ripped off. So – and that helped me to work with different people.

MS O'NEILL: And this morning you spoke with one of the lawyers, Simone.

5 MR STRIKE: Yes.

MS O'NEILL: And you said that the one-to-one conversation - - -

MR STRIKE: Is much better. And – having two people at you all the times, you know.

MS O'NEILL: And so preparing and listening and watching - - -

10 MR STRIKE: Mmm.

MS O'NEILL: - - - what goes on. So we were able to prepare before coming today.

MR STRIKE: That's right. That's right.

MS O'NEILL: And then we were going to talk about accessibility, particularly in the area of Health. Robert, what would make it difficult for people with disability to

15 communicate with doctors, nurses and other health people?

MR STRIKE: I can't remember what I said, sorry.

MS O'NEILL: Yes, no problem. Just as well you've done so much work, because I have our notes to refer to. So some things that you told me was it depends a lot on how people talk with people with disability.

20 MR STRIKE: If they look at the person and if they don't look at you, that's okay because they are listening to you but they are shy. Some people are shy and some people aren't. So we have to work with what we get.

MS O'NEILL: And that it's helpful for health people to - - -

MR STRIKE: To understand everybody, and listen. Listening is good for people.

25 So if people don't listen, then you can't – you won't get any reaction out of people.

MS O'NEILL: And putting – you talked about putting words - - -

MR STRIKE: And putting words in other people's mouth, like your mouth, and trying to take words out of your mouth. I think that's wrong. I think it's important for us to explain things to us, make certain we are listening, and watching what's

going on, because I watch around the room and I pick up things. A lot faster than anybody else.

MS O'NEILL: And not being rushed.

5 MR STRIKE: No, not being rushed. Otherwise, it makes it hard for the person to do things. If you rush them, then they might clam up. So some people might do that and some people won't do that.

MS O'NEILL: What problems have you seen in the way health people work with people with intellectual disability?

10 MR STRIKE: They are a problem, first and foremost. The problems I've seen is many different problems in the way of speaking to people, and not – not explaining to people what the – what's going on. My daughter has a disability too. So I work with her and I explain to her what's going on, and then I get her to ask them. If you have a problem, I'm here. I'm always behind her or next to her.

15 MS O'NEILL: You said that sometimes people might be frightened to speak up because of past experiences.

MR STRIKE: Past experience is a good one to go on, because some people might be – clam up because they're talking too fast or they're talking not directly at you, they talk over you. And then – and that makes it hard for the person to understand what you're saying.

20 MS O'NEILL: And one thing that we talked about and that we agreed that I might say is that health people, like doctors and nurses, might do well to understand that lots of people with disability who come to see them might have a history of experiencing trauma, and so they might not want to talk about that with the health person.

25 MR STRIKE: That's right.

MS O'NEILL: But the health person needs to be aware and be sensitive - - -

MR STRIKE: That's right.

MS O'NEILL: - - - around that.

30 MR STRIKE: But also, their parent or their advocate with them, to make certain they are being listened to, because that's important. If you don't have people listen to you and understanding what you're saying – that's the most important for any person with a disability. Because I believe that we can try and do it together as one, and work in a better system.

MS O'NEILL: And you've commented that it's good for people to be allowed to talk - - -

MR STRIKE: Yes.

MS O'NEILL: - - - when they're ready to do that.

5 MR STRIKE: I agree.

MS O'NEILL: Yes. And not be pushed.

MR STRIKE: No.

MS O'NEILL: Okay.

MR STRIKE: If they are pushed, they clam up. Because in – like, you people, you

10 get stubborn. I'm one of those people. So it's important for us to realise that we are people first and disability second.

MS O'NEILL: And, Robert, when we were preparing – we've heard a lot at the Royal Commission about hard stories.

MR STRIKE: Yes.

15 MS O'NEILL: And you've commented on some of the things that don't work well. When we were preparing, you also said that you felt you had often been treated well within the health system.

MR STRIKE: Yes.

MS O'NEILL: And so we thought we would talk about what works well, what

20 you've experienced that has worked well, like being talked to with respect.

MR STRIKE: Being treated as a person, first and foremost. Making certain I understand what they're saying is important too. And it's important for people like me – can understand totally and carefully.

MS O'NEILL: And to be able to ask questions?

25 MR STRIKE: Yes.

MS O'NEILL: And - - -

MR STRIKE: And ask questions about any backlash, because that happens to people with disability. I think it's wrong. So we try and work in the way that – you've got a voice, speak it. Show – tell people.



MS O'NEILL: And getting your questions answered.  
MR STRIKE: Yes.  
MS O'NEILL: And getting information you need.  
MR STRIKE: And getting across clearly and concisely.  
5 MS O'NEILL: And you used to volunteer - - -  
MR STRIKE: Yes.  
MS O'NEILL: - - - at Westmead Hospital.  
MR STRIKE: Yes. I did.  
MS O'NEILL: What did you do there?  
10 MR STRIKE: Voluntary service. It was taking the patient from admissions to the ward and any files to the ward.  
MS O'NEILL: And how did you help people in that role?  
MR STRIKE: By talking to them on the way, making them feel at ease. So – because whatever operation they're going for, I don't – I try and avoid that and get  
15 away from that, so they can feel comfortable being in the hospital.  
MS O'NEILL: So everyone in the hospital system or in the health system has a role - - -  
MR STRIKE: Yes.  
MS O'NEILL: No matter what they're doing, has a role in helping people feel  
20 comfortable and even able to ask questions.  
MR STRIKE: Yes.  
MS O'NEILL: What makes people be included? What helps to make people feel included?  
MR STRIKE: By asking them. By giving examples, showing them what needs to  
25 be done, make certain the person understands what you're trying to say to them.  
MS O'NEILL: And having a supporter sometimes?

MR STRIKE: Yes. A support person or parent with you to put the question together with you. It's important for the person to understand that you're no different than anybody else. That's what I think.

MS O'NEILL: And so the supporter can be helpful?

5 MR STRIKE: Yes.

MS O'NEILL: So long as the supporter doesn't become the only person that's talked to.

MR STRIKE: No. The support – I get mad when they do that. I say – I look at them – they say – or my kids used to say, “Uh-oh, dad's getting angry.” My

10 daughter says, “No way, dad. Be cool. Be calm.”

MS O'NEILL: When you went to the UN, you talked about Easy Read.

MR STRIKE: Yes.

MS O'NEILL: What are the benefits of – or do you want to say what Easy Read is and what's good about it?

15 MR STRIKE: Easy Read is easy words put – put pictures together on a page that understands what you're trying to get across. And it's – also, Easy Read is not plain English. It's a picture book where words are in – written in plain, simple words and to try to make people understand what they mean.

MS O'NEILL: And do you just give the document, the Easy Read document, to

20 someone and send them away?

MR STRIKE: No. You explain it to them. And make certain they understand what that's for. And if they don't want it, that's okay too.

MS O'NEILL: And if they – if somebody doesn't understand straight away or needs some more time - - -

25 MR STRIKE: Then we will say to them, “You take it away. Then if you want to come back, come back.”

MS O'NEILL: Okay. And what if an organisation doesn't know how to write in Easy Read?

MR STRIKE: Well, you get CID or Self Advocacy to do it and show them. We

30 always bring the people in and show them how to do it.

MS O'NEILL: So you can learn - - -

MR STRIKE: Yes.  
MS O'NEILL: - - - how to write in Easy Read?  
MR STRIKE: Yes.  
MS O'NEILL: And how do you know that what you write in the Easy Read is the  
5 right information? What can you do about that?  
MR STRIKE: You look at it on a computer.  
MS O'NEILL: Yes. And we do some - - -  
MR STRIKE: Do some research.  
MS O'NEILL: - - - research and some testing.  
10 MR STRIKE: Yes.  
MS O'NEILL: Talk - - -  
MR STRIKE: Make certain, we show people that anybody can do Easy Read if you  
have the patience and the chance to put it across.  
MS O'NEILL: What else can help with communication? What else is good?  
15 MR STRIKE: Signing.  
MS O'NEILL: Signing. Yes.  
MR STRIKE: I do signing too.  
MS O'NEILL: Okay.  
MR STRIKE: I'm sorry. I know you don't know signing so I'm trying not to do it.  
20 It makes it harder sometimes. Communication is if you talk to the person directly  
and ask questions, then they might look at you, they might not. That's okay. I  
always look at – look at the person as a person first and disability second. I have  
always done that. Always, I say you might have a disability, let's work together on  
whatever you want. And that's what we do. We do it in Self Advocacy and CID.  
25 MS O'NEILL: And if people don't know how to communicate with people with  
intellectual disability - - -  
MR STRIKE: Then we teach them.  
MS O'NEILL: So you can do training?

MR STRIKE: Yes.

MS O'NEILL: You can learn.

MR STRIKE: Yes. I do a lot of training with support people, and they are surprised what training I can do. And people – people with disability can train many different

5 ways, by talking, by roleplaying, and by showing pictures and putting words together in an easy way.

MS O'NEILL: So people with intellectual disability can do the training.

MR STRIKE: Yes.

MS O'NEILL: Can lead the training.

10 MR STRIKE: Yes.

MS O'NEILL: Creating the training.

MR STRIKE: Oh, yes.

MS O'NEILL: Yes.

MR STRIKE: We do it at Self Advocacy. There's the proof there.

15 MS O'NEILL: And, finally, what about when policies are being made? Is it important to work with people with intellectual disability to make sure you get the policy right?

MR STRIKE: And understanding. It's not easy to redo policies. I get them and chuck them in the bin. I knew somebody would ask. I think policy is too wordy

20 sometimes. They need to be put in Easy Read. We need policy to make certain the organisation runs well or the government runs well. It's important for that to happen.

MS O'NEILL: And to write a good policy - - -

MR STRIKE: Yes.

MS O'NEILL: - - - about something that affects people with intellectual disability,

25 which is most things - - -

MR STRIKE: Yes.

MS O'NEILL: - - - then you need to talk with - - -

MR STRIKE: Talk to the person with a disability or people with a disability to be able to make certain it's Easy Read.

MS O'NEILL: Easy Read, and that what's in it is a good policy too.  
MR STRIKE: Yes.  
MS O'NEILL: Yes. I think that is all the questions that we had prepared.  
MR STRIKE: Good.  
5 MS O'NEILL: Yes. Thanks, Robert.  
MR STRIKE: You're welcome.  
MS FRASER: Thank you so much, Robert and Justine, for being our final witnesses here for the health hearing in Sydney. Robert, there were so many important things that you've just told us about. But I think if we take away one message from what  
10 you just said, for us all to reflect on at the conclusion of what feels like a long but very interesting hearing, the most important thing is that we all, in your words, see a person with a disability as a person first and their disability second.  
MR STRIKE: That's right.  
MS FRASER: Thank you so much.  
15 MR STRIKE: You're welcome.  
COMMISSIONER SACKVILLE: Robert, thank you very much for coming and talking with us.  
MR STRIKE: No worries.  
COMMISSIONER SACKVILLE: And, yes, we agree, that's the thing that should  
20 be taken away from your evidence, first and foremost.  
MR STRIKE: Okay.  
COMMISSIONER SACKVILLE: Thank you. And thank you, Justine, for your contributions in talking with Robert and also for all of the assistance you've given during the course of this hearing. Thank you very much. We appreciate it.  
25 MS O'NEILL: Pleasure. Thank you.  
COMMISSIONER SACKVILLE: Thank you.  
MS EASTMAN: Commissioners, we have completed the evidence for this aspect of the public hearing. And, Chair, I know that you wish to make some closing remarks. We also have some administrative matters that we need to deal with. And we  
30 thought, if it was convenient, just to have a short adjournment rather than take the

full lunchtime break now. So if we have an adjournment – I don't know how long the Chair needs, but maybe 10 minutes?

COMMISSIONER SACKVILLE: To do what?

5 MS EASTMAN: So that I can make sure that I've got all of the detail that I need to convey in relation to the tendering of any final exhibits.

COMMISSIONER SACKVILLE: Right. You want to attend to some matters.

MS EASTMAN: So I want to attend to that. I want to make sure we've confirmed with the parties if there's any issues arising from the tender of material. And then I know you wish to make some closing remarks. So if we had - - -

10 COMMISSIONER SACKVILLE: Are you going to make some closing remarks?

MS EASTMAN: I'm not going to make any particular closing remarks.

COMMISSIONER SACKVILLE: Right.

15 MS EASTMAN: I think people have heard enough from me during the course of the two weeks. But we do have some directions that you're going to make in relation to what will happen after this hearing. So I just need a few minutes - - -

COMMISSIONER SACKVILLE: Yes. All right.

MS EASTMAN: - - - to make sure that's in order.

COMMISSIONER SACKVILLE: Well, we will take 10 minutes or so. And then I will deal with any closing remarks and any orders or directions that need to be made.

20 MS EASTMAN: Thank you.

COMMISSIONER SACKVILLE: Thank you very much. Thank you again, Robert.

MR STRIKE: You're welcome.

25 <THE WITNESSES WITHDREW [12.56 pm]

ADJOURNED [12.56 pm]

RESUMED [1.10 pm]

COMMISSIONER SACKVILLE: I am very impressed that a number of people have stayed in the room. Ms Eastman, yes.

5 MS EASTMAN: Can I just deal with the balance of the evidence. So I would like to formally tender into evidence the remainder of the documents that we have been using or referring to during the course of the hearing. And some of these are documents that are annexures to the witness statements. And the Commissioners will recall there have been references to part D and part E of the tender bundle. So if the documents in part D of the tender bundle, which is tabs 1 through to 192. And a final index of these documents were circulated yesterday evening for any comments  
10 by the parties with leave to appear. There are no comments or objections to that material being received into evidence. Could they be marked as a group exhibits 4-41 through to exhibit 4-229. And we have a detailed index which will accompany that.

15 COMMISSIONER SACKVILLE: Yes. That can be done. Thank you.

**EXHIBITS #4-41 – #4-229**

MS EASTMAN: Then with the documents that are in part D of the tender bundle – sorry, part E - - -

20 COMMISSIONER SACKVILLE: Part E. Yes.

MS EASTMAN: - - - of the tender bundle, and these are tabs 1 through to tab 229 – and, again, a final index of the part E documents was circulated yesterday for comment by the parties with leave to appear – if they could be received into evidence and marked exhibits 4-230 through to exhibit 4-451

25 **EXHIBITS #4-230 – #4-451**

COMMISSIONER SACKVILLE: 451. Yes.

MS EASTMAN: That completes the tender of the documentary material. And I, on this occasion, don't wish to make any closing remarks other than to thank everyone for their assistance; that includes the witnesses, their lawyers, and their support  
30 people. And also to thank the team that puts together a hearing for the Royal Commission. It's too vast to name and identify everybody, but suffice to say they have been an extraordinarily great team this week in getting – or in the last two weeks – to getting the hearing up and running and to getting us to the close of the proceedings today. Thank you, Commissioners.

35 COMMISSIONER SACKVILLE: Yes. Thank you very much, Ms Eastman. I should ask, Ms Furness, is there anything you wish to say or add at this stage?

MS FURNESS: Only, Commissioner, that, as I understand it, the email my friend refers to was received at 7.20 by my solicitor - - -

COMMISSIONER SACKVILLE: Sorry. Which email are we talking about?

MS FURNESS: The email setting out the indexes.

5 COMMISSIONER SACKVILLE: Yes.

MS FURNESS: And, for some reason, the text didn't download. And so there were the two, I think, indexes annexed without any text. I think it's now downloaded, but it wasn't at the time. And so while we have no objection, I would like to be able to check that the documents that are included cover all of the documents that we have

10 provided.

COMMISSIONER SACKVILLE: Yes. Certainly. Well, you will have that opportunity. If there is any difficulty, please, if you would communicate directly with Ms Eastman or, if that's not convenient, with the Office of Solicitor Assisting and if there's any issue it can be resolved it stage.

15 MS FURNESS: Thank you, Commissioner.

COMMISSIONER SACKVILLE: Thank you very much. Now, is there anybody else who would like - - -

MS MUNRO: No, thank you, Chair.

20 COMMISSIONER SACKVILLE: All right. Thank you very much. Now, Ms Eastman, the directions that I've been asked to make, may we take it that there's no objection to those?

MS EASTMAN: I've only very briefly raised those directions with the parties whose legal representatives are behind me but I understand these are the directions that you propose to make.

25 COMMISSIONER SACKVILLE: It's what I propose to make. My question was whether there's any difficulty in making them. Not as far as you're aware?

MS EASTMAN: No.

30 COMMISSIONER SACKVILLE: All right. Well, if there is any such difficulty then counsel appearing for the parties can raise it. The first matter is that, by the 13<sup>th</sup> of March 2020, any witness who took questions on notice during this hearing should provide his or her answers in writing to the Office of the Solicitor Assisting the Royal Commission. We would be assisted if those answers could be targeted and concise and not address additional or unnecessary matters.



In addition, in the lead-up to this hearing, the Office of the Solicitor Assisting the Royal Commission sent a number of letters to individuals and institutions for reasons of procedural fairness. Therefore, by the 13<sup>th</sup> of March 2020, those individuals or institutions should provide any submissions they wish to make in response and,  
5 together with any other material that they wish to put to the Commission, any reasons should be given for the provision of any additional material. And all correspondence relating to these matters should be directed to the Office of the Solicitor Assisting the Royal Commission.

10 Next, Counsel Assisting the Royal Commission will consider any additional material and determine if any further steps need to be taken and, by the 20<sup>th</sup> March 2020, Counsel Assisting will tender whatever additional material she considers appropriate. Counsel Assisting the Royal Commission will then prepare a document setting out a brief outline of the evidence during the hearing, a number of the key themes that  
15 have emerged from the evidence, and some of the possible recommendations that the Royal Commission may wish to make or further lines of inquiry that may be pursued. By the 17<sup>th</sup> of April, this document will be made available on a confidential basis to the parties who have leave to appear at the hearing, to the witnesses who gave evidence, and to any institutions or entities that received a procedural fairness letter from the Office of Solicitor Assisting. Anyone who wishes to make submissions in  
20 response to that document should do so by the 8<sup>th</sup> of May 2020. Those submissions in response, again, should be concise and should not include any additional proposed evidence. Following consideration of the document prepared by Counsel Assisting, along with any submissions received in response to that document, the Royal Commission will prepare a short report on this hearing and that report will be made  
25 public in due course.

These nine days of hearing in Homebush have been very significant. During the hearing, as you know, the Royal Commission has investigated the provision of health care and health services for people with cognitive disability. On the first morning of  
30 this hearing, Tuesday last week – and it does seem a long time ago – I said that the consequences of neglect and abuse by or within the health system for people with cognitive disability are as disturbing as they are profound. I also said that the extent and consequences of neglect and abuse should shock the conscience of all  
35 Australians. We have heard a great deal of evidence that amply bears out that assessment. In some ways, it has been a very difficult experience for everybody who has either been in this room or followed the proceedings. The evidence has frequently been distressing, sometimes even heartbreaking. But it is essential that the Royal Commission, as its Terms of Reference require, exposes neglect and abuse in all settings, including the health system.

40 Important and compelling evidence has been given over these nine days of hearing by people with cognitive disability and by the parents or family of people with cognitive disability. We are extremely grateful to all of them. We are especially grateful to Ms Kylie Scott, Mr Jack Kelly, Ms Ruth Oslington, Ms Tara Elliffe and

Mr Robert Strike AM, from whom we heard today. We hope that you have derived satisfaction from sharing your experiences with the Royal Commission.

Professor Trollor, from whom we heard recently, and other dedicated researchers have done ground-breaking work which demonstrates the depth of the chasm  
5 between the life expectancy of people with cognitive disability and that of the population at large, as well as revealing the extent to which people with cognitive disability experience other serious health conditions, that is, comorbidity. The expert evidence from Professor Trollor, Dr Small and Professor Lennox is critical to appreciating the extent and consequences of neglect and abuse of people with  
10 cognitive disability within the health system. But the human impact of that neglect and abuse can only be fully understood through the direct lived experience of people with cognitive disability and their family members.

The witnesses who have been generous and determined enough to give evidence at this hearing have not only recounted their often deeply traumatic experiences, but  
15 have explained what we need to do in this country to transform an unacceptable state of affairs. That is, to achieve practical realisation of the right recognised by Article 25 of the Convention on the Rights of Persons with Disabilities to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.

This hearing has also demonstrated the crucial role that can be played by disability advocacy organisations and individual advocates at both a systemic and individual level. The evidence from the representatives of the Commonwealth and the State of New South Wales, from whom we heard yesterday, demonstrates the significance of the work of the New South Wales Council for Intellectual Disability and other  
25 advocacy organisations which seek to advance the wellbeing of people with cognitive disability. The evidence from Ms Mills about the value of microboards is an illustration of the innovative ideas that can be generated by individual advocates. The form and content of this hearing owe a great deal to the contributions of the CID. In particular, to Robert Strike, Mr Jack Kelly, Mr Jim Simpson and Ms Justine  
30 O'Neill, who was in the witness box today, or the notional witness box, in any event. The novel way in which this hearing room has been set up is as a result of suggestions from the council.

I hope I can be forgiven for referring to something with a legal flavour. Oliver Wendell Holmes, a famous judge of the Supreme Court of the United States, once  
35 said that lawyers tend to regard the common law as a brooding omnipresence in the sky. These words can perhaps be adapted to describe the CID as a brooding omnipresence in the halls of government and policy making. The CIDs endeavours and those of other advocates for people with cognitive disability have already achieved significant gains, but I suspect that their most successful days are yet to  
40 come, perhaps in the not too distant future.

The Terms of Reference for the Commission require us to take account of previous inquiries of which there have been a great number. The evidence over the past two

weeks shows that the path to genuine reform has often been mapped out pretty clearly. What is needed is a stimulus to governments to move much more rapidly upon the path of reform so as to bring about the changes that are needed to give full effect to the rights of people with cognitive disability. It's part of the role of this  
5 Royal Commission to provide that stimulus.

It is also very much part of the Commission's responsibility to inform the Australian community of the nature and extent of violence against, abuse, neglect and exploitation of people with disability. That responsibility extends to attempting to transform public attitudes towards the experiences of people with disability,  
10 including, of course, people with cognitive disability, with whom we have been principally concerned these past two weeks.

We have heard graphic evidence of the consequences, sometimes catastrophic, of lack of understanding and entrenched bias in the delivery of health services. The impetus for reforms will be very much driven by a recognition within the Australian  
15 community that a grave injustice has been inflicted on a very large number of vulnerable people. It is self-evident that the media have a key part to play in informing the community and, thereby, changing attitudes. This can be done, among other ways, by accurately and fairly reporting the evidence at public hearings and the proposals for change that have been put forward. It is not the role of the Commission  
20 to tell the media what to report. However, we do wish to commend the reporting by significant sections of the mainstream media of this hearing. In particular, the ABC, as befits a national broadcaster, has fully reported the proceedings and given prominence to the issues that have been explored. SBS and other free-to-air channels have also given prominence to the issues which, prior to this Commission  
25 commencing its work, have received relatively little coverage. Guardian Australia is another that has provided coverage of the hearing.

Finally, I wish to thank all those would have been involved in preparing for and conducting this hearing. It is an extraordinarily difficult and complex task involving all sections of the Commission. The hearing would not have been possible without  
30 the dedication and commitment of the staff of the Royal Commission. They have done outstanding work under the usual extreme pressures of time and resources, which will not diminish over the life of the Commission. That the hearing has run so smoothly is a tribute to all people who can be seen around the precincts of this hearing room and many others who have worked behind the scenes.

I want to express particular thanks to the Senior Counsel Assisting the Royal  
35 Commission, Ms Kate Eastman SC, and to junior Counsel Assisting the Royal Commission, Ms Simone Fraser and Ms Georgina Wright. They, together with the Office of Solicitor Assisting, have worked prodigiously and with the utmost most professionalism to give voice to people with cognitive disability in this hearing. The  
40 Commission will now adjourn and we will resume when we have our next public hearing, which will be dealing further with the issue of education. Thank you very much.

**MATTER ADJOURNED at 1.26 pm ACCORDINGLY**

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