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TRANSCRIPT OF PROCEEDINGS

**THE HON RONALD SACKVILLE AO QC, Chair
MS BARBARA BENNETT PSM, Commissioner
DR RHONDA GALBALLY AC, Commissioner**

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

10.01 AM, WEDNESDAY, 19 AUGUST 2020

DAY 2

**DR K. MELLIFONT QC, appears with MS KATE EASTMAN SC, as Senior Counsel
Assisting**

COMMISSIONER SACKVILLE: Good morning, everybody. We commence with the Acknowledgement of Country. We acknowledge the Gadigal People of the Eora Nation, the Elders past, present and emerging and we also acknowledge and pay respects to First Nations people who may be viewing these proceedings.

5

Thank you, Ms Eastman.

MS EASTMAN: Good morning, Commissioners and good morning to those following us on the webcast this morning. This is the second day of the Royal Commission's hearing into the impact of COVID-19 on people with disability.

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Commissioners, I want to start with a statement provided to the Royal Commission by Ricky Buchanan. She is unable to give evidence in person and she has provided a very comprehensive statement to the Royal Commission. I will shortly play a short video that she made for an SBS program earlier this year.

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Commissioners, you will have a copy of Ms Buchanan's statement in tender bundle part A, tab 4 and there are some annexures to the statement which appear at tabs 5 to 9. Commissioners, can I ask you to receive the statement into evidence and mark it Exhibit 5.3, with the annexures being marked 5.3.1 and 5.3.5.

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EXHIBIT #5.3, STATEMENT OF MS RICKY BUCHANAN

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EXHIBITS #5.3.1 AND #5.3.5, ANNEXURES TO MS BUCHANAN'S STATEMENT

MS EASTMAN: Ms Buchanan says in her statement that she is 45 years old and she lives in Melbourne. She's been disabled since her teenage years and she is bedridden. That's an expression that she uses. Part of her evidence addresses planning for disasters and she says in her statement that last year there were a number of bushfires occurring and the air was full of bushfire smoke. That caused her to think about disasters. She said that given she lives in metropolitan Melbourne, she knows that bushfires are probably not a direct threat to her, but she was concerned about the smoke. So this then caused her to think about what plan did she need to have in the event of an emergency. And so she found the website Collaborating 4 Inclusion and around this time she saw Associate Professor Michelle Villeneuve, who will give evidence immediately after Ms Buchanan's evidence, talking about a person-centred emergency preparedness approach.

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Ms Buchanan then worked her way through the information on the website and started to develop her own emergency plan. She went through a process of working out what did she need to do to prepare for an emergency. This resulted in her developing a very thorough emergency plan and that is a plan that she put into action when COVID-19 struck.

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So her statement deals with this in some detail. Other aspects of Ms Buchanan's evidence is to talk about the personal impact on her and her life. She makes particular reference to the second Melbourne lockdown. She says that the
5 COVID-19 outbreaks in aged care have been a bit scary because disability support workers often work in both aged care and disability services.

During the second wave, she tells the Royal Commission, she had four of her support workers' shifts cancelled due to the workers who were scheduled to work being in
10 contact with other people who had been tested for COVID-19.

One thing she highlights over the period of the second Melbourne lockdown was that through her contacts on social media, she was hearing that it was difficult or impossible to get home testing for COVID-19 in Victoria. She said that in Victoria
15 there was a helpline but once you called it the person on the end of the line didn't have any information about home testing. Now, some of this has changed, even since Ms Buchanan prepared her statement.

But the impact of home testing for people with disability I think is borne out by what
20 Ms Buchanan says about a friend of hers. She says that one person she knows had to wait nine days to get a COVID-19 test at home. The difficulty with this was that the service providers immediately pulled services. So until the person with disability had a negative COVID-19 test, then services would not be provided. Ms Buchanan's friend went for nine days without a carer. She had no assistance with meals or
25 personal care and her friend ate muesli bars and stayed in bed for the whole of the period. So these are matters of concern that Ms Buchanan wanted to raise with the Royal Commission.

But Ms Buchanan also tells us of some of the positive things that have arisen for her
30 during COVID-19. She will speak for herself in a moment, but one will read her statement to see that the access to telehealth and NDIS webinars, film festivals, music concerts, free online courses and going to the zoo have been, as she said in her own words, "the stuff I've been asking for for years" and her worry is that these will go away once the pandemic is over. She says this:

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*Everything I have been campaigning for, for 20 years, has now been dropped in my lap and I'm so scared they are going to go. I keep doing so much but it is all up there in my computer. I feel I've been starved for 20 years and then dumped in an all-you-can-eat buffet restaurant and of course you will eat
40 everything. This means I'm so ill I can't pace myself.*

So she makes the very strong point in her evidence about the accessibility of many of the community activities, as she says, that we take for granted.

45 At this point, I would like to play a short video that Ms Buchanan prepared for SBS and SBS have given us permission to use the footage. As the Commission pleases.

COMMISSIONER SACKVILLE: Yes.

VIDEO OF RICKY BUCHANAN BEGINS

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MS BUCHANAN: My name is Ricky Buchanan. I'm 45 and I live in Melbourne. I've been home-bound and bedridden for most of 20 years. When I was at university in the end of 1994, I got glandular fever except that I just never got better from it. I just got sicker and sicker. I have really severe chronic fatigue syndrome. I can't sit up in bed. I can't walk more than about 20 steps so that's, kind of, used up by trips to the bathroom. Apart from that, I need to be lying flat down like this.

SUPPORT WORKER: Hey, Ricky what, were you thinking for lunch?
15

MS BUCHANAN: I have paid support workers through NDIS that come in twice every day and they do all the cooking, all the cleaning, all the housework, all the shopping.

20 I use the computer a lot and I do online short courses. I've taught myself to draw using the trackpad and the computer. I really love listening to podcasts, audiobooks, talk radio. I have to spend a lot of time every day where I'm just pretty much lying still with my eyes closed and resting so it is really good to have stuff to listen to.

25 I have an awesome flatmate named Josh through the Home Share Melbourne Program. Instead of paying rent, he helps me with stuff.

How you been?

30 JOSH: Pretty good.

MS BUCHANAN: It's just really nice to have someone around who is not paid to look after me. He kind of brings the world in and it makes my life a lot bigger. COVID-19 has been, like, surreal and weird for everybody but it's been really amazing to access telehealth.

35 Access to medical care is something that is a huge problem for people who are bedridden and homebound. If telehealth is still available in the future after this is over, it would just be amazing. I really, really hope that happens.

40

I've been able to listen to Melbourne Symphony Orchestra concerts online; I've been able to watch a disability film festival online; and I was able to see Tim Minchin in Jesus Christ Superstar when it was available online for a few days. It was just such an amazing emotional experience to be able to see a live concert that you knew was being played at the moment that I was seeing it. It was just incredible. I've watched a whole bunch of them.

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I really hope that a lot of these opportunities stay around once COVID-19 isn't such a big problem for everyone because people like me are still going to be isolated and home-bound, even after most people aren't anymore. And it would just be heart-breaking if all of these opportunities became unavailable again.

5

I think the biggest thing that I've been telling everyone around me when they've been asking me about how to cope with this is it's really hard. It's okay that it's really hard. Everybody when they are first homebound, it is traumatic, it's upsetting. You get angry, you get sad, you cry. So if all that people with manage is to get to the end of this and still be alive, and to be more or less okay, then I think that's fine.

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VIDEO OF RICKY BUCHANAN CONCLUDES

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MS EASTMAN: Thank you, Commissioners, and we thank Ricky Buchanan for her evidence and wish her well.

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COMMISSIONER SACKVILLE: Thank you. And we, of course, endorse that.

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MS EASTMAN: Now, you heard in that part that I've read of Ricky Buchanan's statement that she prepared an emergency plan, and at this point I would like to call Associate Professor Michelle Villeneuve and she will give some evidence about the emergency planning exercise that Ricky undertook, but to assist the Commission more broadly on these issues.

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COMMISSIONER SACKVILLE: Yes, thank you. If you would please take the oath or affirmation, which my Associate will administer in one moment.

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MICHELLE VILLENEUVE, AFFIRMED

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COMMISSIONER SACKVILLE: Thank you, Associate Professor Villeneuve. Ms Eastman will ask you some questions.

EXAMINATION BY MS EASTMAN SC

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MS EASTMAN: You are Michelle Villeneuve?

A. Yes, that's correct.

50

Q. And you are an Associate Professor in the Faculty of Medicine and Health at the University of Sydney?

A. That's correct.

Q. You have prepared a statement for the Royal Commission dated 31 July 2020?

5 A. Yes.

Q. Are the contents of that statement true?

A. Yes, they are.

10

MS EASTMAN: Commissioners, a copy of the statement you will find in tender bundle part B behind tab 12. I ask you to mark the statement as Exhibit 5.24.

15 **EXHIBIT #5.24, STATEMENT OF MS MICHELLE VILLENEUVE**

MS EASTMAN: There are annexures behind part B in tab 13 and some annexures in part D behind tabs 35 to 59. Collectively I would ask you to mark those as Exhibits 5.24.1 to 5.24.26.

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EXHIBITS #5.5.24.1 TO 5.24.26, ANNEXURES TO STATEMENT OF MICHELLE VILLENEUVE, DATED 31 JULY 2020

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COMMISSIONER SACKVILLE: Yes.

MS EASTMAN: For those following us, we will have a full Exhibit List.

30 Thank you for bearing with me, Associate Professor.

Can I start by asking you about your professional background and qualifications? You've set this out in your statement. You are an Associate Professor and you lead the Disability Inclusive Community Development Research at the Centre for Disability Research and Policy at the University of Sydney?

35

A. Yes, that's correct. At the Centre for Disability Research and Policy, or CDRP, a number of us lead streams of research work and the stream that I lead is called Disability Inclusive Community Development. The program of research within that has been dominated by work around Disability Inclusive Disaster Risk Reduction specifically, and in that program of research I bring together what I like to say is the best of community development strategies, working with people to grow good practices at the local community level with the systematic application of research methodologies to bring out the best of what we know, and also look at how we might scale or transfer good practices to other communities and other contexts.

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Q. And you have a website called Collaborating 4 Inclusion; is that right?

A. That's correct.

5 Q. Now, your work has centred on a Person-Centred Emergency Preparedness approach, which you call in the statement PCEP, and the Disability- Inclusive Disaster Risk Reduction. So that is the DIDRR, is that right or have I missed a word?

10 A. Yes. The acronym tends to stuff people up from time to time. But DIDRR, correct.

Q. You say in your statement that a compelling issue driving your research is this question: who takes responsibility for the support needs of people with disability in emergencies?
15

A. That's right.

Q. So, can I start first with Person-Centred Emergency Preparedness. You set this out by way of introduction in paragraphs 9 and 10 of the statement, but can you tell us what is Person-Centred Emergency Preparedness?
20

A. Fundamentally, Person-Centred Emergency Preparedness marries person-centred planning and person-centred approaches with emergency preparedness. What it does is it provides a process tool and framework that allows people with disability to have a tailored emergency preparedness plan that matches two things: their capabilities and their strengths, what they are able to do; and their support needs, what they need support with.
25

30 Before we developed the Person-Centred Emergency Preparedness tool there were no ways for people for people with disability to tailor emergency preparedness to their support needs so we worked in collaboration with them and in collaboration with a number of different stakeholders, including people with disabilities to develop and test that tool, to identify what are the key elements of what we have been calling the capability wheel inside the PCEP.
35

Q. We might go into the capability wheel in the PCEP, if somebody wanted to know how to do that and I might get you to take us through that. Before I do that, I might ask you to take us through paragraph 11 in your statement. Can you give us a brief overview before we get to the detail?
40

A. Yes. DIDRR, Disability-Inclusive Disaster Risk Reduction, is the overarching frame for the program of risk research. Frankly, it is about making sure the needs, voices and perspectives of people with disability are included in disaster risk management practices. And I guess the way that I have always described DIDRR is that it requires cross-sector collaboration. So the capabilities and support needs of people with disabilities in emergencies are unique to each individual and no one
45

person will have the solution for how to support people with disabilities effectively in a disaster. People with disabilities themselves need to be able to take actions and make plans and they need to be able to rely on a supportive network that will be there to support them. So to be able to manage that, DIDRR requires cross-sector communication and collaboration for effective actions for people with disability to make sure they are safe and their wellbeing is recognised throughout the disasters.

Q. And when we are talking about disasters, as you know, the focus of this hearing is a health pandemic and I take it that when you started doing this work that a global pandemic of the kind we have faced with COVID-19 is not what you had in mind, but you were looking at a wider range of disasters and, in particular, natural disasters; is that right?

A. Yes. So DIDRR takes into account an all hazards approach. The program of research has always been all hazards, including health emergencies like the pandemic, but it also includes things like a house fire, which is a high risk activity for everyone in the community, including people with disability. Yes, it includes natural hazard emergencies, cyclones, floods and bushfires, the likes of which we have all been very well aware of over the last two years, let alone the history in Australia.

COMMISSIONER SACKVILLE: Professor Villeneuve, I wonder if you wouldn't mind speaking more slowly because your words are being translated into Auslan and real-time transcript so perhaps just a little more slowly will help our translators. Thank you.

A. Sure. I will do my best.

MS EASTMAN: In the lead-up to developing the PCEP your research had revealed this gap in the availability of any preparedness planning tools that enabled people with disability to tailor their preparedness to their particular support needs, but also a method or a way of planning with their support workers and providers and families what would happen during an emergency. So that then resulted in what is called the PREPARE project, which was the research to address those gaps; is that right?

A. Yes, that's right. We were doing some early work where we were bringing together the disability and service ---

Q. Slow down.

A. -- to bring the disability service sector together with emergency services. And through that initial project what became very clear is that people with disability had not been involved in any conversations or education around disaster preparedness and there were limited resources that were accessible in multiple formats that people with disability could use to tailor plans. A key issue at the time was that although there was some development of organisational preparedness and business continuity

plans and some of that was being directed at community service organisations to have business continuity plans for disaster, there was a gaping hole in emergency preparedness or self-assessment tools for individuals to make plans and take actions themselves to prepare for disaster.

5

That PREPARE project was funded under the Commonwealth Joint Natural Hazards program. It was designed to focus on that self-assessment issue, the design of a tool that people with disabilities, together with their support networks, and at the time a particular focus was on service providers enabling that preparedness and the reason we focused in on service providers is because they have routine interaction with people with disability in the community where they live, work and play and where they provide supports.

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The tool itself was designed as a conversational tool. So the idea was to leverage the routine interactions that service providers had with people with disability in the community to initiate that conversation and awareness raising about preparedness, about the risks and to continue that process of preparedness.

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MS EASTMAN: I'm jumping a little bit outside the order of your statement, but it might be a helpful time to address this issue. We have just seen the video from Ricky Buchanan. And she has provided, as you are aware, a statement to the Royal Commission to say that she came across your website and she's been in contact with you, has she not?

20

A. Yes, that's right. It was ---

25

Q. Pausing there. So what I wanted to ask you was what was, and you don't have to speak directly about Ricky's experience, but what would be the process for someone such as Ricky, she has found your website, she wants to develop a plan, how would one go about doing that?

30

A. Yes, and there lies the challenge for sure. So who is going to actually be there to support and initiate that planning conversation? I would say that was the challenge that Ricky came across when the Black Summer fires were happening and she found the website and she found the resources. But in her community she did not find a service provider trained in the Person-Centred Emergency Preparedness toolkit and resource so she had no one that she could have a planning conversation with.

35

We know from our research one of the most important things is to have a conversation partner. We know that making an emergency preparedness plan is something that many of us will dig our heads in the sand and not want to think about the worst case scenarios, so many of us don't have plans. For people with disabilities, that is increasingly a scary process. It is overwhelming, it induces fear and anxiety for a number of reasons, which we can discuss, and that makes it really hard to sustain a planning process and you need a conversation partner.

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So when Ricky found our website and the resources, but was feeling a little stuck,

I think she was feeling necessarily stuck because the need for the motivational conversational partner to help you take that next step, not the next giant leap, but the next step in your preparedness.

5 Q. So part 1 will be for the person with disability saying, "I would like a plan", but
there is no point taking that much further unless, as you say, there is a support
partner. The support partners will either be disability service providers, they may be
support workers, they may be family members or they may actually be much broader
10 in terms of local government or local council areas or beyond. Can you tell us, who
is on the other side of this conversation in terms of developing a plan and what do the
people on that side need to understand about the planning process?

A. That goes back to how I defined DIDRR initially. It requires cross-sector
collaboration. No one person will have all of the answers. In my program of
15 research dealing with this issue of who is going to take responsibility, who is going
to step up, who is going to check on me, who is going to initiate the conversation,
and many other questions that have arisen as a result of this project, the fundamental
realisation that our entire research group has had is that it has to be multi-
stakeholder.

20 Q. What does that mean, what does "multi-stakeholder" mean?

A. It means all the people who could and should reasonably have a role in this space,
should actively take a role in this space. So thinking about local councils who are the
25 first ones managing a response in a disaster, they are required to have emergency
management plans or disaster management plans at the local community level. It
means they need to understand what are the functional needs of everyone in their
community, including people with disability in an emergency situation.

30 So they can start to reach out to disability organisations, disability advocacy
organisations and services that support people with disabilities to start to look at what
are some of those challenges. We have been working with councils in particular to
develop their capacity for collaboration, cross-sector collaboration with the disability
and the community service sector and introducing the Person-Centred Emergency
35 Preparedness framework and toolkit and approach and through council, and through
the community inter-agency and disability inter-agency roles and activities that are
already ongoing in place within councils, using those roles to help support and
sustain the capacity of community services to engage these conversations. Now the
other ---

40 MS EASTMAN: Can I ask you about local councils and local government. What
would that mean at a practical level? I think you have done some work in
Queensland at the coalface, so to speak. What has that involved and how have you
worked with councils?

45 A. We're working right now on a project in Queensland to develop DIDRR actions
at the local council level. Now, I should backtrack a little bit because the other two

stakeholder groups --- I've already been mentioning, community and disability support providers, service providers in general who provide support to people with disabilities or chronic health conditions in the community. But also people with disability and their disability advocacy organisations.

5

MS EASTMAN: Can I just ask you to slow down again.

A. Yes. Sorry, I get very excited about it.

10 MS EASTMAN: We have time.

A. I talk passionately about it. So in that project we are looking at bringing all three stakeholders together. Part of the project is about what individual responsibility do each of the three stakeholders have in increasing the awareness and preparedness of people with disability for disasters and supporting them to have a plan and then looking at what the gaps are and responding with effective disaster risk management processes. So that is one aspect of it.

15
20 The other aspect is how do those three sectors begin to come together on that topic and begin to communicate and develop effective plans.

So, going back to your question about local councils, fundamentally they are required to have an emergency management plan that covers the needs of people in their community. So depending on the state, that might have different names. In Queensland, in this example, it is the Local Disaster Management Plan. So we are working with a council, for example, Rockhampton has been taking a great lead in this project in initiating a Disability-Inclusive Disaster Risk Reduction working group and that working group, led by council, has membership from these other two stakeholder groups and including emergency service agencies who have roles in community engagement and safety. Those groups have been coming together to look at what are the challenges in Rockhampton to the inclusion of people with disability and they've responded with a very specific action very recently when they have been undergoing their annual risk assessment process, they've brought the Disability-Inclusive Disaster Risk Reduction working group to the table to look at what are the needs and challenges in our risk assessment for our disaster management planning processes and how can we make sure we are addressing the risks of people with disability and ensuring the inclusion of those needs in our next iteration of our Local Disaster Management Plan.

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40 MS EASTMAN: And so what is the extent to which the disability advocacy organisations have been involved in that process as well, which lifts it to the more general rather than perhaps the case-by-case specific person's concerns?

A. Sure. There are two parts to that, I suppose; the first part is attached to the idea of the Person-Centred Emergency Preparedness tool. Remember I said we had originally targeted service providers in the design of that tool because the opportunity service providers had to start a conversation that people don't generally

have conversations about in their day to day life. Well, what we did in the Queensland project, beginning in January of this year, we have been working on a – Person-Centred Emergency Preparedness Peer Support and Leadership Program. So we partnered with the Queenslanders with Disability Network and they have
5 a program already of peer support. So they have a program of peer leaders, these are all people with different disabilities who run peer support groups across the state in Queensland and we initiated an Emergency Preparedness Leadership Training Program with these leaders. And we've been instigating through that process, turning
10 our target audience around. No longer is it necessarily just about the routine interactions that service providers have to open the conversation, now we're looking at the development -- and we've just developed the Person-Centred Emergency Preparedness Workbook. It is a conversation guide for people with disabilities to open up and initiate that conversation, and that's where Disabled People's Organisations come in and advocacy groups because they are not individuals with
15 disability, they represent the needs of many people with disabilities.

So when we think about the role of that program and that project, I think we need to think about the disability organisation as a whole and how they are supporting these individual peer leaders and how these individual peer leaders support a number of
20 people with disability at the local level in their communities. So it's about initiating this conversation and allowing the awareness raising about risk and the action planning and responsibility by people with disabilities.

Now the other piece of that is them connecting in and asking important and
25 sometimes pointy questions of their local councils about what is there for them when there are gaps in their emergency plan. So a big part of developing their capacity at QDN of these peer leaders to engage in Person-Centred Emergency Preparedness is also developing their capacity to connect in with councils, connect their members in with councils and have a dialogue about what will we do when there are gaps that
30 outstretch my capacity to manage in an emergency situation and put me at greater risk.

MS EASTMAN: Can I move this work that you've been doing into the COVID19 framework. In your statement at paragraph 46 you set out in some detail the barriers
35 for people with disability and what people with disability face during an emergency and these are matters such as loss of power for life-sustaining equipment and transportation, inaccessible environments, local emergency managers don't have sufficient information.

40 How have the matters that you've identified in the context of the natural disasters or the acute immediate home disasters translated into COVID-19 and what has this meant for the development of your research during the course of this year?

A. One of our participants said that COVID put a real spanner in the works and that
45 in fact it was the ultimate test of our shelter in place plans. That was, you know, I was up running this workshop together with our 20 peer leaders and QDN staff on February 24 and February 25 of this year. I went up to Rockhampton and

Townsville shortly after that and continued discussions with some of our partners in those areas about their DIDRR projects and I flew home on March 3 back to Sydney. And then the whole COVID became very real within a couple of weeks after that. It was at that time that we had to obviously create changes to our plans.

5

Our original plan was that after the training our peer leaders would start introducing the PCEP into their peer support groups and with a little bit more support from our research team, five of these peer leaders would go on to do some individualised mentoring as part of the program. None of that was going to happen in the same way because of the physical distancing restrictions.

10

So QDN first pivoted, Queensland Disability Network pivoted in their support and put everything online and worked really quickly to get some of their members up to speed with technology and accessing technology so that they could continue to support their peers as they normally do anyway.

15

At the same time, the Queensland Government and QDN reached out to me and said, "Can we tailor the person-centred tool very specifically to COVID and the situation?" So we very rapidly developed a COVID specific PCEP planning guide and put that out as quickly as we could. I believe we managed to get it physically out there by 1 April, but our peer leaders were having a go with the various iterations of it throughout March in their peer support groups. So, in a way, it didn't delay our project, it actually sped our project up. The PCEP and the framework was introduced through the COVID-specific planning guide. I think I might have said in that statement about ten peer support groups at the time. Since looking at our data, we now have 17 peer support groups throughout that period of time.

20

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Q. When you say that you got the material out there, is that material publicly available and accessible?

30

A. Yes. All of our products that we co-design and produce are available on my website, collaborating4inclusion.org. We have a feature project, Disability and COVID19, right now, and very quickly on the heels of developing that Queensland-specific guide, the ACT got in on the act and said, "Can we have an ACT-specific guide", and then very shortly after that the Australian Government Department of Health also said, "Can we make this national and nationally relevant, including can we make it Easy Read access?" That supported us with the resources to turn the planning guide also into an Easy Read format.

35

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Q. And do you know what the uptake has been in terms of the number of people who have started to use the workbook and the toolkit and have developed plans?

A. Well, we do know that with our Queenslanders with Disability Network that the PCEP planning guide for COVID-19 has reached up to 300 of their members. And we do know that their members have been informally sharing it with others in the community. So I think I can comment more on the reach and general engagement. It's definitely spurred tonnes of interest and motivation. So the number of mentions

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and feedback that I get from other people in terms of reach of that tool guide is quite large. For example, some of the organisations we're working with in Central Queensland said they distribute it to over 800 of their member organisations, and so on.

5

I think it is also one of the strategies we need to think about is: how can we begin to track use of the guide and what impact it is going to make on people's lives.
Anecdotally ---

10 MS EASTMAN: Is it too early to say what the impact of the implementation of the plans have been? So for people who have developed a plan, are they using the plan in COVID-19? Is it too early to say how the plans are working, whether they have been successful, what we've learnt from the planning process?

15 A. Yes. Well, I suppose I can comment more specifically on the peer leaders that we are working with directly. Those are the ones that we are gathering information with immediately. So when we think about our peer leaders, and we'll take 20 of them, there is another five who are supporting us and they are more advanced in their plan. So I will talk about the 20 who had, before our workshop and training, never
20 thought about their own disaster management plan and certainly had never thought about pandemic planning before. All of those 20 people have plans and have put their plans into action and all of those 20 people have shared through their peer support groups how that planning process works with other people. We've watched and tracked the progression of those 20 peer leaders moving from never being aware
25 to raising awareness, but not having a plan and preparedness to moving well along the spectrum.

So we have these 20 peer leaders now who have a plan, their plan is disability specific and most of them, I can't say all of them, we're still working with a few to
30 make sure that plan is communicated with the people who are actually there to support them in emergency situations. For some people part of the reason they haven't felt the need to do an official, sort of communicate their plan, is because they have high support hours and they have regular contact with a support provider, whereas others have felt quite motivated to make sure their plan, sorry, their support
35 people, including the formal paid services that come in and do support work with them, have a copy of their plan in hand. And it has a number of things because of COVID, which includes how they are going to keep themselves safe, what happens if they get sick with COVID or need to go to hospital. But those plans are necessarily tailored to the individual person. We've been beginning to collect their plans so we
40 can start to look and discuss further about what does it look like when you then document a plan and when you share that plan and communicate it with the people who are there to support you.

MS EASTMAN: Right, so this might be something that the Royal Commission
45 could come back to you before the end of the work of the Royal Commission to see how the evaluation process is going?

5 A. Yes, I think that would be good. By all accounts we are in very early stages of the testing of this whole model and approach, let alone designing the COVID-specific tool and gathering information, and that project runs until June of next year. The project that we've just initiated in New South Wales runs over the next three years.

10 Q. The last thing I want to ask you about, and the Commissioners may also have some questions, is that part of your statement that deals with overcoming the barriers. So I'm taking you back out of COVID19 but more generally now. This is matters you have set out at paragraph 50 and following. Can I ask you to, bearing in mind the detail that you have in the statement, just to speak to what you see are the keys to overcoming the barriers for a person-centred and disability-inclusive approach to preparedness for emergencies?

15 A. Yes. I guess it comes back to that notion of responsibility and who has what part in that responsibility and how can we best knit that together. The way that I have tried to outline what I think should happen is to look at these three different groups, if you will: people with disabilities, and their representative organisations;
20 community services in the broadest sense of the word, so including health, including disability services; and local disaster managers at the local level. Each of them is going to have a different role to play, but fundamentally I think people with disabilities need to be included. They need to be part of the conversation. They need access to disaster risk reduction information, tools and resources in formats that they can understand and that they can use. Even our resources, as we co-design them, are
25 increasing in their accessibility over time, and the local councils that I'm working with, specifically on this action-oriented outcome, if you will, making their resources more accessible, are working on what are the processes to get them from where they are at now with the access to resources to improve access of information for everyone in the community. So I think that is the starting point.

30 Also, people with disabilities need disability-specific opportunities. It was very clear -- I should take you back. Last year in Queensland when we started the project, we started with an inclusive community engagement approach. We brought the stakeholder groups together to learn together about the capabilities and the support
35 needs of people with disability in emergencies. People with disabilities, for them it was the first time they had been invited into the conversation. For emergency managers, many of them it was the first time they met someone with a disability. So bringing the groups together was a transformative experience for everyone involved. At the time people with disabilities called for disability-specific tools and resources
40 that would help them tailor their plans.

I think that reinforced and reenergised our focus of the Person-Centred Emergency Preparedness tool and opened up people with disabilities themselves and their representative organisations as having a leadership in this space and a particular role
45 in this space, and now that we've been showing the model working with Queenslanders with Disability Network, we've shown disability organisations the capacity of their members to take a leadership role in this space and to be able to

initiate that conversation.

5 I think that is the balance we have to play here: the local councils won't know how to
make the resources accessible unless they have good dialogue with people who need
those resources in different formats and we've shown clearly through that project,
when you open up that dialogue and create that space for communication, councils
are very willing to make those changes. In fact, they find it quite simple to make
those changes once they understand what they are. But the same is true for people
with disabilities. They need access to information and they need to know what is my
10 risk in emergency, who is going to be there for me, is that evacuation centre
accessible or not? They can't pre-plan for something they don't know about. So that
communication needs to happen in both directions.

15 The last group that tends to slip under the radar is the community services folks.
That is a really tricky space to work in because there is nothing in Australia that
legislates service providers to have a role in the space. So we've been working on the
goodwill, the passion, and the motivation of service providers in the health, disability
and community services sector. Most of them have experienced disaster and have
become first responders in their community and they know what the issues are and
20 they easily jump on board with our projects and help us to support this pre-planning
for everyone in the community. But because there is no legislative role, there is no
place where the PCEP officially fits into a planning package or a care package for
someone, it makes it very difficult for service providers to wholly embrace the
approach to the person-centred tools and resources.

25 MS EASTMAN: Commissioners, can I ask if you have any questions?

COMMISSIONER BENNETT: No.

30 **QUESTIONS BY THE COMMISSION**

35 COMMISSIONER GALBALLY: I have a question. Yesterday we heard from
Leonie Jackson from the Deaf Society and in her statement she described a tool
called Get Ready with the New South Wales Rural Fire Service and New South
Wales State Emergency Services. I was very struck by Deaf people and hard of
hearing people often being left out of some of this planning and I just wondered
whether you knew of that and whether you have a way of bringing those folk in?

40 A. Yes, in fact, we have an active working relationship, a long-term working
relationship with the Deaf Society. Our Australian Research Council funded project
has them as one of the many Disabled People's Organisations and carer organisations
who we have partnered with on that project. And, in particular, the Deaf Society is
45 an important member of our technical advisory committee because of the
development of the Deaf Liaison Officer role, which has been quite successful
through the Deaf Society and their engagement on that project, and colleagues who

were on our research team were fundamental in the original design of the research that went into the Get Ready Program.

5 I sort of feel that what we are doing around peer support and peer mentorship in this space with Queenslanders with Disability Network extends that model beyond people who are Deaf to people with all types of disabilities in the community.

COMMISSIONER GALBALLY: That's great to hear. Thank you.

10 COMMISSIONER SACKVILLE: Professor Villeneuve, thank you for your work which is obviously very important. I can understand your enthusiasm for the work that you are doing. I noticed that in paragraph 47 you say that people with disability have different expectations and different responses to potential emergencies. Some
15 people perceive themselves as a burden on others, you say, and that influences individual choices, for example, not reaching out to neighbours. Others want to be self-reliant.

What I wanted to ask you is, I think I understand why there is such an emphasis upon
20 councils and service providers, but what about using disability organisations themselves as the principal sources of communicating with people with disability about these plans? One of the things that is perfectly clear from our work is that for many people with disability there are real issues about communication and reaching out to them, engaging and so on. Is there not more of a role for disability
25 organisations themselves as the principal source of advice and information?

A. Yes, thank you for that question. In fact, when I speak about disability advocacy
30 organisations and the example I gave of the peer leadership and peer support program, that is exactly through disability organisations, their members and their advocates, developing and leading in that space. And that has been the focus of the program.

That came out of the point that I made in paragraph 47. In that consultations we did
35 last year --- we did seven of these inclusive community stakeholder conversations, if you will, they were quite extended over the course of a day in each of those communities --- what was really clear was the stigma and discrimination of people with disabilities and their absolute exclusion from the conversation. So the entire development of our DIDRR framework for Queensland, it is a roadmap, if you will,
40 to bring all three stakeholders together, but recognise people with disabilities and their representative organisations as leading in this space.

In fact, just this morning I had a call from one of our disability reps out in Ipswich,
45 very excited about the leadership role that he happens to be playing with Ipswich Council in the development of accessible resources through the emergency management program, and that is all being led by the disability organisation as a result of the opportunities that this project has sort of revealed by way of awareness raising among all the stakeholders.

COMMISSIONER SACKVILLE: Thank you. Thank you very much.

MS EASTMAN: That concludes the Associate Professor's evidence.

5 COMMISSIONER SACKVILLE: Professor Villeneuve, thank you very much for your statement, your work and for appearing today to give evidence. Thank you.

A. Thank you very much. My pleasure.

10

THE WITNESS WITHDREW

MS EASTMAN: Commissioners, the next witness is Sheree Driver.

15

COMMISSIONER SACKVILLE: Thank you.

MS EASTMAN: Commissioners, just before we start, you will see on the screen a number of people. You will probably recall Ms Downing who gave some evidence
20 yesterday and she has been working with Ms Driver as an advocate. But Michelle Jenkins is also on the call, and she is counsel for Ms Driver and Ms Jenkins may want to make her appearance.

MS JENKINS: Good morning, I appear on behalf of Ms Driver.

25

COMMISSIONER SACKVILLE: Thank you very much.

Can we please administer the oath or affirmation?

30

SHEREE DRIVER, AFFIRMED

COMMISSIONER SACKVILLE: Thank you, Ms Driver. Ms Eastman will ask you
35 some questions now.

EXAMINATION BY MS EASTMAN SC

40

MS EASTMAN: Good morning, Ms Driver. How are you? I know you are feeling a little nervous about coming to the Royal Commission today.

MS DRIVER: Yes, a couple of nerves, but you've made me feel really comfortable.
45 I feel very supported so thank you.

MS EASTMAN: All right. I will just do some formalities. I want to let the

Commissioners know that a copy of Ms Driver's evidence is behind tab 10 in part A of the tender bundle. I have to ask you to mark the statement as Exhibit 5.4.

5 **EXHIBIT #5.4, STATEMENT OF MS SHEREE DRIVER**

MS EASTMAN: There is one correction we need to do.

10 Q. Can I confirm that you are Sheree Driver?

A. Yes, that's correct.

Q. And the Royal Commission has your address?

15

A. Yes.

Q. And are you a disability support worker?

20

A. Yes, that's right.

Q. And you've made a statement to the Royal Commission on 12 August?

A. Yes.

25

Q. And in your statement, if you have a copy with you ---

A. Yes.

30 Q. --- there is a table that you set out as part of paragraph 22.

A. Yes.

Q. And in the table there is the second line, the date that says "Tuesday, 21 July
35 2020".

A. Yes.

Q. And you wanted to delete that date ---

40

A. Yes.

Q. --- because the entry there applies to Monday, 20 July; is that correct?

45

A. Yes, correct. Thank you.

Q. And with that change, can you tell the Royal Commission whether the statement

is true?

A. Yes, absolutely, it is absolutely true. Yes. Yes.

5 Q. Can I start at the beginning? You live in Melbourne?

A. Yes.

10 Q. And you are currently in the middle of the stage 4 lockdown?

A. Yes, we are, indeed. Challenging.

15 Q. And that has had an impact on you personally and your work as a disability support worker?

A. Yes.

Q. So you work as an unregistered sole operator supporting NDIS participants?

20 A. That's true.

Q. And you started working independently in March this year?

25 A. Approximately March, yes.

Q. And you've been supporting a number of clients across a range of disabilities; is that right?

30 A. Yes.

Q. And that's been a little challenging during the course of the lockdown in Melbourne and managing the COVID-19 experience; is that right?

35 A. Yes. Yes.

Q. The evidence you want to give to the Royal Commission today is not about you or your clients or your work, it's about your very dear sister, is that right?

40 A. Yes, my very dear sister. She is why I'm here and why I have the courage to be here, so, yes.

Q. And if you feel at any stage that are you feeling a little wobbly at all, I understand Ms Downing is prepared to step in. Is that right?

45 A. Yes, she's very supportive, so thank you for that, Ms Downing.

Q. Your sister is in her 40s and she lives alone in Melbourne?

A. Yes, that's true.

Q. And she's lived alone for about six or seven years now, hasn't she?

5

A. Yes. Yes.

Q. She has a psychosocial disability and some very complex needs; is that right?

10 A. Yes.

Q. She's an NDIS participant?

A. Yes, that's true.

15

Q. And the assistance that she needs is pretty much the fundamentals, isn't it; she needs support to prompt her to follow her daily routine?

A. Correct, yes.

20

Q. She needs support to get out of bed in the morning?

A. Yes.

25 Q. She needs support to keep her personal hygiene in order?

A. Yes. Yes.

Q. To eat?

30

A. Yes.

Q. And to ensure that she has social contact?

35 A. Yes. That's all true. Yes.

Q. And, without these supports, you know your sister, she would be totally withdrawn; she would stay in bed and your great fear is that her mental health would decline?

40

A. Yes. Yes. And we have seen that. Yes.

Q. You live about 25 minutes away from your sister?

45 A. Yes.

Q. And prior to the COVID-19 pandemic you would normally visit her three or four

times a week, sometimes more?

A. Yes, that's true. Yes.

5 Q. And you talk to her a lot, don't you?

A. A very lot. If I could see her more, I would see her more.

10 Q. And the visits are not only important to your sister, but they are also important to you. She's a very close member of your family, isn't she?

A. She is the most important person in the world to me. Yes.

15 Q. So, your sister has eight hours of support a week from a disability support worker who comes to see her twice a week; is that right?

A. Yes. Yes.

20 Q. And your sister is mostly at home. She has done some voluntary work over the past five years. She's done a little bit on computer courses at a beginner's level, but she is not somebody who is in any active or paid employment; is that right?

A. That's right, yes.

25 Q. I want you to look at paragraph 12, because I think you can say this far better than I could.

A. Okay. So my sister and I have a strong bond and love each other dearly. Just one second. I will just compose myself.

30 Q. Take your time.

35 A. I am so grateful for the love and meaning she brings to my life. She is an incredible person with great values. I don't just love her because she's my sister, I love her for who she is and the heart that she has and that's why I think she deserves the very best. Yes.

40 Q. You've been through a number of really challenging matters in your family over the years?

A. There's been a few, which has bonded us even more. Yes.

45 Q. And you wanted to tell the Royal Commission about the impact of the pandemic on your sister's life?

A. Yes.

Q. So could we start back in March when it was early days of the pandemic and you say in your statement about the first lockdown, that your sister went to stay with one of your cousins for about three months?

5 A. Yes. Yes, that was great.

Q. Well, it was good, was it, because the family was concerned how she would go if she was isolated in lockdown and what impact that might have on her mental health so being with a family member might be a safe place for her during that first
10 lockdown?

A. Absolutely.

Q. And you noticed that while she was staying with your cousin she really
15 improved?

A. Yes, there was --- I recognised a few areas, particularly like when she went back home that in that first week that we noticed some changes. Sorry.

20 Q. So some of those changes were what? How she was getting out and about or cooking? What sort of things changed?

A. It was, I still got her the food and I went over and cleaned her house, we clean the house together, but, for example, she engaged in that cleaning, we cooked together
25 and her mood was up and in the first week she was cooking for herself. It was quite heart moving to see these changes and getting up earlier but that only lasted for about a week.

Q. So what happened?
30

A. I put it down to that without that constant contact and that motivation, like, if I sum up my sister, I think it is that the motivation and the initiative, but with someone there to prompt her it improves. So when she went back home she didn't have that person there, that constant, as my cousin was in those three months for her,
35 motivating her to eat, to say, "Chop up this food", to go for a walk at lunch time. So without that, I witnessed it, that she declined very quickly and went back.

Q. And when we get to where things started to get a little worse for Melbourne towards the early part of the end of June, early part of July, you became particularly
40 concerned about what any further lockdowns may mean for your sister and the impact on her; is that right?

A. Very, very much so. And I can add to that if you like.

45 Q. Of course.

A. We did as a family talk about my sister going back to my cousin and my cousin

was very open to that idea and invited her back but my sister --- that meant that I would be removed as a constant. Because I'm a disability support worker, my cousin felt that --- she was very conscious of the COVID and that meant I couldn't be seeing my sister, going and taking her out and then bringing her back. So my sister, which is just beautiful again and demonstrates the bond that --- she opted to stay home so that we could have that constant contact, yes.

Q. Things really came to a head on about Monday, 20 July. I just want to walk through the days and what you've been dealing with over the last couple of weeks. So can we start with that? And if you feel you need a little break, let me know.

A. Okay.

Q. So your sister had the support worker coming into your sister's home to help with the support needs that we've talked about earlier.

A. Yes.

Q. But on the weekend, about 19 July, there was some concern about the support worker's health, is that right, and on Monday, 20 July, the support worker had a COVID-19 test?

A. Yes, that's right. Yes.

Q. And at that stage you were a little concerned about how would your sister be supported. So you decided to apply to the NDIA for special consideration so that you could step in and be your sister's support worker if anything happened; is that right?

A. Yes. If I can add to that, my sister was already very hypervigilant about COVID and made the comment to me that, "I can't afford to catch it. If I catch it, I will die." So, yes.

Q. So, Ms Downing has been assisting you in relation to some of the applications to the NDIA in terms of special consideration and the response to that; is that right?

A. Yes, she's been amazing. Yes.

Q. So let's come back to what occurred. So, on Monday, 20 July, the support worker had the test. And by the Wednesday, which is 22 July, the support worker's test came back as negative.

A. Yes, that's right. Yes.

Q. So you went to see your sister on the Friday, that's 24 July.

A. Yes.

Q. You saw her then and you leave. The support worker also came to your sister's home on that day.

5 A. Yes, that's right. After me. Yes.

Q. We're talking Friday, 24 July.

A. Yes.

10

Q. That's the last day that your sister has had a support worker in her home?

A. That's correct. Yes. She's been alone.

15 Q. She's been alone since that day?

A. Yes.

20 Q. And this is what happened: on the Sunday, your sister was unaware that her support worker started to feel unwell and you spent the day with your sister on that day.

A. Yes.

25 Q. The next day, your sister started to feel some symptoms, the sore throat, the runny nose, the things that we've been told are the symptoms of COVID.

A. Yes.

30 Q. So you wanted your sister to get a test; is that right?

A. She actually --- she's very compliant and is --- she knew straight away she needs to get a test. She even initiated that, yes.

35 Q. So she went to get a test on 28 July?

A. Yes.

40 Q. That's the Tuesday. Normally her support worker would come on that day, but the support worker was away sick; is that right?

A. Yes, I believe so, yes.

45 Q. Now, on the next day, the support worker confirms that she's going to get another COVID test. So this is the second test.

A. Yes, that's right, yes.

Q. And the next day, so we're now up to Thursday, 30 July, the support worker tests positive.

5 A. Yes. Yes, that was a very challenging moment. A very Yes.

Q. So it was the support worker's employer, the service provider, who contacted your sister to tell her the results of her support worker's test; is that right?

10 A. Yes. Yes.

Q. And your sister is very close to the support worker, they have a very close relationship?

15 A. Yes, she cares about her immensely, yes. And it upset my sister --- she is very selfless, my sister, so she would almost worry about someone else before herself.

Q. Then when you got that news you thought, look, I better get tested too. So you went to have a COVID-19 test?

20

A. Actually, I was --- my sister was aware that I was on my way driving to get a test. So my sister waited, called me and said --- made sure that I was parked before she told me that -- so I just parked to go get tested in a drive-through and my sister said, "Are you parked, are you stopped, engine off?" And she shared with me that she was

25

Q. The support worker was positive?

A. Yes, that's right. Yes.

30

Q. And what impact did that have on your sister when she found out that news?

A. Again, my selfless sister, which we're working on that, straight away thought --- was so riddled with anxiety because of all the implications that meant that she had been in contact with me, that she had been in contact with my cousin, because we had picked her cat up from there, and that we had dropped food off to her son, all these things, and she just worried. Her anxiety was through the roof for me. All I could think about is that my sister was --- I didn't. Yeah.

35

40 Q. On the next day, your sister received her results and she had tested positive?

A. Yes.

45 Q. So what was the impact for you and your family and your sister in terms of learning that your sister was positive? And she is by herself, isn't she, there is no one there?

A. Yes. Because at that time I'm in isolation and --- maybe I wasn't --- no, I can't --- sorry..... So all of our lives stopped. We kept it from our dad, but myself, my sister and my brothers, our lives just stopped. We couldn't do anything. We just supported each other on the phone, supporting my sister, trying to keep strong.

5

Q. What about your sister being able to get access to the supports that she needed? You've said in your statement, and you've told us today, that she's had no supports in her home since 24 July and she's been working through her two week mandatory isolation. So I assume it is not safe for somebody to come into her home, but what supports have been available to her?

10

A. Yeah, it's just fortunate that the family --- so my brother stepped in for me to --- the things I would normally do, like the food shopping and my sister and I would normally go and do that. So my brother stepped in there. And what support She had her --- the worker's organisation, someone from there was contacting my sister every day, checking in on her over the phone. But in terms of any sort of, yeah, contact, no, there was --- legally there was no contact allowed at that moment, but after that has passed there has been no contact at all.

15

20 Q. What about any access to any medical treatment? How has your sister being in terms of her managing her symptoms of COVID-19 over the past few weeks?

A. So I went into survival mode and thought, okay, to make sure my sister is most supported and prepared and that from a distance how can we support my sister. So I went and organised for an oximeter to get sent to her and a temperature gauge so that we could do those checks throughout the day and night. She was offered a support of a nurse coming in from the company of the support worker but my sister said --- we talked about it and my sister said that because she doesn't want to risk someone else coming into the house. She just couldn't have that. So she said, "No". We wanted the nurse to be in, but the anxiety around that was too high. We just wanted to keep our sister safe. And most of all my sister said, "No" to that.

25

30

Q. And how is she at the present time?

A. Yeah, thank God, she has no symptoms. Thank God. Her mental health is, you know, as I mentioned, has declined. She has our contacts so in terms of over the phone, we've been contacting her regularly and make sure we're doing FaceTime, but I've definitely noticed that prompting her to --- with the hygiene and eating has declined. We agree that we've recognised that. Yes.

40

Q. I want to come back to your application to the NDIA for special consideration to be your sister's disability support worker during COVID-19.

A. Yes.

45

Q. You say in your statement that on 27 July, so that is the day your sister had the

first symptoms, that the Local Area Coordinator called you to let you know that your request was not approved and he sent you an email. And you've set out the text of the email in your statement at paragraph 21. It has the subject line "NDIS Policy" and it says this:

5

NDIS in their policy will not let other family members work for family members who are participants. During COVID-19 there was an interaction on their site in April stating that this, sorry. The request has been through multiple teams and has come back to me to let you know.

10

So you received that request?

A. Yes.

15 Q. And you weren't particularly happy with that request and you wanted to take that further?

A. Yes.

20 Q. So what did you do next? You have in your statement on 2 August, on the Sunday, you went back to the Local Area Coordinator and said, "Look, now my sister has been tested positive to COVID-19, I'm asking you to look at how she can be supported further." What happened then?

25 A. Then I sent an email. I didn't really have --- I was in a bad way myself. So I sent a very short email to the NDIS saying, asking, "Can you please reconsider this" and updated them that my sister has COVID now and it is likely that it was contracted through her support worker, and I attached the original letter that I had sent them, which really detailed that I could support my sister, I am a disability support worker,
30 I would support her in line with her goals and really asked them to reconsider it based that on that.

Q. You also told them that you had tested negative and ---

35 A. Yes.

Q. --- and that your concern was at the time that your sister's support worker became very ill and the support worker ended up in hospital in the Intensive Care Unit. And these were all factors that you wanted the NDIA to take into consideration
40 to allow you to be the support worker at this particular time; is that right?

A. Yes. Absolutely. She was in an induced coma, the worker. So it wasn't looking --- so, yes.

45 Q. You've had a response from the NDIA, a senior planner, saying that the request will not proceed and drawing your attention to some parts of the law in terms of what the *NDIS Act* says in relation to family members and informal supports. Is that right?

You've set that out in your statement.

A. Yes. Yes. Yes.

5 Q. And you say ---

A. Could I correct that so it is 100 per cent accurate. She sent it to my sister's support coordinator and my support coordinator forwarded it and contacted me advising that. Yes.

10

Q. So you've said you understand the rationale of family members not being paid to support and how the NDIS scheme --- you say you understand all of that and do accept that.

15 A. Absolutely.

Q. But the question that you raise in your statement is that during a crisis like this, and particularly the hard lockdown in Melbourne at the present point in time, you've raised whether there can be some flexibility to support your sister given her particular circumstances at that time; that's right?

20

A. Yes. That's right. Yes.

Q. Have you taken the issue any further? Have you continued to pursue whether you can support your sister in that way? What happened?

25

A. Yes. I've contacted the NDIS and asked for an appeal of her NDIS plan and interesting enough, when I was on that call of course I got a reaction that that can't be on the NDIS plan review, but I insisted, in a nice way, just saying we want that along with other things in the plan review. That has been submitted verbally, yes.

30

Q. So there are still a few legal issues to resolve in relation to that application for the review; is that right?

A. Yes. Right now, my sister hasn't had the support, as you mentioned, so is the expectation from the NDIS that my sister just doesn't get a support person there throughout the duration of COVID? In Victoria, we don't know when that ends, you know. And I guess that's a really important point. I was asking --- in my request it was for the duration of COVID. It was just during that challenging time when there was a high risk.

40

Q. The final thing you say under the heading "Recommendations", can I ask you to read paragraph 47 of your statement and then Commissioners may have some questions for you.

45

A. I said:

If it was my decision, I would focus on what the participant needs, not what is written in text. We have the legislation as a default but we should look at individual circumstances, with safety and quality checks in place to avoid exploitation of the system and to ensure the participant is receiving the care.

5 *For family workers, there would need to be some structure similar to other disability support workers, to keep them accountable, but I would allow family workers in these extreme circumstances. To avoid a real risk of decline in someone's mental health and physical health, I would approve these measures on a temporary basis and then review it at a later date. There is no one closer*

10 *than family. They will take the upmost measures to keep their family safe.*

MS EASTMAN: Ms Driver, I know this has been a very distressing time for you and you were feeling a little nervous about giving evidence today, but thank you very much for your evidence. I will just check now with the Commissioners whether they

15 have any questions.

A. Thank you.

COMMISSIONER SACKVILLE: Commissioner Galbally?

20

COMMISSIONER GALBALLY: No questions, but thank you very much.

A. Thank you. Thank you for having me here.

25 COMMISSIONER SACKVILLE: Ms Driver, thank you very much for coming. I reiterate what Ms Eastman has said. We understand what a difficult time this has been and thank you for coming and sharing your experiences and those of your sister. We appreciate it very much. Thank you.

30 A. Thank you for your time. I really appreciate you allowing me to be here, Commissioner.

COMMISSIONER SACKVILLE: Thank you.

35 MS EASTMAN: Thank you, Ms Driver.

THE WITNESS WITHDREW

40 MS EASTMAN: Commissioners, that concludes the evidence for the first part of the morning. If it is convenient to take the morning tea adjournment now and return at quarter to?

45 COMMISSIONER SACKVILLE: Yes, if we return at 11.45, we'll have 22 minutes instead of 20, but we will use the extra two minutes.

ADJOURNED

[11.24 AM]

5 **RESUMED**

[11.45 AM]

COMMISSIONER SACKVILLE: Yes, Ms Eastman.

10 MS EASTMAN: Thank you, Commissioners, the next witness is Rachel Spencer.

COMMISSIONER SACKVILLE: Thank you.

15 MS EASTMAN: Perhaps while we are waiting for Ms Spencer ---

COMMISSIONER SACKVILLE: I think Ms Spencer has miraculously appeared on the screen. If you wouldn't mind taking the oath or affirmation, which will be administered.

20

RACHEL SPENCER, AFFIRMED

EXAMINATION BY MS EASTMAN SC

25

MS EASTMAN: Good morning, Ms Spencer. Can I ask you to confirm that you are Rachel Spencer?

30 A. Yes. Confirmed.

Q. You are a Senior Manager, Inclusion Projects, with the New South Wales Council for Intellectual Disability?

35 A. Yes.

Q. You've made a statement for the Royal Commission dated 11 August.

A. Yes.

40

Q. Correct. Are the contents of the statement true?

A. Yes, they are.

45 Q. Commissioners, a copy of the statement can be found in tender bundle part B behind tab 14, and there are a number of annexures which are in tender bundle part E behind tabs 16 and 17. If you could mark Ms Spencer's statement as Exhibit 5.25

with the annexures being 5.25.1 and 5.25.2.

EXHIBIT #5.25, STATEMENT OF MS RACHEL SPENCER

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EXHIBITS #5.25.1 AND #5.25.2, ANNEXURES TO THE STATEMENT OF MS RACHEL SPENCER

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COMMISSIONER SACKVILLE: Yes, thank you.

MS EASTMAN: At the outset, Ms Spencer, it is customary, is it not, that for CID, where you participate in forums or give evidence that you would give evidence with one of your colleagues with intellectual disability, and you wanted to explain the circumstances today; is that right?

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A. Yes, that's correct. It is really unusual for me or other colleagues of CID to be speaking for people with intellectual disability but through the process of our consultations and the work we've done around COVID and leading up to this hearing, our members and staff with intellectual disability who were involved requested that I present this evidence on their behalf. And I hope I do them justice.

20

Q. Can I start with your role at CID. You are the Senior Manager, Inclusion Projects, and this is a role you have had since August 2018. And, prior to that, you had the Information and Inclusion Manager role. So you have qualifications in social and community development and you currently are studying a masters of law, human rights and policy at UNSW.

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30 What precisely is your role at CID in terms of inclusion projects?

A. Yes. So CID, as well as being a rights based systemic advocacy organisation, we also work a lot to build the capacity of people with intellectual disability, and we have a number of projects that are funded by a range of government departments and agencies and also other funding that we generate through our business. I oversee the team, the projects, the relationships with the funders and ensure that our staff and our members with intellectual disability are involved in the co-design and development of our work and also that they are involved in facilitating and presenting different work that we do. So it comes with all the roles of managers in regards to budgets and reports, but also still has a very, I guess, on the ground, grassroots element to it.

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Q. And people with intellectual disability are at the front and centre of everything CID does, both as decision makers, staff members, board members and campaigners; is that right?

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A. Yes, that's correct. Over half our board are people with intellectual disability. We also have a number of staff members in our team across all our projects and areas

who are people with intellectual disability. And we also work with other people with intellectual disability who might be members of our organisation or just members of the community.

5 Q. And CID takes an approach that might be described as a human rights approach; you work with people with intellectual disability so people with intellectual disability can be heard and you speak up on the big issues and campaign for change; is that right?

10 A. Yes, that's right. Some of the areas that we have focussed on in recent years and times is health, transport, the NDIS, education and jobs, and safety.

Q. Some of your colleagues gave evidence to the Royal Commission at the 4th Public Hearing earlier this year on the issue of access to health care for people with cognitive disability. And Jim Simpson was one of the witnesses who gave evidence at that hearing. Mr Simpson has been involved in some of the consultations around the Australian Government's response to COVID-19; is that right?

20 A. Yes, that's correct. He's been one --- sorry, go ahead.

Q. So in early April, the Australian Government established an Advisory Committee for the COVID-19 Response For People With Disability and Mr Simpson was part of the Advisory Committee; is that right?

25 A. Yes, that's correct.

Q. And the consultation with the CID members is something that you have addressed in your statement and I want to ask you a few questions about that.

30 So from CID's perspective, the role on the Advisory Committee was to work with and help the Government develop a plan that was specific to people with a disability during the course the COVID-19 pandemic; is that right?

35 A. Yes, that's correct. And why we feel that Department of Health should have started earlier on a disability plan, once they talked to disability representatives they acted really quickly and collaboratively and the make-up of the Advisory Committee was, and still is, impressive and brings together with people disabilities, their representatives, key professionals, senior representatives from health, NDIA and the Quality and Safeguards Commission.

40 Q. And you say in your statement that the response to the extreme and immediate risks from COVID-19 was that the plan was prepared in a very concentrated process over the course of a week.

45 A. Yes. And there was a real urgency to get the plan developed and CID certainly supported that urgency. But the speed in which it happened meant that there wasn't the time and capacity to have direct input from people with intellectual disability.

Q. And you've said in your statement that that created the risk that issues important to people with intellectual disability may not have been captured in that initial plan, which I think was released either on 16 or 17 April?

5

A. Yes, that's correct. And that's what prompted us to run consultations with people with intellectual disability because we knew we'd be able to input into the operations of that plan.

10 Q. Can you tell us about the nature of the consultations of people with intellectual disability following the release of the plan in mid-April? What happened then?

A. Yes, so we spoke to 15 people with intellectual disability across three States, so, New South Wales, South Australia and Tasmania, and we spoke to people with, I guess, a mix of life experience and situation. So some people, three people, were living in supported accommodation or group homes, some people were living at home with families, some independently. We had two First Nations people in our consultations and one from a diverse cultural background. People from city areas, regional areas and a mix of, kind of, work and life situations.

20

For most people in the consultations, it was the first time they had been asked about the impacts of COVID on their life, so people really embraced that opportunity to share their experiences. We gave people the option of over the phone or online platforms and for some people it was the first time they had ever used an online platform, so we were able to build people's skills in that space as well.

25

Everyone that we consulted with wasn't aware of the plan. That wasn't surprising because it was still very new and had been developed quickly. But people were really impressed and excited to hear that it existed and that the Government was considering them and taking action. They wanted to know more about it and they expressed a keenness to be involved in the implementation and review over time.

30

We found people were very generous with sharing their experiences and their feelings and it really highlighted to us people's resourcefulness in such a stressful and different time.

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Q. The outcome of that consultation process was the preparation of a report, which you have included in your evidence. That report is "COVID-19 Leave no one behind". And I might ask you to say a little bit about the recommendations, but before doing that, were there any particular personal experiences that came through the consultation with people with intellectual disability that highlighted some specific issues touching on the lives of people with intellectual disability during COVID-19 that perhaps was surprising or unexpected?

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A. Yes. For us, some of the experiences that people had through their work and employment was, I guess, a little surprising and certainly confronting. Some people had been given the opportunity to work from home, other people were told to still

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come to work. One person wasn't provided with PPE but told to bring their own. And another person, or several people, I think I said, were told to stay at home and not work.....

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WITNESS SCREEN FROZEN

10 MS EASTMAN: Commissioners, we have a slight freeze. Bear with us and those following us on the broadcast that we've had a slight ---

COMMISSIONER SACKVILLE: How do we have a slight freeze?

15 MS EASTMAN: I'm saying that with the hope and anticipation that by the time I finish speaking the freeze will no longer be in place.

To explain to those following us on the broadcast, we have just had a freeze. So the good people who assist us with the technology will let us know whether we need a short adjournment to remedy this or it will be remedied shortly.

20

I think we have you back, Ms Spencer.

A. Sorry, the connection has dropped out a couple of times this morning. I will continue.

25

I guess the impact on people's mental health and their sense of self-worth and their relationships with family members and people in their community has been impacted and that was a real standout for us.

30 And also the people we spoke to who lived in supported accommodation or group homes or whose lives are dominated by service provision, perhaps through an employment service or a day program, just massive impacts with a lot of shutdown and blanket restrictions being brought in on people's movements within their homes and out in the community, with visitors they were or were not allowed to have.

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There is one example that isn't in the report but came through after the report was written through these consultations of someone's day program being closed down. I believe a lot of day programs for people with disability were closed over the period, the initial period at the end of March. As day programs started reopening, one in southern Sydney wasn't able to reopen because the site, which was owned by a local council, had been used as a testing site for COVID. And while CID supports testing sites being set up, and we don't advocate for day programs, it just really highlighted to us the devaluing of people with disability and people with intellectual disability and the services that support them, that it could just be shut for the use of a testing site.

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5 Q. So the report made 12 recommendations and many of those recommendations were directed to ensuring that information was available in an accessible and appropriate format for people with intellectual disability, but one recommendation I want to ask you about was recommendation 5. And the recommendation --- and all of these recommendations were directed to the Commonwealth --- is:

10 *DoH [Department of Health] should ensure strategies are in place so that people with intellectual disability are safe and aware of safety measures when using public transport.*

15 What brought about that particular recommendation? Had there been an issue in relation to public transport?

20 A. Yes, so a lot of people with intellectual disability rely on public transport, whether that be to get to work or out in the community and to visit family and friends. It is one of the biggest issues that our membership and our advocacy group raise. So it's not surprising that it is still an issue during this COVID period.

25 People are nervous about, I guess, being in public places and in confined spaces. They are concerned that other members of the public won't necessarily respect the rules or the guidelines around physical distancing and so there are the risks for people who are actually going to still use public transport, but then there is the risk for people who won't use it and, therefore, become more isolated.

30 Q. And one of the other recommendations, this is recommendation 8, was a recommendation that:

35 *DoH [Department of Health] and the NDIS [Quality and Safeguards] Commission should brief and consult the Advisory Committee in relation to the use and misuse of restrictive practices in group homes during COVID19, especially when residents are required to self-isolate in their rooms.*

40 What came to CID's attention in relation to the situation in group homes, but more specifically both the use and misuse of restrictive practices?

45 A. Yes. So several of the people we consulted with talked about isolation and being isolated within their group home and one person in particular spoke about his experience of being isolated in his room for three to four days, I believe it was. And that was because he had potentially been exposed to someone with COVID who was being tested. And although he still received support from staff and the service, due to his intellectual disability and dual diagnosis of mental illness, he found it extremely stressful and even commented to our facilitators hosting the consultation that he had suicidal thoughts during that time.

Q. And one of the other recommendations concerns the testing, including the access to COVID testing. I want to come back to that in a moment because you've received a very direct experience which you want to read out what you've been told. So I will

come back to the testing issue.

A. Okay.

5 Q. But in relation to the report: 'COVID19: Leave no one behind', that was published on 11 June this year and the initial findings and the 12 recommendations were presented to the Advisory Committee on 2 June.

A. Correct.

10

Q. And the report has also been shared with the New South Wales Health Disability --- sorry, the New South Wales Health Disability Community Practice For Respiratory Pandemic Preparedness. So the report has been prepared also with the New South Wales Government; is that right? I think we have another freeze. I thought that was just me.

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WITNESS SCREEN FROZEN

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MS EASTMAN: Just bear with us.

Ms Spencer, sorry about that. I was just asking you about the report being provided also to the New South Wales Government.

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A. Yes.

Q. This hearing is focusing on the Commonwealth's response. Was there any Commonwealth response to the report, or is there anything that you are able to share with the Royal Commission in terms of the recommendations and whether or not the Department of Health has accepted those recommendations or worked to incorporate those recommendations in further revisions to the plan?

30

A. Yes. So the committee really strongly applauded the report and the consultations we'd done and the Department of Health committed to providing a formal response to the report, which they have done and have pursued some of the key issues and recommendations.

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One of those is increasing the availability of Easy Read information, which is information that is developed in a way that is easy to read and understand and specifically targeted for people with intellectual disability. So they've increased the availability and gathered it into one common place on their website and that includes some of our resources and other agencies' resources, which is great.

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And they've also, yes, pursued the option of saliva testing for people who cannot tolerate nasal swabs. And a range of other recommendations --- well, all of the recommendations they agree with in principle, and a number of those they agree with

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and are actioning. So we feel confident with their response so far.

5 Q. You wanted to share the experience of a person with intellectual disability who had some difficulties in terms of navigating the testing regime and you have included in your statement a narrative of that story. Can I invite you to read that, please.

A. Yes, certainly. So this is a story of my experience with COVID, May 2020:

10 *I was feeling really sick so I went to the doctor and because I had no temperature she said that I just had a common virus. I was still sick for a few more days so I called up the Coronavirus Information Helpline 1800 number.*

15 *I had heard that anyone in South Australia could get a COVID test if they felt unwell or they wanted one.*

20 *When I called the Information Helpline they just said I needed to go see my doctor to make a booking to make a test. They didn't seem to know that the rules in South Australia had changed. I asked where I could go to get the COVID test done near me. They just said to go back to my doctor so I left it at that.*

25 *A few days later I still knew I could go and get the test, but was trying to find out where. I heard that I could go to some hospitals for the COVID test but didn't know where to go, where to park and all of the details. I wanted to go to the drive through place. I didn't want to go in to the hospital. I called the information line again to try to find out where I could go to get the test again. They said again to just go to my doctor and they would call some government place to organise an appointment to book it. But I knew that this wasn't right and that I could just show up for a test but didn't know where.*

30 *Third time lucky I called the information line again. The person I spoke to this time gave me the phone number for the Hospital where I could get testing, she said I had to book and gave me the number I had to ring. I didn't book, I knew someone who was a carer who had just gone through so I drove there and tried my luck to get tested. I couldn't get in, they wouldn't test me because you had to book in so I left again. I was going to my doctor the next day so I figured I'd ask at the doctor.*

40 *I went for my appointment and she had some COVID tests there so she said, let's just do it on the spot. I did the test and the doctor said that I would get the results on Monday. It was Saturday when I got tested. The next day I got a text message from the pathology place saying I could click on the link on my phone to get my results. I clicked it and nothing happened, I couldn't get it to work and there were passwords and an account you had to set up and it turned out the internet on my phone wasn't working so I couldn't get my results. I called my doctors on Monday to see if they could tell me the results and the receptionist said that they didn't have the results yet and to call back on*

5 *Tuesday. I called back on Tuesday and they still hadn't sent the results through to my doctor. The receptionist spoke to my doctor and got her to call to find out the results. They managed to get the results to me on Wednesday and the receptionist of my doctors called me back to let me know that it was negative. It was stressful waiting for so long knowing I could have got the answer a few days earlier on my mobile phone but that I had to chase it up with my doctor instead. I hadn't been able to go to work in that time because I didn't know if I had a positive or negative test.*

10 MS EASTMAN: What are the lessons we take from this person's experience and how does that fit with the recommendations that you've made in the report to the Advisory Committee but also some of the observations that you make in the final part of your statement?

15 A. Yes. So, it really highlights a number of barriers that people with intellectual disability face in health services, in communicating with mainstream services. Access to information is a key one of those and being able to get local and accurate knowledge about your situation and your location is really important.

20 It also highlights the amount of information that, I guess, is out there, whether that's kind of factual and put out publicly by governments or agencies or just hearsay by members of the community. That is a lot of information for people to filter through and to choose from.

25 It also highlights the reliance on internet and devices and being able to access accounts and remember passwords. This is something that a lot of people with intellectual disability struggle with, in a range of areas.

30 It also highlights the tenacity and resourcefulness of people with intellectual disability and I'm not sure how many of us would have persisted with the information line and also the results process and I guess it really highlights to all of us the risks that people with intellectual disability maybe face in either not being tested, not finding out their results and, therefore, not following the correct procedures and rules and treatments around that.

35 MS EASTMAN: Ms Spencer, thank you for your evidence. I will check with the Commissioners if they have any questions arising from the evidence.

40 **QUESTIONS BY THE COMMISSION**

45 COMMISSIONER BENNETT: Thank you very much for your evidence. On page 16 of the 'COVID19: Leave no one behind', you reference technology and the importance of the technology. In fact, your evidence has talked about problems that people have had getting their results, using their phone, the internet. The NDIA made some changes to the assistive technology policy recently. Do you think they are ad

equate or address the issues that you have found in the consultations that you have done?

5 A. The changes will certainly have a positive impact on people who are NDIS recipients and are aware of those changes and can access and utilise them. You know, there are a lot of people who are not NDIS participants and also it is one thing to have, I guess, perhaps some funding to be able to purchase or access equipment, but the skills and confidence to be able to use those programs and devices is also really key. It is something we've been doing at CID with our staff and members with
10 intellectual disability and we've been really impressed with how people can absolutely learn and adapt to the equipment but, yeah, it doesn't happen naturally and instruction booklets are generally not easy to follow. So, you know, there is support and additional resources that are required.

15 COMMISSIONER BENNETT: Just one follow-up.

Are you aware if in packages are the support workers able to provide that assistance to help someone to easily understand new devices that they might have or the technology or would the person have to go to another service such as your own to get
20 that assistance?

A. I can't say for definite, but I am confident that support workers would be able to spend their time, particularly if they are in a community access role or supporting someone in their home, those positions generally are involving a lot of life skills and training or mentoring or role modelling, so, yes
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WITNESS SCREEN FROZEN

30 COMMISSIONER SACKVILLE: Commissioner Galbally, did you have a question you wanted to ask?

35 COMMISSIONER GALBALLY: I did, yes.

COMMISSIONER SACKVILLE: We may have to wait for the unfreezing to take place.

40 COMMISSIONER GALBALLY: Thank you.

MS EASTMAN: Ms Spencer, I think we have you back again.

45 COMMISSIONER SACKVILLE: Ms Spencer, have you finished your answer to Commissioner Bennett's question before freezing took place?

A. Okay, I'm back on.

COMMISSIONER SACKVILLE: Thank you. Had you finished the answer to Commissioner Bennett's question?

5 A. Hopefully you got the end of it, yes.

COMMISSIONER SACKVILLE: Thank you, I think Commissioner Galbally has a question.

10 COMMISSIONER GALBALLY: Thank you, and thank you for your evidence.

Look, CID is so pioneering in making it clear that unless intellectually disabled people are at the table, on advisory groups, in meetings, putting their own perspective and your research showed that when you went out, very valuable insights have come from that and Rosemary Kayess yesterday mentioned that she didn't think there were enough people with disabilities on the Advisory Council. She thought there should have been more. Do you think it would have been valuable to have had an intellectually disabled person on that committee as a matter of principle as well as practice?

20 A. Yes, that would have been ideal and certainly something that still can be considered going forward. I guess there is a number of benefits in that; A, it brings the person's lived experience and hopefully the experience of their peers and other people with intellectual disability, but it also provides an opportunity for them and perhaps CID or whoever would be supporting them to, I guess, role model and show how to include people with intellectual disability at the table. And that's a lot of the work that we do in advisory groups and other settings. So, yes, we'd definitely be supportive of that.

30 COMMISSIONER GALBALLY: I noticed that Laura in your research made that point very strongly in that she said, "People with intellectual disability like me."

MS EASTMAN: We seem to have someone else in the room.

COMMISSIONER GALBALLY: Laura said:

35 *People with disability like me need to be included....*

And I thought that was very valuable.

40 COMMISSIONER SACKVILLE: Thank you very much, Ms Spencer, for coming and giving your evidence and your statement today. We do appreciate your assistance to the Royal Commission. Thank you.

45 A. Thank you.

THE WITNESS WITHDREW

MS EASTMAN: Thank you, Ms Spencer. Commissioners, I will just do a pause.

5 Can I just make sure that people who have leave to appear in the Royal Commission proceeding keep their microphones on mute.

The next witnesses will be a panel, Kirsten Deane and Leah van Poppel.

10 COMMISSIONER SACKVILLE: Yes, thank you.

Could we please administer the oath or affirmation. Thank you.

15 **KIRSTEN DEANE, AFFIRMED**

LEAH VAN POPPEL, AFFIRMED

20 **EXAMINATION BY MS EASTMAN SC**

25 COMMISSIONER SACKVILLE: Thank you very much. Ms Eastman will now ask you some questions.

MS EASTMAN: Before I do that, I might just deal with location of the material in the tender bundle. Could I start with Ms Poppel's statement? You will find a copy of that in tender bundle B, behind tab 16, and an annexure to the statement at tab 17.
30 Commissioners, this statement and the annexure will be marked Exhibit 5.27 with 5.27.1.

35 **EXHIBIT #5.27, STATEMENT OF MS LEAH VAN POPPEL, DATED 14 AUGUST 2020**

40 **EXHIBIT #5.27.1, ANNEXURE TO STATEMENT OF MS LEAH VAN POPPEL**

MS EASTMAN: And for Ms Deane, you will find a copy of her statement in tender bundle part B, behind tab 15. The annexures to Ms Deane's statement you will find in tender bundle part E, tabs 18 to 19, and if you could mark these documents Exhibit
45 5.26 with the annexures identified as 5.26.1 and 5.26.2.

EXHIBIT #5.26, STATEMENT OF KIRSTEN DEANE, DATED 12 AUGUST 2020

5 EXHIBITS #5.26.1 AND #5.26.2, ANNEXURES TO STATEMENT OF KIRSTEN DEANE

10 COMMISSIONER SACKVILLE: Yes, thank you.

MS EASTMAN: Ms Deane and Ms Leah van Poppel, thank you for bearing with me while we dealt with those formalities.

15 Ms Leah van Poppel, can I ask you about your statement.

So your name is Leah van Poppel?

MS VAN POPPEL: Yes.

20 MS EASTMAN: And you are the Chief Executive Officer of Women with Disabilities Victoria?

MS VAN POPPEL: Yes, that's correct.

25 MS EASTMAN: And you have made a statement dated 14 August?

MS VAN POPPEL: That's correct.

30 MS EASTON: Are the contents of the statement true?

MS VAN POPPEL: Yes, they are.

35 MS EASTMAN: Can I just ask, I'm having a little difficulty hearing Ms van Poppel. Maybe it is me but if Ms van Poppel, can you move a little bit closer to your microphone?

MS VAN POPPEL: Is that a little easier?

40 MS EASTMAN: That is a little easier. Thank you.

Now, Ms Deane, can I turn to you, please.

MS DEANE: Yes.

45 MS EASTON: You are Kirsten Deane?

MS DEANE: That's right.

MS EASTMAN: And you are currently the CEO of Every Australian Counts; is that right?

5 MS DEANE: The Campaign Director of Every Australian Counts.

MS EASTMAN: You have made a statement dated 12 August this year?

MS DEANE: That's correct.

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MS EASTMAN: And are the contents of that statement true?

MS DEANE: Yes, they are.

15 MS EASTMAN: So you are going to give your evidence together. There is a range of questions that might cover issues for both of you and we'll see how we go. But I thought I might start with Ms van Poppel first.

20 In your statement you tell us a little bit about Women with Disabilities Victoria and your extensive work as a disability rights advocate over the past two decades. Can I ask you to tell the Royal Commission a little bit more about the work of Women with Disabilities Victoria?

25 MS VAN POPPEL: Women with Disabilities Victoria is a disabled peak organisation that was formed 25 years ago as a feminist collective. It is made up of and for women with disabilities. So the majority of our board and our staff team are women who identify as having a disability.

30 Our work is across the state of Victoria, as the name suggests. And it is focused on a few key areas. We work to inform government about changes required for women with disabilities. We work to connect and increase the social connection of women with disabilities themselves. And we also work to make sure that violence against women with disabilities is addressed and prevented and responded to appropriately.

35 MS EASTMAN: And your role as CEO means you are responsible for developing organisational strategy and overseeing the implementation of the day-to-day work?

MS VAN POPPEL: That's correct.

40 MS EASTMAN: And this work includes a systemic advocacy to create positive change for women with disabilities in Victoria?

MS VAN POPPEL: That's correct, yes.

45 MS EASTMAN: Ms Deane, can I turn to you. You say in your statement that you have more than 25 years of experience in the disability sector as an academic, policy adviser and campaigner.

MS DEANE: That's right.

5 MS EASTMAN: And you've served on a number of boards and disability advisory boards, include Down Syndrome Victoria, Down Syndrome Australia, the Victorian Disability Advisory Council and the Victorian Ministerial Council on Students With Disabilities and Additional Needs.

10 MS DEANE: That's correct.

MS EASTMAN: There is one disclosure we need to make. You say in your statement that you served as a member and Deputy Chair and Co-chair of the National People with Disability and Carer Council; is that right?

15 MS DEANE: That's correct.

MS EASTMAN: And at the time you served as the Deputy Chair, one of the Commissioners, Commissioner Galbally was the Chair of that organisation?

20 MS DEANE: That is correct.

MS EASTMAN: So Commissioners, I wanted to make that disclosure so that those following are aware that you have had a prior working connection with one of the Commissioners hearing the proceedings.

25 MS DEANE: That is correct.

MS EASTMAN: And during your work on the National People with Disabilities and Carer Council, you wrote the report "Shut Out: The Experience of People with Disabilities and their Families in Australia". That is back in 2009.

30 MS DEANE: That's correct.

MS EASTMAN: And that is a report that is still cited on many occasions, is that right? You are called on to talk about the "Shut Out" report; is that right?

35 MS DEANE: Yes, yes it is.

MS EASTMAN: My apology for elevating you to be the CEO but, as you say, you are the Campaign Director for Every Australian Counts. I wanted to ask you about Every Australian Counts. It was launched in the beginning of 2011, but how did the organisation come about, and then I want to ask you about what the focus is for this particular organisation.

40 MS DEANE: Basically around the time that the idea for the National Disability Insurance Scheme first started to get talked about, that was around 2008, 2009, around the time actually that "Shut Out" came out.

MS EASTMAN: I will jump in here and I will anticipate before I get a signal, can we slow down a little bit. We have plenty of time. Just so our Auslan interpreters can keep up with both of us.

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MS DEANE: My apologies. So at that time there are a number of organisations in the disability sector who came together and said, "Look, we think the idea for the NDIS will really change the lives of people with disability across the country. We think it is the way to make sure that finally people with disability in this country have the same opportunities as everyone else, but we know that the NDIS won't get up unless we fight for it and that we build political and public support for the idea." So they came together and said that we need to work together to make this happen. They formed an alliance called the National Disability and Carer Alliance, and I was the Executive Director of that, and then they went looking for other individuals and organisations who also wanted to work together to make the NDIS become a reality. And that's how Every Australian Counts was born.

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MS EASTMAN: Can I come back to Ms van Poppel. As you know, this particular hearing is focused on the impact of COVID-19 on people with disability, and in your statement you've identified a range of matters that have come to the attention of Women with Disabilities Victoria. I want to ask you about some of the accounts you are hearing and people coming to your organisation to share their experiences. You have said in your statement that women with disability experience higher than average levels of social isolation and this isolation is one of the drivers of abuse against women with disability.

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Yesterday we heard some evidence from Nicole Lee speaking about not only her personal experiences but the work that she has been doing in the area of women and violence. What are you hearing in relation to the experience of women and the risks of violence and abuse against women with disability during the period of COVID-19?

MS VAN POPPEL: Thank you. Just to be clear, I am hearing some of this through Women with Disabilities Victoria, but some of it is also coming to my attention as a personal citizen with networks into disability advocacy and in the disability community.

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For women with disabilities, as I've said, whenever we talk to women with disabilities, one of the key issues that comes up is isolation. And that's isolation from services, it's isolation from supports like family and friends. It is just a general lack of connection sometimes to the outside world. Our work, as I said earlier, is focused on reducing that isolation for women with disabilities.

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Being isolated can mean that a woman is more likely to be targeted by a perpetrator. We are very careful about not framing women themselves as vulnerable, but perpetrators might choose to target women who are more isolated and more dependent on perpetrators or potential perpetrators for support, to do day-to-day

things or for an emotional connection. That's a general issue before you even begin to talk about COVID.

5 We know that women with disabilities experience more violence in different forms from different perpetrators across their lifetime than men with disabilities and people without disabilities. So that holds true even before you get into a situation like COVID. And at the moment what we have is a bit of a "known unknown". We know that anecdotally more women are telling us that they have fewer support workers or fewer family and friends coming to their homes when they are really
10 worried about the complications of COVID and the effect that it could have on them. They might die. So that imposes more isolation on women who may already not have many connections at all.

15 Right now it is very hard to gauge the effect of that because knowing how safe someone is in a very closed environment where they might only have one or two people coming in, that's very difficult because you are not safe to disclose then.

MS EASTMAN: I think you say in your statement there is "the known unknown" around whether and how family and domestic violence has escalated during the
20 pandemic. So it is just that sense anecdotally of the stories that you are hearing. But one thing that is absent, are you saying, is some data?

MS VAN POPPEL: That's correct. Anecdotally what we understand is that family violence hotlines for women who do and don't have disabilities are actually
25 experiencing a lower number of calls at the moment. Lines that are set up to support men who are perpetrating violence have seen an increase in calls. But the general understanding across the board, before you bring disability into the picture, is that women are not feeling safe to make a phone call because they are in such close contact with their perpetrators at this point in time.

30 MS EASTMAN: One of the other issues you identify in your statement is healthcare and you say "We've had a brilliant increase in telehealth e-scripts from pharmacies and this has led to a very real increase in access to support for health care," and you've identified that as an issue for women with disability who find it difficult to
35 leave the home or to travel. But with the introduction of a broader range of telehealth services, have there been any other consequences in terms of women's access to health services during the course of the pandemic?

40 MS VAN POPPEL: I would say there have been two key impacts; for women who may usually go into a doctor's appointment or an allied health appointment alone, and that might be one of the few times they have an opportunity to disclose that they are experiencing violence in their life, that opportunity is now taken away, or much more limited because they have to rely a lot more on telehealth. So it is a bit of
45 a concern, and we would want to more support --- that option for face-to-face support remaining for women with disability.

I also think for women in regional and rural areas, telehealth has some benefits but

what we find is that our regional members are less likely to have good internet access, they are less likely to have computer literacy, and there some supports they need to access in the health system face-to-face, for example if you need to get a mammogram, it is not really a telehealth matter. So there are instances where
5 women need to access face-to-face services and that is creating real dilemmas around going out to protect your general health versus going out and facing the risk of getting COVID.

10 MS EASTMAN: Another area you identify is safety in public spaces and say anecdotally you've heard a number of stories concerning issues of safety for people with disability in public spaces during the pandemic, and that has led to an increased sense in the disability community that if you have a disability, there are things you cannot necessarily control. You give the example of hearing women with disability
15 being shoved in supermarkets and having goods stolen from their trollies during the dedicated shopping hours and people who use mobility devices have had their masks and other personal protective equipment taken from them while they were using the device and not looking. Is that right? What sort of things are coming out in terms of safety in public spaces?

20 MS VAN POPPEL: That's right. So there is a general sense for some people with disability, women in particular, I would say, that safety is a key issue, particularly when there are times of panic buying in supermarkets or a scarcity of products that people might need. But there is also some people have a sense of if you are not able to social distance or not able to understand the rules readily, if the police aren't aware
25 of how to interact with you, your sense of feeling unsafe in the community generally is just a little bit more heightened at the moment.

MS EASTMAN: And for people with disability living in congregate settings, the concerns you raise there about people not being allowed to leave their rooms and
30 some group homes preventing visits by family members; in some cases you are concerned that fewer visitors will make it difficult for clear accountability among the services and support staff and so this process of the informal safeguards may be dropping away a little bit during COVID-19; is that right?

35 MS VAN POPPEL: That's right. And working in the context that everybody has had to adjust really quickly to COVID and that has led to some inconsistencies. Now we are at a point where we know we are in this for the long haul and it is really important that we actively think about that balance of the personal safety of a person with disability living in a congregate setting in the immediate sense of, you know,
40 catching COVID, versus their right to freedom and their right to be seen by the broader community, which is a really important factor in making sure that violence doesn't occur.

MS EASTMAN: Before the hard lockdown in Victoria, you also saw some impacts
45 in relation to employment, both in terms of working from home, but also continuing to attend the workplaces. Can I just ask you to briefly deal with two of the accounts that you've heard concerning women with disabilities and their employment during

the pandemic. The first relates to the person who was working from home, and the second relates to somebody who wanted to return to her place of work.

5 MS VAN POPPEL: Yes. So you hear a number of instances of people with
disability being very concerned, especially if they are working for essential services,
that they might be forced back into their workplace. We are also hearing about
people who might want to return to the workplace. There is a real conversation
going on in the disability community about the lack of visibility that comes from
10 working from home. It creates greater accessibility, it means some people with
disability who otherwise might not be able to work are doing more hours, are finding
that they can work more productively from home, but there is a real sense of concern
that we might lose out when you have people with disability less visible on trains and
buses and city streets and for some people with disability the desire to return to work
is really strong, not just because they want to see their colleagues and peers but they
15 want to make sure that all of the gains we've made in accessibility and all of the gains
we've made in being visible in the community aren't lost. I've had instances of
people having to really fight to be able to access their own workplace if they choose.

20 MS EASTMAN: Ms Deane, I haven't forgotten about you because at EAC you've
been hearing similar accounts, but at EAC you decided to conduct a survey to get
a good sense of what concerns were occurring, but also to help in terms of a strategy
about how you might address some of the concerns arising. So can I ask you from
EAC's perspective, what was the purpose of the survey? How did you fashion that
and who did you include in the survey process? Then I want to ask you about the
25 three sets of strong messages that you say came out of the survey process.

MS DEANE: That's right. During the first wave of the pandemic the NDIA made
a number of changes to the NDIS at this time. We wanted to know from the
perspective of people with disability and their families how they were working on the
30 ground and, perhaps more importantly, what else people thought needed to change at
that time. So we launched a very short, simple survey at the end of April and ran it
through to the beginning of June. We had more than 700 people respond to the
survey. They were primarily people with disability in their families, but there were
also a small number of responses from people who worked in the sector, for example
35 as advocates.

People gave very detailed responses and we are incredibly grateful for that. If I
could summarise them, the three really strong messages that came through in the
survey were: we feel forgotten, we need more support, and when it comes to the
40 NDIS, we need things to be much, much easier.

So the first set of messages about we feel forgotten was that people felt that
government had forgotten about them and they felt that government didn't really
have a good idea of the very real challenges that they were facing at this time. And
45 they noticed it in small ways with things like the fact that the Prime Minister or
Premiers didn't really mention people with disability or their families in their press
conferences, or mention them in the plans that they were releasing. It was also about

the bigger things, and probably the biggest thing was the fact that people who were on the Disability Support Pension, or who received the carer's payment were not given the additional coronavirus supplement as other groups were. And that was particularly frustrating because it happened right at the same time that people were reporting to us that their costs had increased.

So in the survey we asked people: what are the problems that you are facing at the moment? What are the issues that you are facing at the moment? And the most common response was, "My costs have gone through the roof." And they were costs for things really --- really important things, not small things, but really important things like purchasing protective equipment, PPE. In the first wave of the pandemic the NDIA would not allow people to buy PPE with their NDIS funds. So people were buying this essential equipment that they needed to keep themselves safe and well, they were buying that with their own funds. But the other thing that you have to remember is this has all happened in the context of the fact that almost 50 per cent of people with disability in this country live in poverty. So they were facing additional costs and at the same time the lockdown prevented them from the strategies that they usually used to make their budgets stretch further. So they were really pushed to the limit financially.

They were also really pushed to the limit because of the impact of managing their disability or the disability of their family member. You have to remember that for some people they decided to limit their face-to-face support to try and reduce the risk of contracting the virus. But for other people, services stopped when lockdown began. So, regardless of the cause, it meant that people were left to manage the impact of their disability either by themselves or with the help of family members.

We know through Every Australian Counts, and I know through my own personal experience, we have a daughter with Down syndrome who is a participant in the scheme. And I know for many people with disability, life is a juggle at the best of time. There are daily challenges big and small that can make life extraordinarily difficult. By the time you throw in a global pandemic and life in lockdown, some of these very, very precariously balanced lives were thrown into complete turmoil.

Those two things, feeling forgotten and then being completely overwhelmed and stressed with everything they had on their plate, that then framed their response to the changes that the NDIS made at this time. They are the context for the third set of messages, which was basically "We need things to be much, much easier." The overwhelming message that comes through in the survey from people with disability and their families is they say, "We have so much on our plate at the moment and lots of it is not your responsibility and that you can't fix it, but the bit that is your responsibility, the bit that you can control, is try and make the NDIS as easy and as simple and as quick and responsive as you can so that we can get on and do what we need to do to keep ourselves safe and well." And, unfortunately, what comes through in the responses is that that did not always happen for people with disability and their families.

MS EASTMAN: So did you take the results of the survey and these three key messages to the NDIA and have any consultation about what might be possible during this period in terms of simplicity and flexibility?

5 MS DEANE: We did two things. The first is we have just released the report today but I have had a series of meetings with the NDIA to talk them through the results of the survey. I would say that I talk to somebody at the NDIA most days to try and talk to people about the feedback that we are hearing about people's experiences and what still needs to change.

10

MS EASTMAN: Okay. One area that you cover in your statement is changes to the assistive technology policy, and this has required you to become a bit of a master of the Zoom conference. Can you tell us what steps you have taken in terms of bringing the NDIA, together with members of the community, to understand what the policy is in relation to assistive technology?

15

MS DEANE: So in the early days of the pandemic we were really overwhelmed with the number of questions people were asking us about the NDIS. And there was a real problem at the beginning about people getting information about what was happening and then explaining it to them, what it would mean for them. So what we asked the NDIA was that we wanted them to hear directly from people with disability in their families about what the issues were. So we organised a Zoom forum with one of the general managers from the NDIA. We went out to the Every Australian Counts community and asked people to send in questions that they wanted us to ask the general manager and then people also came in online and asked questions directly online. We had I think about 250 people attend that forum with Scott McNaughton, who was the General Manager.

20

25

MS EASTMAN: What happened at the forum, what sorts of questions were asked and what information did the NDIA tell you?

30

MS DEANE: One of the questions that was asked, and I think probably in the lead-up to the forum it was one of the most common questions that was asked, is people wanted to know if they did not have some kind of smart device currently, could they purchase one with their NDIS funds to keep up with their disability supports at this time? We heard Ms van Poppel talk about the importance of telehealth during this period but having devices was important not just for telehealth but for people to be able to access their other kinds of disability supports at this time, really vital things like speech therapy or psychology or other forms of support that people were doing online. So the question was asked: could NDIS funds be spent on those devices because up until now the answer had been "No". And so ---

35

40

MS EASTMAN: Sorry, so this is about 9 April this year.

45 MS DEANE: That's correct.

MS EASTMAN: What were you told in terms of what people could or couldn't do?

MS DEANE: So at that forum, Mr McNaughton explained that you could purchase a smart device with your NDIS funds if you didn't already have one and if you needed it for your disability support at that time and that you hadn't been able to
5 arrange one through some other kind of system.

MS EASTMAN: And what happened after that announcement? You have covered this in your statement in terms of getting to a final policy in relation to this.

10 MS DEANE: So that was really positively received. Not only did everybody on the Zoom forum hear the news, but we shared it on social media and we let people know. Unfortunately, what happened after that is that the NDIA changed the information about this new change on their website over the next few weeks. To be honest,
15 I have lost track of how many times the information changed on the NDIS website, but it was at least three times in that period. And the final policy didn't land until, I believe, April 27.

Finally, when that policy finally landed, the answer was you could purchase a device with your NDIS funds if you needed it for your disability supports, if you didn't
20 already have one and couldn't get one elsewhere, but they also added a recommended price range. They added that it had to be one that was the lowest specification that could do the job and, perhaps most importantly, that you had to ask a provider to give you a letter of support to say that you needed that device.

25 MS EASTMAN: Is it fair to say that you've been somewhat both disappointed and critical about the communication of this policy so that people with disability who are NDIS participants know exactly what they can and can't do?

MS DEANE: So I think, and it came through in the survey, that people were very
30 grateful for the opportunity to purchase a phone and that comes through strongly in the survey, but they were really frustrated with the constant changes of policy. They found it very confusing. We were also contacted by people who were really scared and worried that they had purchased a device before the rules changed and that they would get into trouble or they might be forced to pay the funds back, money that they
35 didn't have. And so people were really frustrated. Even though it had a good outcome, they were frustrated with their confusion and the anxiety that it created.

I personally also was critical of the policy because it introduced a step, it introduced another hoop, and made it even more complicated for people to get something that
40 they desperately needed for their disability support at this time. It also meant that --- it was counter to the principles on which the NDIS was founded. The NDIS was founded on the principle of giving people with disability greater choice and control over their disability support, and that they would have the choice and control to choose how and when disability supports were provided for them. This was
45 a retrograde step because it meant that people had to go cap in hand to providers and say, "May I do this, please?", and get their permission to do it. It wasn't really clear to me why that was necessary, why the purchase of a device was different from any

other purchase of a support within the NDIS, subject to the same tests, which are: is it reasonable and necessary and is it related to your disability, as everything else in the NDIS. Quite practically, it also added to the cost of devices. People had to pay providers to write letters to say that they needed it and it added a cost. It was
5 complicated, confusing and a retrograde step.

MS EASTMAN: In the time we have left. Both of you have given us a lot of suggestions about the future and different ways, perhaps, of delivering services and addressing the needs and rights of people with disability. Can I ask you both to
10 perhaps take the key points out of your respective statements to tell the Royal Commission what the key differences might be because I anticipate some of the Commissioners may have some questions and I will also anticipate the Chair might want to make sure that I don't trespass over the 1 pm luncheon adjournment.

15 Ms Deane, can I start with you: what are the key points that concern you at the moment?

MS DEANE: I think what people are saying in the survey is that --- they say the same things that they say to us all the time, that we hear all the time at Every
20 Australian Counts, which is they want the NDIS to be quicker, simpler, easier, they want it to be more flexible, they want simple, clear information to let them know what is changing, and what it means for them, and they just need it to be responsive. And they need that every day, but in the middle of a global pandemic, they need the NDIS to be responsive to what they need. Essentially, get out of the way so they can
25 get on with everything that they have got on their plate.

I would add two extra things from my perspective of running Every Australian Counts during the pandemic: in addition to the NDIS issues, we need more funding for advocacy, both systemic and individual advocacy. During the pandemic I had
30 cause to speak to a number of advocacy organisations either to refer people for help or to share information and resources. And I am aware that many advocacy organisations have closed books and some of them have even closed their waiting list. I think in the middle of a global pandemic when people urgently need help, that isn't acceptable. We also need funding for systemic advocacy because it is those
35 organisations that are working with government to make sure that government responds appropriately and that people aren't left behind.

The other thing that I would say is I'm acutely conscious of the limitations of both
40 Every Australian Counts and the survey that we ran. There are lots of people out there who did not fill in our survey and who do not come out to our Community Forums and who do not make contact with Every Australian Counts in any way and their experiences aren't reflected in the survey as a result. But we need to find a way to hear from them. We need to find a way to engage with them because if we don't, and if we don't hear about their experiences, and if we don't have their voices heard,
45 then all the plans that we make, and all the responses that we make, will be inadequate and they will leave people behind and they will leave people to fall in the gaps because we haven't heard what the issues are for them.

And I note that one of the ways that we reach those people, for example people, as Ms van Poppel mentioned, who live in congregate care, one of the ways we reach them is through advocacy and that is why it is so critical.

5

MS EASTMAN: Ms van Poppel?

MS VAN POPPEL: Ms Deane mentioned earlier that people with disability felt forgotten because people weren't hearing their stories or even statistics about disability represented through reports of politicians, the media, government bureaucrats. And while we appreciate, certainly here in Victoria, that the Government has been working very hard to try and fix things and adapt very quickly to the situation that presents itself, it is important that disability is considered and disability in the community is heard throughout the pandemic. That is, as Ms Deane said, partly through advocacy but it is also through sharing information about what is happening with people with a disability on a day-to-day basis. When there are outbreaks, what numbers of people with disability are affected and making sure that our community understands the level of impact that is had on people with disability.

20 But I think it is also about understanding that this is going to have a longer-term impact for people with disability. Some people with disability won't come out of something that looks like a stage 3 or stage 4 lockdown until there is a vaccine regardless of what the Government does because they are so frightened. So that isolation that I talked about earlier is going to persist much longer, and the risk of violence going unseen and un-noted and unreported is going to exist for far, far longer for people with disability across this country.

30 So we need to be clear in thinking about resourcing supports for women and people with disability more broadly who are experiencing violence in the medium to long term because of COVID. We also need to be really clear about making sure that we address some of the underlying drivers of that. So addressing issues of isolation as best we can through the provision of AT and addressing the underlying issues of attitudinal discrimination that leads to that lack of courtesy on the streets and leads to some of the issues that we are starting to see with employment or access to consistent health services.

MS EASTMAN: Thank you both. I will just check with the Commissioners whether any of Commissioners have any questions?

40 COMMISSIONER SACKVILLE: Commissioner Galbally?

QUESTIONS BY THE COMMISSION

45

COMMISSIONER GALBALLY: Yes, I have a question for Ms van Poppel. In terms of your emphasis on isolation which predated the virus, I take it, from what

you are saying, what are your suggestions or strategies to overcome that? It sounds like a huge risk factor.

5 MS VAN POPPEL: It is a massive risk factor. I think there are a number of things we can do to overcome that. The more services that provide a different array of options for access, so that tension I was talking about with telehealth that for some women that will work really well and for some women it is going to increase isolation. The more array of supports we have available for women with disabilities, the better. The more advocacy services and safe spaces for women so they are supported in a range of different ways throughout the pandemic to reach out to women, the better, because there may be instances where women are not able to disclose violence by picking up the phone and calling the Family Violence Service. But if they have access to social gatherings, if they have access to advocacy around disability, they are given other safe spaces. So it is really important that we support disability services, broader women's services and an array of mainstream service solutions.

COMMISSIONER GALBALLY: Thank you.

20 COMMISSIONER SACKVILLE: Thank you very much. There are some questions that if we had more time I would be very happy to ask, but Ms Eastman limits me to watching the clock so we shall now have to adjourn for lunch. Thank you very much, both of you, Ms Deane and Ms van Poppel, for your statements and evidence today. We very much appreciate it. Thank you very much.

25

THE WITNESSES WITHDREW

30 MS EASTMAN: Thank you, Commissioners. Could we adjourn now until 2.00 pm. For those following the proceedings for the afternoon, we will resume at 2.00. We'll then go through to 3.45. We'll have a break for 15 minutes and then our witness from Geneva will join us at 4.00 pm and we hope to run through to 4.30 this afternoon.

35

COMMISSIONER SACKVILLE: And that will be the UN Special Rapporteur?

MS EASTMAN: Yes.

40 COMMISSIONER SACKVILLE: Thank you very much. We'll adjourn until 2.00 pm.

45

ADJOURNED

[1.04 PM]

RESUMED

[2.01 PM]

COMMISSIONER SACKVILLE: Yes, Ms Eastman.

5 MS EASTMAN: Thank you, Commissioners.

There are a number of witnesses who wanted to participate in this hearing but were unavailable to give evidence during the course of this week, and also some of the witnesses we spoke to who expressed a preference of providing the Royal
10 Commission with a written statement, but having the opportunity to prerecord some of their evidence. I can say that our attempts at the pre-records were a little bit of an experiment for us at the Royal Commission and we were able to prerecord some of the evidence over the week before the Royal Commission commenced.

15 I want to tender some evidence from two of the witnesses who have prepared statements for the Royal Commission, that have also done a pre-record, and to play the prerecord of their evidence for you.

The first is Samantha Dwyer. You will find a copy of her statement in the tender
20 bundle at part A, tab 22. And the pre-record of her evidence we've also included as a separate annexure to her evidence, and they can be dealt with together and if you could mark the document behind, or the recording behind tab 23 as Exhibit 5.7.1.

COMMISSIONER SACKVILLE: Yes, thank you very much.
25

EXHIBIT #5.7, STATEMENT OF MS SAMANTHA DWYER

30 **EXHIBIT #5.7.1, PRERECORDED VIDEO OF STATEMENT OF MS SAMANTHA DWYER**

MS EASTMAN: We'll deal with Ms Dwyer first.
35

COMMISSIONER SACKVILLE: We are going now to play the pre-recorded interview.

40 **VIDEO OF SAMANTHA DWYER BEGINS**

MS EASTMAN: Commissioners, I welcome Samantha Dwyer, who has done a pre-recorded video for the Royal Commission.
45 I will start by asking Ms Dwyer whether she will make an affirmation.

SAMANTHA DWYER, AFFIRMED

EXAMINATION BY MS EASTMAN SC

5

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

10 A. Yes, I do.

Q. And your full name is Samantha Dwyer?

A. Yes.

15

Q. And you have provided your address to the Royal Commission?

A. Yes, I have.

20 Q. And you've prepared a written statement for this hearing; is that right?

A. Yes.

Q. Can you confirm that what you've said in the statement is true?

25

A. Yes.

Q. Thank you.

30 So, may I start with asking you to tell the Royal Commission a little bit about yourself? You've set this out in the statement but what would you like to tell the Royal Commission?

35 A. I'm 28 years old. I've been diagnosed with Friedreich's ataxia since I was 10 years old. My sister also has it. We have just moved to be living in the same building in separate apartments. Three weeks ago, before we moved, we were living in a group home.

40 Q. And how has the change been from living in a group home to living in your own apartments?

A. It's been amazing. So much more choice and control.

Q. Choice and control about what sorts of things, Sam?

45

A. Like being able to choose our own support workers and even things like choosing our own food. We didn't get to do that.

Q. So, Ms Dwyer, this hearing is looking at the impact of COVID-19 on people with disability and you've provided a statement to the Royal Commission to talk about that impact. And you've said in your statement that your disability places you at
5 a higher risk to the impact of COVID-19 compared to others. Can you tell us a little bit about the impact of COVID-19 on you?

A. So I am at a higher risk because I have 30 per cent lung capacity and I have heart disease, which places me at the high end of risk. So during the pandemic, I had to
10 self-isolate for three months. It was very lonely. I felt like people who don't have a disability did not take it seriously.

Q. And what has it meant for you in terms of accessing essential supports and services? That is something you talk about in your statement. What would you like
15 to tell the Royal Commission about supports and services?

A. There was no change to the way I accessed support. A lot of my services were cancelled and I wasn't able to access them.

20 Q. And what did that mean for you and your day-to-day life?

A. It just meant that everything changed. I had to stay home a lot more.

Q. And what about information during COVID-19? What sources of information
25 have you used to find out about COVID-19, or information about COVID-19 and people with disabilities?

A. I found that social media was really helpful.

30 Q. And what did you find helpful about the social media?

A. The news websites, like Channel Nine and Channel Seven, they would go live any time they had an update.

35 Q. Okay. Now, there is one message that you wanted to give the community and you said in your statement "Welcome to my world". What can you tell the Royal Commission about the message that you want to say in relation to "welcome to my world"?

40 A. So for people with disability, they have to stay home a lot more. Like, for example, an able-bodied person may take 10 minutes to get ready and shower in the morning and then they can go off. And someone with a disability, it can take three hours to get ready in the morning. So, with able-bodied people being made to stay home, they got to find out what it was like having to stay home for something that's
45 out of your control.

Q. So, your message is that people without a disability may have some

understanding about the experiences of people with disability because of isolation and staying at home?

A. Yeah.

5

Q. Right. And you've said there's some positives to come out of the pandemic. And what do you think the positives have been?

A. I would say that one positive is that people understand what it's like to have to stay home for something that's out of your control.

10

Q. And we're in the middle of the pandemic it seems. It may be ongoing. What would you like to say in terms of looking forward to the future and how we manage COVID-19?

15

A. I wish that the community knew that even though they are healthy and able-bodied, they need to make sure they are not carrying the virus because they could carry it to an elderly person or just someone with an underlying health condition. So, unless you want to be responsible for accidentally killing someone, you need to take this seriously.

20

Q. So we all need to be aware of how serious the impact may be on people with disability who have serious underlying health conditions?

A. Yes, very.

25

Q. Ms Dwyer, thank you very much for your evidence to the Royal Commission.

A. Thank you.

30

THE WITNESS WITHDREW

35 VIDEO OF SAMANTHA DWYER CONCLUDES

MS EASTMAN: Commissioners, the next person who provided a statement to the Royal Commission and also pre-recorded his evidence is Anthony Mulholland. You will find a copy of his statement at part A of the tender bundle, behind tab 20, and the pre-record of his evidence is at tab 21. Could I ask you, Commissioners, to mark Mr Mulholland's statement as Exhibit 5.6 and the pre-record as 5.6.1.

40

45 EXHIBIT #5.6, STATEMENT OF ANTHONY MULHOLLAND, DATED 10 AUGUST 2020

EXHIBIT #5.6.1, PRE-RECORDED VIDEO OF STATEMENT OF ANTHONY MULHOLLAND

5

MS EASTMAN: You will see his prerecord which he did assisted by his support worker.

10

COMMISSIONER SACKVILLE: Yes.

VIDEO OF ANTHONY MULHOLLAND BEGINS

15

ANTHONY MULHOLLAND, AFFIRMED

EXAMINATION BY MS EASTMAN SC

20

MS EASTMAN: We're joined by Anthony Mulholland and his support worker David. Anthony, can I confirm your name is Anthony Mulholland?

25

A. Yes.

Q. You have an intellectual disability?

A. Yes.

30

Q. You identify as a First Nations man?

A. Yes.

35

Q. And you're a self-advocate and a member of the New South Wales Council for Intellectual Disability?

A. Yes.

40

Q. Now, Anthony, you have prepared a written statement for the Royal Commission; that's correct?

A. Yes, that's correct.

45

Q. And are the contents of that statement, so what you've said in that statement, is that all true?

A. Yes, it is.

Q. And do you promise that the evidence you'll give today, which is the questions and answers between us, that what you will say in answer to the questions is also true?

5

A. Yes, it will all be true.

Q. Thank you, Anthony.

10 Can I call you Anthony?

A. Yeah, you can call me --- or Tony, I don't mind.

15 Q. So, can I ask you first of all, when COVID-19 happened, you got most of your information from the news and you said that the news was very negative and there was too much information at one time. Did that cause you to feel quite confused?

20 A. Yeah because they kept on changing their mind day after day. And when --- especially when the news started, at first I didn't think much of it. I thought, "Okay, this will be over and done with", but then it got worse and the news started becoming more and more dramatic and more and more quickly --- over time it came more quickly so it was very confusing and they kept changing the story day-to-day. And also they'd then change the story and there was no consistency. So one story was said by one person, then another person said it, and another person said it, and 25 by the time it came to the fourth person, which was me, it was way out of whack and I didn't know which way to turn.

30 Q. Ok, so, pausing there, you relied on your support workers and your family to give you the correct information; is that right?

A. Yes, sort of, yes.

Q. And that's helped you work out what the rules are during the COVID-19?

35 A. Yes, it made me work out the rules and regulations regarding access to the community, which was vital for me because being independent and not living at home without my parents and only having a support worker for a certain period of time, based on my income from the NDIS, I was 98 per cent of the time by myself.

40 Q. Yes. So you have felt very isolated and lonely during COVID-19, haven't you?

45 A. I felt very isolated, especially the first few weeks when there was not many people to see. And I felt miserable because being lonely I didn't have my family and coming close to Easter, I didn't get to see my mum and dad, and it affected me very much so ---

Q. Did you talk to them on the telephone?

5 A. Yeah, I talked to them on the telephone. I was nervous to go into their house because the Government had put down a law that you could get fined and all this stuff. I don't live near my parents. My parents live about a 20-minute drive --- because I don't drive, it is about a 50-minute bus/train trip ---

Q. Okay. And you were also nervous going out to the shops to get groceries from the supermarket, weren't you?

10 A. Yeah, because every time I was watching people getting fined. I had to go by myself because I can't rely on my worker all the time because obviously I only have support for a certain number of hours. I only needed to go out once in a while to get obviously milk, bread and all the necessities, but it was hard going out to get this stuff because I was always worried about being caught out. And people, even when
15 I was going to my local shopping centre, were starting to make comments as well, like, "Why doesn't he get caught out?" And I became nervous because being by myself I had to access the community.

20 Q. And one time the police actually asked you what you were doing and where you were going; is that right?

A. Oh, yes.

25 Q. And that made you pretty scared, didn't it?

A. Made me scared but also made me confused because I think it was --- it happened within my boundary of my area. So it was before I went onto the main road to cross to the station, which is about three minutes from my house. I was just about to leave my area of my units and I had to go past some bins and all of a sudden this vehicle
30 stopped. I knew it was a police vehicle. I knew automatically. There is no doubt about it. You can tell what a police vehicle looks like compared to other vehicles. So I immediately walked past --- towards the place where I was going and all of a sudden the police officer and he produced a badge, a badge of himself saying and okay, he had like a phone like this and he was ready to take all details down and all
35 that type of thing. So I started to get nervous and I was thinking --- so I didn't act nervous, I just showed him my ID and he was quite satisfied.

Q. And you were able to go and finish your shopping and come home?

40 A. Yes.

45 Q. Anthony, can I ask you something else. So, during the COVID-19, you've been helping some of the clients of your service providers deal with the changes and you used to go to group homes and take some of the people who lived in group homes out to the park on day programs. But that's been quite hard for the people living in group homes because they haven't been able to go out as much and it's hard, you say in your statement, it's hard for them to understand social distancing.

So what have you done to help the people that you have worked with in group homes? How have you helped them during COVID-19?

5 A. I sort of encouraged --- it was hard at first because the restrictions obviously affected me as well. Initially at first I couldn't do much because of the restrictions, but I started --- once the restrictions were lifted a little bit, I started doing more things. I started taking them out. I tried to encourage them that everything is going to be okay. I tried to reassure them. It was hard because they're all used to routine.
10 That was hard. The routine had changed. So instead of going to the park, I had to come somewhere like --- we had a day program at our head office. Our head office had a day program which had plenty of things for them to do. I tried to make it somewhere that was comfortable for them. Not dangerous or risky for them to be, or scared, in the community.

15 Q. And so, Anthony, you've said that you wanted to reassure those people that they are not in trouble or they are not going to be punished in any way and you've been helping them by explaining what is happening using pictures; is that right?

20 A. Pictures and symbols. It was hard because finding symbols was nearly impossible. I found what would have helped is they all have iPads and their iPads are communication devices and communication devices to them is like us having a phone. So if I had some way --- if the Government gave me or if someone gave me an app or developed something there it would have helped me. The only way I
25 could do is show pictures, this is what we could do, this was what we couldn't do. It was hard because every time I would see them something would change or this would be suddenly okay and then it would change. And it was hard for me as well to adapt to how do I explain to them. They are so happy they can do this, but now they can't do this and they have got to do this instead.

30 Q. That is one of your suggestions, isn't it, to see if some technology can be developed to have apps that might help improve communication; is that right?

A. Yeah.
35

Q. The last thing I want to ask you about is the final thing you say in your statement is that you don't know what the future is for people with disability during COVID-19. And what you want to know is what's going to happen for people with disability while COVID-19 is ongoing; is that right?
40

A. Yeah. I want to know what's the day-to-day things going to be like. You see, a lot of us are not technology smart. We still have to rely on the old-fashioned way of doing things. Unfortunately I'm not a fan of technology. I wouldn't go too far in that. It was hard for me and others with disability because we did the old-fashioned way of communicating. We would go to the shops. We would do banking. We
45 would do our post shop. But everything's now changed during the coronavirus. And there were regulations around how many people can be in shops, how many things

can be done here and there. So a lot of the concerns with me is what do we do when we've got no skill, we've got no hope, or everything's changed so that everything's gone back to a new way of thinking? Obviously it's hard to adapt to change, and I found it really hard because I'm not confident in using online, I'm not confident using
5 technology. I'd rather see somebody face-to-face. And that's what a lot of my friends would like to do. And it also gets them out of the house, because a lot of them are lonely and we live by ourselves, like me, and we just want to meet people. And so interaction in the community was something that I'm concerned about, particularly during coronavirus because I'm finding less community access because
10 everything is closing down or things are changing. And sometimes the changes may be good for one group but may be hard for another group to adapt to. That is what was really hurting me. For me and my friends, it was the changes. For me, it was constantly changing the way things were. Changing the way you could do shopping, you could bank, the way you could cook, the way you could interact, the way you
15 had to wear a mask, the way people were behaving was becoming nervous. I was getting very nervous of people. I was starting to wonder if people --- what people are. So I started becoming very nervous because I was worried people how --- how to react to people's behaviour through coronavirus. It's turned --- the behaviour of some people is becoming very hard for me to handle.

20

Q. Anthony, thank you so much for sharing your experiences during the coronavirus period with the Royal Commission and we're very grateful for your time today. Thank you very much.

25

THE WITNESS WITHDREW

VIDEO OF ANTHONY MULHOLLAND CONCLUDES

30

MS EASTMAN: Commissioners, I will now hand to Brisbane.

COMMISSIONER SACKVILLE: Dr Mellifont?

35

DR MELLIFONT: Good afternoon. The next witness is Sarah Yahya. Her statement is to be found in tender bundle A at tab 4. I ask the Commission to mark that as Exhibit 5.8.

40

EXHIBIT #5.8, STATEMENT OF MS SARAH YAHYA, DATED 10 AUGUST 2020

45 COMMISSIONER SACKVILLE: Yes, thank you.

DR MELLIFONT: Might the affirmation be administered.

SARAH YAHYA, AFFIRMED

5

EXAMINATION BY DR MELLIFONT QC

10 DR MELLIFONT: Can you please state your name?

A. Sarah Yahya.

Q. And you have made a statement dated 10 August 2020?

15 A. That's correct.

Q. Are the contents of the statement true?

A. Yes.

20

Q. And do you have two jobs, one of which is as a MediaLink Reporter with Multicultural New South Wales where you translate and summarise news items from Arabic to English?

25 A. Yes.

Q. And you have previously worked in communication for the Disabled People's Organisation?

30 A. Yes.

Q. And you have experience as an advocate for young people from a refugee background?

35 A. Yes.

Q. And you yourself are profoundly hearing impaired?

A. Yes, I am.

40

Q. And you came to Australia as a refugee at the age of 13 from Iraq?

A. Yes.

45 Q. Can you share with us what, of this pandemic, you have found to be particularly difficult?

5 A. During this pandemic I have found it difficult to absorb a lot of information that is changing constantly. As a person with a hearing impairment, communication has been incredibly difficult. I rely on lip reading, making sense of sound, on facial expressions and since these things have been taken away with the social distancing and the mask which has made it incredibly difficult for me to communicate with other people and that just brought feelings of alienation.

10 During --- particularly in this pandemic --- it has always been that way for me, however, lately it's been about how other people are helping me as well to be conscious of the fact how they are communicating. It is particularly important of the use of their mask and so on. But, yes, it has been a very, very lonely experience.

Q. With respect to the use or non-use of masks, what helps?

15 A. I guess --- can people realise why other people can't communicate when someone is wearing a mask. For example, there have been so many fantastic news outlets who have been communicating with people who have been open about the use of live captioning, interpreting, not using masks when delivering the news and explaining to other people why they are not using the mask during that time. It is incredible
20 because a lot of people are much more aware that there are people out there who are taking in news and information quite differently. And that's been incredibly helpful and I'm very supportive of these measures as well.

25 Q. So you would commend any news readers who take the time to explain to the audience that not using a mask while they are communicating assists in accessible communication for hearing impaired people?

30 A. Yes. That --- there has been many of them. I follow a lot of news, in particular the young person, this is how I read a lot of news. There is a lot of people been asking why are news anchors using mask, why are they not adhering to social regulations. So explaining it that way makes it so much easier for me if somebody were to ask me, I would have an easier time explaining because there is a lot of information and awareness out there.

35 Q. Okay. Thank you.

Your statement speaks about reading social media and there having been endless comments about how COVID-19 is about the survival of the fittest where our elderly, chronically ill people, and people with disability are the "unfortunate loss" and may not be prioritised if the health care system is overwhelmed.
40

What are your views about people posting comments such as this?

45 A. Incredibly insensitive. I can't turn away from reading stuff like this. I can't look away. I'm very intrigued by what I read because for me it reaffirms one of my worst fears about what inclusion is. We talk so often about making positive steps towards inclusion and accepting people but when a crisis like this happens, all the time when

a crisis like this happens, people with disability automatically take a back seat. And it just makes me feel incredibly vulnerable. It makes you feel what are other people thinking at the moment. Am I able to be open about my disability if this is what they think, if this is how they think.

5

Just before my appearance right now in the Royal Commission I was having a discussion with my sister who is also hearing impaired and she currently works as an assistant nurse and is currently on placement in her final year. And she was saying, "It is really, really hard for me, I can't seem to communicate." And I said to her, "Please be open." And she said, "I feel extremely vulnerable being open like that because we know what people are now thinking." If I were to come to somebody else and tell them, who has the time to make accommodations, who has the time to actually accept what I'm going through as well. And it's these feelings like this that keep festering inside of you, and as a person, particularly coming from a CALD background, there have been a lot of things that make you feel low, being a refugee, for example, or being a woman, for example, and then on top of that being a person with disability, you feel very aware of how, you know, small you might feel.

20 I would only ask for people to be conscious of what they post and to be aware that there are so many young people who are reading these things and it impacts how we go on about our lives and how we present ourselves to other people and we might be hesitant to come forward. In my case, I'm less likely to tell other people that I'm hearing impaired as a result.

25

Q. So you would note, as a message to people who post such things, that their comments are harmful in a very real way?

30 A. Yes. It's not just --- you are not just posting this stuff to hurt somebody's feelings, more than feelings. It's about --- for me, as an example, as a person with disability, I think about okay, well, how is this affecting where I go to work in the future, or where I go study and interact and make friends with other people, if this is how they think? You are more hesitant if you feel that way.

35 Q. Thank you, Sarah. I will ask you to slow down a little bit with your responses.

A. No worries.

40 Q. Just to finish on that point, you say in your statement that such statements are extremely counterproductive and it makes you feel that we haven't progressed in terms of inclusion and that when you couple that with the prejudice that sometimes attaches to you as a person of colour, you find yourself wondering why we always have to remind and explain our worth to others, and that it is continually being questioned during times like these; they are your sentiments and ones you hold to?

45

A. Yes.

Q. You use the word "CALD", which is an acronym commonly now used for Culturally and Linguistically Diverse communities; correct?

A. Yes.

5

Q. And you have considerable experience working with CALD people with disability; correct?

A. I do have experience working with CALD people in general, yes, and some with disability.

10

Q. Thank you. What do you see as some of the critical worries for CALD people with disability during this pandemic?

A. The continued uncertainty. There is a lot of uncertainty about what is going on, to you, to your family, to your community as well and how it is affecting you. When I used to do community interpreting some years ago I realised how difficult it is for people from a torture and trauma background to take in a vast amount of information and to remember that information. And with it being updated so constantly, I worry sometimes what they might know at the moment might be a little different to what the updated information we might have because of the changed circumstances in this pandemic.

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There has also been a lot of concern for me about carers changing for people with disability, with severe disability. I worry if they know that they can still access those services, whether they have the language skills to know that they can still access those services. One of the biggest things for me during this pandemic, and I've been really focusing on, is the message and how we are communicating with CALD communities. There has been so many translated information from all organisations and that has been incredibly great, but it's not about translating word-to-word. There is much more to it than that. There are different layers to it. How are we developing trust with the CALD communities so that they can understand what is going on? There have been a lot of health directions such as following the three hand washing and things like that. We need to explain what these things are, why are we doing them and how do they keep us safe. It's not enough just to give those directions because the story is about building trust. How we are connecting that messaging to community values is also very important and how are we working to deliver those messages and across different mediums and different channels, not just the news but also communities, religious leaders, community leaders, trusted messengers such as GPs.

45

My biggest concern remains when people are afraid, in particular coming from a refugee background, when they are afraid, given the nature of this pandemic, they might take it to the extreme and isolate themselves and their families completely, not getting the support that they need, emotional and mental support and also for their health and disability support as well. So these have been some of my worries.

5 Q. Sarah, I just want to take you to the issue of the importance of community
messaging. It is your view that when there is messaging from Government or
organisations to the CALD communities, it is essential to take into account several
layers of experience, in particular that for former refugees who have endured severe
hardships, torture and trauma, they may have a mistrust of authority, that they might
be taking their information from international news, which doesn't match up with
what they need to do here in our current situation. And so from your perspective, as
part of effective messaging, the messaging needs to include an explanation of why
the restrictions are in place; is that correct?

10 A. Yes, that is very important because it's not just about taking in what you are
given, but it is also about explaining why. Once you explain why, once you break it
down, that's when it becomes much easier for people to adhere to those regulations
and to maintain all that they need to do to maintain their safety and others.

15 Q. Appropriate community partnerships are particularly important in developing the
trust relationships between Government and service providers and members of the
CALD community, particularly those with disability; is that right?

20 A. Yes, community leaders, religious leaders play a very crucial role because they
are seen in the community as people who have the connection, who have the
language skills and who have the trust in the community and the care for their
community to actually tell them what is going on.

25 DR MELLIFONT: May I ask if the Commissioners have any questions, please?

COMMISSIONER SACKVILLE: Commissioner Galbally?

30 **QUESTIONS BY THE COMMISSION**

35 COMMISSIONER SACKVILLE: May I ask you a question. You've said in your
statement and in your evidence that what you have seen on social media can be
extremely distressing and you've explained why. Have you had that experience
outside social media in your interactions with people other than through the social
media that you use from time to time?

40 A. During the pandemic, no, and that's mostly because I don't tend to come forward
that I am hearing impaired. I hide it underneath my hair and I have had some
miscommunication with a lot of people when they are wearing masks but I've always
just noted it down to, you know what, I'm not understanding you and I'm sorry and it
can be incredibly embarrassing. Whereas I do note that it is better for me to come
outright with it, I just don't quite feel comfortable being very open to strangers about
45 these things, especially since I don't know how they would perceive it and how they
would understand and communicate.

There has been a cheat sheet for people who are hard of hearing that I see circulating where it tells to other people to be kind, to be courteous and understanding, that there are other people who are hard of hearing and cannot communicate quite well. I don't really --- for me when I look at it, I say, well, I would like for other people to demonstrate that for me to actually start trusting or start feeling open to that.

So, no, during the pandemic I haven't been open and it has caused quite an issue, but I would prefer to have those issues rather than be open. And I guess that is something I'm working on.

COMMISSIONER SACKVILLE: And just one more thing if I may, I see you translate from Arabic into English. I understand that the Arabic community is far from uniform, there are different religions and people from different countries and so on, so the answers won't be necessarily uniform, but to take forward what you have been suggesting, would you have any specific suggestions, for example, as to how messages could be got across more effectively during the pandemic to people within the Arabic communities?

A. Yeah, there are quite a few. One of the things I'm very supportive of is to talk to those people to ask them what their concerns are, and I have said this with my friends before. I have said that in order for us to address what the concerns are, we need to know what they are for us to develop the appropriate messaging.

One of the things that we can look at, for example, is to tailor it to values of those people. What do they really value? In particular the Arabic speaking communities, there is value of families, your elderly grandparent family members. That can be tailored to those messaging. But if you don't follow the social distancing and hygiene and wear masks when it is appropriate, you are risking the lives of your elderly, for example. That's very important.

Faith also plays an important part in this as well.

It is also about tailoring the messaging that this is a health issue. People from refugee backgrounds in particular have always said that we've always been -- we went through so much, we fled the war, we fled prosecution, we have seen it all. So what is a pandemic, it is just an additional barrier for us to get through, whereas if we frame it in a very health-specific way for people to understand that this is not a challenge that we can just get by that easily. So it starts with things like this.

COMMISSIONER SACKVILLE: Thank you very much.

A. Thank you.

COMMISSIONER SACKVILLE: And thank you very much for coming today and giving your evidence. We do appreciate it. Thank you again.

A. I appreciate it. Thank you very much.

THE WITNESS WITHDREW

5

DR MELLIFONT: Thank you. The next witness is Mary Sayers. Ms Sayers' statement is in tender bundle B at tab 18. I ask for it to be marked as Exhibit 5.28.

10 **EXHIBIT #5.28, STATEMENT OF MARY SAYERS, DATED 10 AUGUST 2020**

15 DR MELLIFONT: Ms Sayers refers in her statement to a number of documents. They are found in tender bundle E, tabs 20 through 51 and I ask they be marked as Exhibits 5.28.1 through to 5.28.32.

20 **EXHIBITS #5.28.1 TO #5.28.32, ANNEXURES TO STATEMENT OF MARY SAYERS**

COMMISSIONER SACKVILLE: Yes, thank you.

25 Ms Sayers, if you would take the oath or affirmation, please, which will be administered for you.

30 **MARY SAYERS, AFFIRMED**

COMMISSIONER SACKVILLE: Dr Mellifont will now ask you some questions.

35 DR MELLIFONT: Thank you, Chair.

EXAMINATION BY DR MELLIFONT QC

40 DR MELLIFONT: Can you state your full name, please?

A. Mary Sayers.

45 Q. And you've made a 37 page statement dated 10 August 2020; is that correct?

A. Yes.

Q. Are the contents of that statement true?

A. Yes, they are.

5 Q. Are you the CEO of Children and Young People with Disability Australia, often known as CYDA?

A. I am.

10 Q. And have you held that role since 8 July 2019?

A. Yes.

15 Q. Does CYDA have over 5,000 members, and is the national representative organisation for children and young people with disability aged between birth and 25 years?

A. That's correct.

20 Q. And you have substantial experience as an advocate for children and young people?

A. Yes.

25 Q. Is it correct that CYDA's vision is that children and young people with disability are afforded every opportunity to thrive and achieve their potential and that their rights and interests are met?

A. Yes.

30 Q. And CYDA's purpose is to advocate systemically for those rights?

A. That's correct.

35 Q. Amongst your qualifications are an Arts degree, a graduate diploma in Human Resource Management and a Master of Commerce.

A. Yes.

40 Q. And previously you have worked as the deputy CEO of Victorian Council of Social Service?

A. That's correct.

45 Q. And you are currently, among other things, the Chair and Co-convenor of the Australian Coalition for Inclusive Education?

A. That's correct.

Q. Thank you for your very comprehensive statement which speaks to a great number of issues and includes a number of recommendations that you would like this
5 Royal Commission to consider. Today for most of your evidence I want to focus primarily on the topic of education.

You've read the statement to this Commission by Tim Chan.

10 A. That's correct.

DR MELLIFONT: Commissioners, Mr Chan's statement is tender bundle A, tab 25. I asked that it be marked as Exhibit 5.9.

15

EXHIBIT #5.9, STATEMENT OF MR TIM CHAN

DR MELLIFONT: He has also pre-recorded evidence, which is at tender bundle A,
20 tab 26. I ask that it be marked Exhibit 5.9.1 and there is an extract of a TEDx presentation by Mr Chan at tender bundle A, tab 26A, which I ask be marked as Exhibit 5.9.2.

25 **EXHIBIT #5.9.1, PRERECORDED VIDEO OF STATEMENT OF TIM CHAN**

EXHIBIT #5.9.2, EXTRACT OF TED-X PRESENTATION BY TIM CHAN

30

COMMISSIONER SACKVILLE: Yes, thank you.

DR MELLIFONT: Commissioners, Tim is a 25-year-old man with autism. He has
35 been non-speaking since the age of 14 years, and in a few minutes we will play a recording of his evidence before this Commission. Before doing so, we will play a short extract of a 2014 TEDx talk that Tim did, which shows how Tim communicates. May we extend our thanks to Mr John Yeo of TEDx Melbourne for their permission to play the extract. I will ask for it to be played, please. It goes for
40 about 3.5 minutes.

VIDEO OF TIM CHAN'S TEDX TALK BEGINS

45 MS CHAN: My name is Sarah. I'm Tim's mum. We are very honoured to be here and today I'm giving Tim help with giving his talk. With my hand on his back, Tim gets a better sense of his body in space and I also give him from time to time

occasional reminders to focus. So the title of the talk that he's giving today is "Making Connections".

5 MR CHAN: I don't respond when you talk, talk. I flap my arms, arms, make and
may even lie on the floor. I don't respond when you talk. I flap my arms, make
noise and may even lie on the floor. Dot. This is what you see --- severe autism.
Severe autism means I can only process one thing at a time so I have to work hard to
understand things. I am also hypersensitive and everyday sensations can be painfully
intense. With both these difficulties I am constantly anxious and overwhelmed.

10 My mum saw the unseen, unseen. My mum saw the unseen. Unseen. The potential
to be fully human, human. To live a satisfying life. My mum saw the unseen, the
potential to be fully human, to live a satisfying life.

15

VIDEO OF TIM CHAN'S TEDX TALK CONCLUDES

20 DR MELLIFONT: Thank you. We will now play Tim's pre-recorded evidence for
this Commission. May we extend our gratitude to Tim's mum, Sarah, for her
assistance in putting this together. The pre-record goes for about five to six minutes.

VIDEO OF TIM CHAN'S PRERECORDED EVIDENCE BEGINS

25

MR CHAN: I am a non-speaker on the autism spectrum. My brand of autism means
that I am dealing with a body that is not always in sync with my intentions so it is
very challenging to go through daily life as I am dependent on one-on-one support. I
30 don't speak despite years of intervention and speech therapy. Instead I use assisted
typing to communicate with the support of familiar people who are my facilitators. I
also suffer from hypersensitivities, sensory overload, dyspraxia, high levels of
anxiety and epilepsy.

35 The pandemic has brought unprecedented changes to routines on which I rely heavily
to manage my constant anxiety which has skyrocketed. First, it is the uncertainty as
to what to do and what is best practice with the information from the Government
and other sources. There are a lot of ambiguities surrounding the health guidelines.
For example, some sources say that 1.5 metre social distancing is not really good
40 enough and we should do 2.5 metres. Another source from the Johns Hopkins
hospital said the chances of being infected is low if you are in contact with another
person for less than 10 minutes. But the Health Department has not laid down time
specifications.

45 Secondly, iso life is difficult because I miss the connection with people. I suppose
this is true for each person, with or without disability. However, because I use
non-conventional communication, assisted typing, it is not easy to connect as it takes

trained facilitators with whom I have a personal relationship before I can output typing.

5 Zoom is also hard for me because it's tiring to see people's faces as well as listen at the same time. So I am feeling especially alone and vulnerable.

10 Within the family, I usually go to my dad's place on the weekend, but lockdown has prevented me from seeing him. I miss him and also worry about his health and wellbeing.

Our family get-together with my siblings every Saturday for dinner has been replaced by Skype or Zoom. It is definitely not the same as having everyone over enjoying a family meal together.

15 In addition, there has been disruption to my support network. Support workers have to cancel shifts due to having to quarantine because of family members returning from overseas or has a compromised immune system because of food intolerance and so has to cut back hours.

20 My support workers are my friends as well because they facilitate my type-to-talk communication. It has been lonely. My mum, who I live with, has to take on all the care and supervision of my daily routines and activities. Because she has been without any respite or support, this is taking a heavy toll. Mum's age places her in the high-risk group and I have been worried about her health.

25 Also, if anything happens to her, I stress about who is going to do her job in looking after me. Because things are unpredictable, it is hard for me to get a grip on what to do and keep anxiety at a manageable level. I haven't been sleeping well. Both lack of sleep and anxiety have been the cause of more seizures. At the start of the
30 pandemic in March we were out walking and without warning I had a seizure, falling on my face and losing some front teeth. I had to spend the rest of the day at the dentist, the dental hospital in the Royal Melbourne Hospital.

35 I am also afraid of hurting mum or myself when I have fits in case I fall onto her or when she has to physically keep me from falling. Nowadays, Mum needs to be very vigilant when we walk, which is about three times a day as walking in nature helps me to calm down.

40 Since the second wave commenced with lockdown mark II, Melbournians and now all Victorians need to wear masks when going out. I am hypersensitive to touch as well as other things and face masks are uncomfortable at best and almost invasive at worst.

45 We have friends on the autism and neurodiversity spectrum with sensory issues who also find the same thing. For example, [REDACTED], fellow I Can Network member, posted on Facebook on 29 July 2020, "I have a lot of sensory issues, but I was able to work my way out by practicing at home each day. I can now wear this

without panicking, which is a massive step for me."

I appreciate that there are some people for whom wearing a mask would still be impossible or close to impossible, no matter how much they would like to wear one.

5 In addition, the term "masking" has negative connotations within the autism community because this is the process of how we try to hide or suppress our autistic traits to blend in with others and be acceptable. It may have an impact on how we come to terms with mask wearing.

10 We literally have been walking on a tightrope in a precarious balancing act, managing my overwhelming autistic challenges in navigating the pandemic with all its implications of social isolation and lack of adequate support. We literally have been walking on a tightrope.

15

VIDEO OF TIM CHAN'S PRERECORDED EVIDENCE CONCLUDES

DR MELLIFONT: Ms Sayers, Tim speaks of a number of issues, including
20 isolation, confusion, disruption to his support network, increased anxiety and also worrying not just for himself, but for his family members. Are the types of issues Tim speaks of in his video evidence and his statement ones that you've seen arise for other young people with disability during the pandemic?

25 Just before you answer, I remind you to keep your voice up. Thank you.

A. Thanks very much. We launched a survey just five days after the World Health Organisation declared the pandemic and we published the findings of this report in
30 May 2020. And the CYDA report was titled "More than isolated: The experience of children and young people with disability and their families during the COVID pandemic".

The report set out the findings of the survey on these children and young people with
35 disability and their families, we really want to understand what the unmet needs were and what the challenges were. We had over 700 responses and the data was analysed by Professor Helen Dickinson and Dr Sophie Yates from the University of New South Wales. And the survey results really reinforce some of the things that we heard from Tim.

40 The main findings that we found were 82 per cent of survey respondents said they lacked information targeted at children and young people with disability and their families. This was consistent throughout the first 5.5 weeks of the pandemic and the survey period. And this lack of information really exacerbated the stress and
45 uncertainty.

Uncertainty about education was also a prominent theme, including school closures and the challenges with learning from home, with a concern that the progress gained

by students with disability would be lost during the period.

5 Q. Pause just a moment, I will ask you to slow your rate of speech. We have enough time. It is important that we hear what you've got to say and that can be translated in real-time. Thank you.

A. Thank you.

10 We also found from our survey half of survey respondents reported a decline in their mental health or the mental health of their child, with this figure increasing over the period of the survey. Also remembering that this was a time when there was stockpiling occurring, which impacted on all Australians. The majority of our respondents to our survey said they could not buy essential supplies which were
15 critical for the support of their child or young person with disability, things like special dietary products, hygiene and incontinence products, and this was particularly at the commencement of the pandemic.

We also, remembering again this was the first five weeks, had a third of the survey responses say that they had cancellation of support workers, either by cancelling
20 themselves for fear of infection or self-initiated at times by the service provider.

Q. What was the overwhelming finding of the analysis of the survey?

25 A. The overwhelming finding was that information about COVID-19 was not appropriately targeted at children and young people with disability and their families.

Q. Mrs Sayers, you've read the statement of witness ABB; correct?

30 A. That's correct.

DR MELLIFONT: Commissioners, there is a non-publication order in respect of witness ABB and a pseudonym order, both made on 12 August 2020. The statement of witness ABB is at tender bundle A, tab 27. I ask it be marked Exhibit 5.10.

35 **EXHIBIT #5.10, STATEMENT OF ABB**

40 DR MELLIFONT: There are exhibits relevant to that statement at tender bundle A, tab 28. I ask it be marked 5.10.1. And there is pre-recorded evidence at tender bundle A, tab 29, I ask it be marked Exhibit 5.10.2.

45 **EXHIBIT #5.10.1, ANNEXURES TO STATEMENT OF ABB**

EXHIBIT #5.10.2, PRERECORDED VIDEO OF STATEMENT OF ABB

COMMISSIONER SACKVILLE: Yes, thank you.

5 DR MELLIFONT: We will now play a video of witness ABB's evidence.
Obviously, given the nature of the non-publication and pseudonym orders, what will
be publicly streamed will not include a visual of the witness. The video is
approximately 15 minutes long, a little longer than some of the other videos you've
heard so far but it does cover quite a deal of territory. I ask that it be played.
10

VIDEO OF ABB BEGINS

15 DR MELLIFONT: Do you affirm that the evidence you will give to the Royal
Commission will be the truth, the whole truth and nothing but the truth?

A. Yes.

20 Q. You've made a statement for this hearing. Are the contents of your statement true
and correct to the best of your knowledge and ability?

A. Yes.

25 Q. Can you tell the Royal Commission something about yourself, please?

A. I am a mother of two children, a boy and a girl and I work in IT.

30 Q. Can you tell me about your daughter, please?

A. My daughter is 12 years old. She has Down syndrome. Her speech is limited.
She also has a sensory processing disorder. I decided early on that I wanted my
daughter to have a fully inclusive life in the family, the community and especially at
school. And this year she started high school in a mainstream setting.

35 Q. Does she like going to school?

A. She does. She's usually quite excited to put her uniform on in the morning and
always ready to go on time for school.

40 Q. Your statement speaks of your experience of gatekeeping in the transition to high
school, a reluctance for your daughter to attend; is that correct?

A. Yes.

45 Q. And did this include the principal pointing his finger at your daughter stating
words to the effect that, "unless the school is able to secure enough funding for

a full-time aide, this is not going to work"?

A. Yes.

5 Q. And also suggesting that a special school would be better for her.

A. Yes.

10 Q. Now, in the end, when your daughter did start school there this year, did you feel they weren't ready for her and they had very low expectations of her?

A. Yes, I did.

15 Q. Can you give the Commission an example of how the school's lack of preparation was evident to you?

20 A. Well, there wasn't an Individual Education Plan at the start of the year, even though I had made contact with the school earlier in the year prior starting high school but, in the end, most conversations were around the lack of funding rather than the supports they could provide to my daughter. And then when she started early in the year, it became quite evident that, you know, the work she was getting was just --- I mean, it was mostly colouring activities, very low-level tasks. So it really showed that they didn't have a good understanding of what she could learn and how she could learn.

25

Q. So mainly colouring-in activities?

30 A. Colouring-in activities. One was colouring by numbers and things like this as a maths activity. And when I questioned it, I was told to be patient and wait for the school to settle all the students and then they would address my daughter's learning.

Q. Okay. Were you able to speak directly to her teachers about this?

35 A. No. When I made an attempt, I was stopped and I was told everything had to go through the learning and support team. I did say I was making myself available to teachers whenever they felt that they wanted to talk to me but no classroom teacher has ever made direct contact with me.

40 Q. Does your daughter have an IEP now?

40

45 A. She does now. So we had a meeting on 22 July. There was a meeting arranged just before the COVID crisis but that was cancelled because of that. And then during that meeting I was pushed by the principal but also learning and wellbeing officer and the psychologist to have my daughter re-assessed. She's currently in a --- has been assessed as a moderate intellectual disability. She's had two assessments done and we're pushing for a new assessment to try and get her into the severe category because that would increase the funding for her and would secure the school enough

funding for a full-time aide for the remaining of the year.

I was also asked if we could --- if I could investigate a potential autism diagnosis for her.

5

Q. This push for reassessment to severe category and/or into autism, an autism diagnosis, how did that affect you?

10 A. Well, it's quite upsetting. It's showing that they really don't understand my daughter's disability, but also just trying to paint the worst picture of my child in order to gain funding, as opposed to finding ways to support her.

15 Q. To be clear, you've only just recently got the IEP in place, and that's despite the school knowing that you were enrolling your daughter, and they knew that from the period of --- in 2019?

A. Yes. I made contact with the school in term 1 of 2019 to advise them that she was coming to the school.

20 Q. What happened when the school was closed for attendance during pandemic?

A. Well, that was quite a difficult time for us, especially in the early stages because I felt that my daughter was an afterthought. The first thing that happened was an email from one of the learning and support teachers that indicated that she had not been added to the Google Classroom, which is the platform that all the other students were using. And, instead, I was sent a set of worksheets but those worksheets were, you know, straight downloads and didn't have anything to do with the work --- year 7 work, basically. And so I actually asked that teacher to add my daughter to the Google Classroom so that this, you know, would give me an opportunity to see what work was set by the teachers. But also, what's good about Google Classroom is there is a general chat with all the students and also a private chat directly with teachers. So, yes, I had to actually explicitly ask for that to happen.

35 So some work started to trickle down but it was quite slow. Some of it was really not suitable for her. So I took it upon myself to revise some of the work that was submitted to the whole class just showing to teachers, you know, what kind of activities they could do with my daughter. Some teachers were quite good after that and they started to submit some work that was, you know, aligned to what the other students were doing but there were a couple of teachers that it didn't matter what I submitted, I never got a response from them at all. There was also --- one of the teachers was running live Zoom sessions and the first time that happened, I wasn't aware of it. I don't think it was intentional to leave us out of the session, but it just kind of emphasised again the issue of communication between teachers and myself.

45 I followed up and asked for a list of future dates and times and for the second session I was actually given the wrong time. So we again missed out on the live class session. So, yeah, that was a bit upsetting, again. And then also during that time

I was able to schedule some regular sessions with my daughter's teacher aide. We agreed that we would try to communicate a couple of times a week. The information that I got from her is she wasn't being supported by teachers in terms of, you know, what work she could do with my daughter. So we just took it upon ourselves to
5 decide on some books that she could read to her. And also towards the end, the school --- all the students were learning a song, so as a whole-school choir, so she decided to teach my daughter the song in sign language. There's a group of students, a whole group of students who will be learning it in sign language. That ended up being quite a nice activity to do but it took some time to get there.

10

Q. Did the Google Classroom setting give you some insight into the class curriculum?

A. Yes, absolutely, because I was able to see what work was handed out to the
15 students, to the whole general classroom. So, it was good. It really reaffirmed that there's a real disconnect between my daughter's learning and what happens in the classroom.

I mean, typical things that I see is --- whereas, you know, year 7 students will receive
20 quite mature content, my daughter will receive very cartoonish-style elements and you can tell from some of the material that things, you know, have been downloaded straight from some random, you know, teacher website with no real modification and no real alignment to what the other students are doing.

25 So, in terms of creating a sense of belonging, that's not the best way to go about it. Also, it is just showing the really low expectations they have of my daughter.

Q. How did your daughter cope during this period?

30 A. Well, especially at the start of the shutdown she would often write her name, her friends' names, her teacher's aide's name and she would point at those names and show them to me, as if to say, "Where are these people"? But over time she just started to become inactive and withdrawn and lacked motivation to engage in activities.

35

Q. How did you cope?

A. Well, I think, like most, it was a difficult time being a single parent, having to
40 supervise two children and at the same time as working from home was a big juggling act. But also on top of that, having to modify the work for my daughter just added to the pressure and that made it quite difficult to support everyone at home. Yeah, it was quite a stressful time.

Q. Hard on you and both of the kids?

45

A. Yes. Definitely.

Q. You also had ---

A. --- (overspeaking) --- was very difficult.

5 Q. You also had the worry, of course, of your family being in Europe, also going through the pandemic?

A. Yes, absolutely. So, I'm here in Australia by myself with all my relatives back home.

10

Q. Is your daughter back at school now?

A. Yes, she is. She's back at school.

15 Q. Now, in the first three weeks, you had to manage her travel to and from school while you were working out the NDIS budget which for you and your daughter is a self-managed budget and you obviously didn't want her travelling on public transport. What were your challenges there?

20 A. So the challenge was the announcement that was made by the Premier that we would have this, kind of, going back to school, this staggered going back to school over a five-week period of time starting with one day, two days, and increasing that time. I decided early on I wasn't going to bother with one or two days a week. That would be more disruptive than helpful to us, but then she made an announcement
25 very quickly that students were to go back full time. So that did not give me the time to get reorganised for transport to and from school. So I had to take some time off work to do that myself. So I worked reduced hours and also I wasn't really keen on my daughter travelling on public transport.

30 Obviously she has health vulnerabilities to the virus so that was a big consideration for us. So finding new support workers who were able to use their own vehicle and were willing to work really short shifts, that proved to be quite difficult. It took about three weeks to put those supports back in place for my daughter.

35 Q. Okay. And what about hiring somebody to do the pick-up and staying with your daughter whilst you were at work. Was that an option for you?

A. Well, I have to juggle our NDIS budget. So I had --- because we were never
40 fully funded for that to happen. So at the start of the year my daughter was being picked up by a support worker and dropped off at an after-school care centre in a primary school setting, which was not ideal, being a high school student. But, financially, that's all I could afford. At the time our NDIS budget came through, I knew we didn't have enough money, but I didn't have the energy because I was going through the transition to high school at the same time so didn't have the energy to
45 apply for a review at that time. I thought we'd just make do. But that was another thing to deal with.

Q. Now that school is back, is the online platform continuing?

A. No. The teachers have discontinued using that platform.

5 Q. Is that a problem for you in any respect?

A. Well, it's taken away that ability, that transparency in terms of the learning that occurs in the classroom for the other students. So I'm not really able to see what, you know, what work and if the work my daughter receives aligns with the work of other
10 students.

Q. Okay. And through that Google Classroom setting, during that time you were able to have direct contact with the teachers using that platform; are you able to have direct contact now?

15

A. No.

Q. Can I ask you, do you have any final comments you would like to make about education?

20

A. Well, I think one of the biggest issues was the obvious lack of preparation in terms of supporting my daughter's learning, especially during the COVID shutdown. I think at the core of this there is some deeply rooted ableism where there is a view that students with disability are an add-on, a burden, that they belong somewhere
25 else. It's pretty evident that my daughter is not a full member of her classroom. I mean, during the shutdown, she had zero contact with any of her peers. And I think this should be turned around and that students with disabilities should be made a priority rather than an afterthought.

30 I think it would be good to see some kind of independent national board as well that could advise educational jurisdictions on inclusion, including especially in times of crisis like this pandemic, really.

Q. When your daughter is included, what do you observe?

35

A. It's usually great to see how she becomes more confident and more independent, seeing a sense of pride on her face as well. Little achievements for her are huge achievements for her. So when this happens, it's actually really quite amazing to see her experience success like this.

40

Q. Okay. Thank you very much for your time. Thank you.

VIDEO OF ABB CONCLUDES

45

DR MELLIFONT: Commissioners, can I just observe that with respect to the

captioning, at one point it read colouring activity as a "mass" activity, it should have said "maths", short for mathematics.

5 Ms Sayers, ABB speaks of the fact that an Individual Education Plan wasn't in place for her daughter prior to the pandemic contributing to educational difficulties during the pandemic. Is that an issue which has been emerging for your stakeholders?

10 A. Yes. And before answering that question I would like to acknowledge the testimony of ABB because, sadly, this is a story we hear over and over again. And our education survey that we will talk about, which we completed during the pandemic, found that only 9 per cent of our survey respondents had their Individual Education Plan updated during the pandemic. But many said IEPs are not effective at promoting inclusive education even before the pandemic.

15 Q. All right. ABB speaks of her daughter at first being excluded from the Google Classroom setting it, in effect, being presumed that her daughter wouldn't or couldn't participate in such an online forum. Is that an issue which you have seen emerge during the pandemic?

20 A. Sadly we also have heard this time and time again. We heard stories like ABB's where everyone else needed to be set up in the class before the student with disability was, and this led to social isolation and disconnection from their peers.

25 Q. And what of her observation that once her daughter was included, that modified work that aligned to the class wasn't provided for her daughter?

30 A. Again, this sadly is not a surprise for us. We heard stories of really low expectations. Things like worksheets being sent home, like wash the car, clean your room, do the dishes. That is not modifying the Australian curriculum and differentiating it for students with disability.

35 We also heard the opposite, that complicated work was sent home and that was not modified and that work was left for the student to try and work it out for themselves. We know the disability standards for education, which sit under the *Disability Discrimination Act* put an onus on schools to reasonably adjust and differentiate the curriculum for students with disability. Clearly this did not happen for many during the pandemic.

40 Q. In July 2020, CYDA published a report entitled "Not even remotely fair: experience of students with disability during COVID". And that reported on the results of a survey over seven weeks, across April to June 2020 in respect of which there were over 700 responses, plus over 1,100 text comments; that is all correct?

45 A. Yes, and also included Catherine Smith from the University of Melbourne who helped analyse that data.

Q. Okay, together with Professor Dickinson, Dr Yates and Professor Bertuol?

A. That's correct.

Q. What are some of the key findings of the analysis?

5

A. One of the major findings was that 72 per cent of students with disability were more socially isolated than their classmates, such as we've heard today, being excluded from working with their peers or not being included in Zoom or virtual classrooms. There was also the significant reduction in the usual supports provided for students with disability, most notably, supervision, social supports and individual support workers.

10

So, 61 per cent of surveyed respondents said that students with disability had not received adequate educational support during the pandemic. Worryingly, more than half had not had regular contact from their education provider to ensure that the learning was accessible. And many felt, as we mentioned before, that individual education plans were not operating well before the pandemic and modifications were not being made to support remote learning.

15

On a different tack, NDIS needs changed for many of the participants during the pandemic, but these changes were not met. Some families hadn't requested changes. As they said to us, they didn't have capacity for that battle and they didn't have the time or energy required to navigate a plan review.

20

Others applied for a plan review and this was not provided, and only 5 per cent had requested a plan review that had been approved.

25

Q. So both of the surveys showed that around half of children with disability in their families reported experiencing a decline in mental health?

30

A. Yes, that is correct. And research from the disaster literature tells us that children and young people are more likely to experience trauma during disasters and that this impacts on their mental health. So these results are not surprising given the existing educational inequality that students with disability already face, which was exacerbated by the pandemic.

35

Q. You are aware that the March 2020 OECD framework, and OECD is of course the Organisation for Economic Cooperation and Development, they had a framework to guide an education response to the COVID-19 pandemic and it noted that absent an intentional and effective education response, the COVID-19 pandemic is likely to generate the greatest disruption in educational opportunity worldwide in a generation. You are aware of that observation?

40

A. Yes.

45

Q. So here in Australia the Australian Coalition for Inclusive Education, of which you are the Chair and Co-convenor, developed a paper entitled "Principles and

Recommendations for Providing Inclusive Education for Children and Young People with Disability in a Time of Crisis", adapted for students, that is adapting the OECD paper to Australian students with disability, and the Coalition also convened a roundtable on 20 May 2020 with Federal, State and Territory Government representatives, unions and educations and others. That is all correct?

A. That's correct.

Q. And the aim of that paper was to provide advice about what needed to occur to prevent disadvantage to students with disability during the pandemic. Is that correct?

A. Look, that's correct. We, as a collective of disability advocacy organisations working for children and young people with disability, we were really concerned about the early impacts that we were seeing and the seeming absence of planning by governments across Australia for students with disability.

Q. Ms Sayers, I will remind you to slow down a little.

I take it from the results of those two surveys we spoke of earlier, and other information which has been coming to the Coalition and to CYDA, is that the disadvantages you were hoping to avoid have in fact been experienced by some students with disability?

A. Yes. And I would say that it is more than "some students with disability", but a large proportion of students with disability, based on our research.

Q. Have you and your work with CYDA and the Coalition identified what you believe to be some of the key drivers of these disadvantages?

A. Yes. And I think the overarching driver is a lack of planning, an absolute absence of pandemic planning for the needs of children and young people with disability.

Q. I ask you to pause for a moment. We can barely hear you. So it might be at our end, and if it is, we'll get it turned up. I will get you to continue and again just slow down a little. Thanks.

A. Thank you. So, as I said before, the absolute lack of planning across State and Territory Governments for children and young people with disability and the Australian Government.

The ableist attitudes were informing the public narrative and we heard this from our leaders. The need to eradicate this narrative of placing the blame on the individual student with disability and their family and their inability to cope with the remote learning situation, but rather we need a refocus to ensure that Government provides students with disability and their family supports so that their human rights can be upheld.

5 We need that focus of a move away from the deficit to the focus on ability and human rights. The findings from our research show that when students with disability were provided with the right supports, they can access remote learning in an equitable way.

10 So our survey shows that supports were withdrawn from schools throughout the pandemic. Curriculum modification, social inclusion support, support workers and much more. So, as a result, students were therefore made to feel that they are not part of the learning community and when supports were dropped, students were not able to engage in learning.

15 One of the really important findings from the research was the importance of social support to help ameliorate these negative findings. Social inclusion creates educational inclusion.

20 Q. You've also learned of circumstances or cases where students were provided with good supports, were provided with accessible information, were provided with modified curriculum, that they actually did really well during the pandemic; is that correct?

25 A. Absolutely. And the key finding from the research was if schools could do one thing during the pandemic, it is to actually ensure the inclusion of students with disability with their peers to make them feel part of that learning community, and then all those other supports that followed. So when that happened, students did really well.

30 Q. Moving to the topic of involving children and young people with disability in emergency planning. Currently CYDA is partnering with the University of Melbourne on a project entitled "Disaster Recovery for People with Disability across the Life Span: a scope and review", the intention of which is to conduct a rapid review of the literature regarding disaster recovery experience and the needs of people with disability looking at needs across age groups and life stages; is that correct?

35 A. That's correct.

40 Q. Some research into the Christchurch earthquake on the impact of disasters on children and young people with disabilities indicated that while children with disability are often seen as passive victims in disasters, they show good understanding of natural hazards and self-protective actions for disasters; that is your understanding of that research?

45 A. Absolutely. And the research shows that it is an absolute must at all levels. It needs to happen at the school level, at the regional level, and at the State and Territory level.

Q. When you say "it must happen", you are talking about participation in disaster reduction initiatives by that cohort; that is correct?

5 A. Absolutely. And the research from Christchurch found that children and young people are often excluded from disaster risk and recovery and that good disaster responses can only be made when children and young people with disability inform those responses and representative organisations like CYDA needed to be included as we bring the voices of our over 5,000 members.

10 Q. CYDA was asked to join the Department of Education skills and employment --- Education and Employment Sector Pandemic Preparedness Committee --- quite a mouthful --- on 2 April 2020. Some seven weeks into the operation of the Committee; is that correct?

15 A. That's correct.

Q. That Committee was tasked with considering issues regarding all students; correct?

20 A. Yes.

Q. It wasn't specific to students with disability; is that correct?

25 A. Yes. And we really tried to amplify the voices of students with disability but we really struggled in that forum. We were asking questions like, what is the impact as schools start going back from remote learning? Are more students with disability being self-isolating and not returning to school? And we found it very difficult to get any information or data from either the Commonwealth or State and Territory jurisdictions.

30 Q. That particular Committee ceased its operation on 24 June 2020; is that your understanding?

35 A. That's correct. And we were really concerned and provided our concerns because at that stage we knew many states still had active COVID cases, particularly Victoria. So we were quite concerned that it was packing up, it seemed, prematurely.

40 Q. It is your current understanding that there is no national Government-led coordinating committee considering the needs of students with disability during the pandemic? Is that your understanding?

A. That's correct.

45 Q. And obviously that is a concern to you for the reasons you've just expressed; correct?

A. Yes, and particularly when we are seeing such significant impacts for students

with disability. We're also seeing a non-compliance with the disability stance for education, but we also need to plan for the long-term impacts, and we are worried that some students with disability may have disengaged completely from education while we know that this situation is not going to resolve until there is a vaccine or treatment.

5
10
15
Q. Right. I wonder if we can move to the topic of increased risk to children. Your statement speaks of a body of research indicating that family violence rates are increasing in Australia and internationally and the Commissioners have heard something of that already this week. And your statement speaks about research indicating that in times where children are likely to be spending significantly more time at home than usual, the risk of domestic violence to them increases exponentially; that is your understanding of the research, referred to in your statement?

A. Yes. And we know that children and young people with disability are already currently overrepresented in child protection systems in Australia.

20
Q. And you are concerned about the sufficiency of pandemic planning, which has specifically considered that risk?

A. Yes. We're not aware of anything specific that has happened, but we also know that there is large safeguarding gaps for children and young people with disability with fragmented responses and responsibilities that sit across the NDIS Quality and Safeguarding Commission and State and Territory-based protections.

25
30
Q. I'm just moving to the last of my questions. You spoke earlier of convening a roundtable on 20 May 2020. That is the National Inclusive Education roundtable. That work was done without funding; is that correct?

A. That is correct.

35
Q. Why did you consider it necessary to organise that roundtable with Government and others?

A. Look, we perceived a large gap in leadership from governments to address the needs of students with disability over the period of the pandemic till that date. We were deeply concerned that as a group of advocacy organisations, we had to do that work on top of our existing commitments and without funding, but we needed to make sure that the needs of students with disability are at the forefront of emergency planning and response. Sadly this goes to show us how far we have to go to ensure the needs of children and young people with disability are at the forefront of emergency planning and response.

40
45
Q. Thank you, Ms Sayers. Before I hand to the Commissioners to see if they have any questions, may I just express the Commission's gratitude to Maeve Kennedy and Tasha Ritchie of CYDA for their assistance in facilitating the pre-recorded evidence

of witness ABB and Mr Chan.

Commissioner?

5 COMMISSIONER SACKVILLE: Thanks, Dr Mellifont.

QUESTIONS BY THE COMMISSION

10

COMMISSIONER BENNETT: Hi, Mary, thank you for your evidence.

15 We have heard from a number of witnesses about thinking about what is termed "recovery". You mention it in paragraph 123 of your submission. I'm wondering where is your survey --- the members, what are they thinking needs to be put in place for what you would phrase "the recovery stage of education for children with disability coming out of the pandemic"?

20 A. Any recovery to the pandemic cannot be seen in isolation of the existing inequality that students with disability face in their education. Year on year we complete education surveys that tell us the same story, the lack of inclusion, the individual education plans not working, suspension, bullying, restrictive practices, we need to go back in the recovery to a different world for students with disability, not back to the same world, and that can only be done if we tackle the underlying
25 inequality that students with disability face in their education.

COMMISSIONER BENNETT: That would also, I assume, mean that you would want for each individual child a very good, almost a base level so that you can look back at what has been lost and what needs to be done to move into a forward space;
30 would that be right?

35 A. Absolutely. And we need to do the research. We need to look at the research about what experiences have happened, what has been the impact of that disconnection, as we heard from witness ABB, and how is that going to have a long-term impact on children with disability, knowing that, as we heard from Tim, the experience of trauma that children and young people with disability are facing at this time cannot be underestimated, which is why as an advocacy organisation we've been working so hard to partner with the academics to really look at how can we build the evidence and, as a minimum, we would like every State and Territory
40 Government to really form a committee that can look at this huge shock in the system that has happened for students with disability and plan for how the recovery can be made. It's not too late to do that given we know that this was such an enormous shock in the lives of children and young people with disability.

45 COMMISSIONER BENNETT: Thank you.

COMMISSIONER SACKVILLE: Commissioner Galbally?

5 COMMISSIONER GALBALLY: Ms Sayers, in your witness statement you refer to concern that children and young people were omitted from the advisory mechanism, the one national one that was set up, and we heard from Ms Kayess that she thought there weren't sufficient representatives of disability organisations on that advisory committee, but it seems a real omission for that whole cohort of children and young people to not be formally at that table. Can you comment on that and elaborate a bit?

10 A. Yes, the UN Convention on the Rights of Persons with Disabilities talks about the importance of representative organisations like CYDA to actually give voice to the experiences. One of the concerns that we have is in disability spaces the needs of children and young people with disability often get lost and then in children and young people's policy spaces the needs of children and young people with disability get lost again.

15 That's no criticism of the involvement of adults with disability in those processes, but it's not an either/or. It is an absolute essential that children and young people --- and to date there has been a complete absence of visibility of children and young people with disability in all of the national pandemic planning.

20 COMMISSIONER GALBALLY: Thank you.

25 COMMISSIONER SACKVILLE: Yes, thank you very much, Ms Sayers for your statement and coming to give evidence. We very much appreciate your contribution to the work of the Royal Commission. Thank you.

A. Thank you.

30 **THE WITNESS WITHDREW**

DR MELLIFONT: Might we now adjourn until 4 o'clock and you will return with Ms Eastman at that stage.

35 COMMISSIONER SACKVILLE: Yes, thank you. We shall adjourn for 15 minutes. Thank you.

40 **ADJOURNED** [3.45 PM]

RESUMED [4.01 PM]

45 COMMISSIONER SACKVILLE: Yes, Ms Eastman.

MS EASTMAN: Commissioners, we have now a witness from Geneva, the UN's Special Rapporteur for people with disabilities, Ms Catalina Devandas.

5 COMMISSIONER SACKVILLE: Good morning in Geneva, from Sydney and from also Melbourne. Thank you so much for joining us this afternoon here and this morning in Geneva. We very much appreciate your time.

10 May I indicate the Commissioners who are sitting on this hearing of the Royal Commission. I have with me Commissioner Barbara Bennett who is sitting with me in Sydney and Commissioner Rhonda Galbally is locked down in isolation in Melbourne along with just about everyone else in Melbourne. She is joining us by video-link, as are you. So far the videos have been working very well so we hope there will be no disruption.

15 I will now ask Ms Eastman to ask you some questions but firstly, if you wouldn't mind following the instructions of my associate for the affirmation.

20 **CATALINA DEVANDAS AGUILAR, AFFIRMED**

EXAMINATION BY MS EASTMAN SC

25 MS EASTMAN: Good morning. You are Catalina Devandas Aguilar?

A. Yes, I am.

30 Q. And are you the United Nations Special Rapporteur on the rights of persons with disabilities?

A. Yes.

35 Q. And you are joining us from the UN offices in Geneva in Switzerland?

A. I'm joining you from my house in Geneva in Switzerland.

40 Q. You've made a statement for the Royal Commission dated 10 August 2020. It includes a number of documents identified in the statement. Are the contents of your statements true and correct?

A. Yes, they are.

45 Q. The first thing I want to deal with is the role of a Special Rapporteur. Many people following the Royal Commission proceedings will know or have heard of a Special Rapporteur, but there are very many people who do not know what a Special Rapporteur is. Can you tell us about the role of a UN Special Rapporteur?

A. Yes. I am an independent human rights expert with a mandate from the United Nations Human Rights Council to report and advise on the implementation of the rights of persons with disabilities globally.

5

Q. And you are the first Special Rapporteur appointed to deal with the thematic issue of the rights of persons with disabilities?

A. Yes, I am.

10

Q. And you've held that position since December 2014?

A. Yes.

15 Q. What are the specific aspects of your mandate as the Special Rapporteur on the rights of persons with disabilities?

A. Well, as a mandate holder I have to develop regular dialogue with the different stakeholders, including States and representative organisations of persons with disabilities and I do this to identify, change and promote good practices on the rights of persons with disabilities.

20

I also receive and exchange information on violations of the rights of our community. I do make recommendations on how to promote and protect the rights of persons with disabilities. Also I provide technical assistance, particularly to States for the effective implementation of the Convention on the Rights of Persons with Disabilities, and I also cooperate with the broader human rights system at the UN, with the UN entities as well, to promote disability, mainstreaming and inclusion in their work, and I also have to integrate a gender perspective through the work of the mandate.

30

If I may add, in discharge of all these functions I have to act on information submitted to me regarding the alleged human rights violations and I do that by sending letters of allegations to concerned States in order to clarify or bring this information to their attention. I also conduct official country visits upon the invitation of a State to assess the situation of persons with disabilities and the rights in that given country. And I also report annually to the Human Rights Council and to the General Assembly of the UN.

35

40 Q. And is the Convention on the Rights of People with Disabilities relevant to your work?

A. Yes, it is. I am bound in general by the international human rights framework, but in particular I am bound by the Convention on the Rights of Persons with Disabilities. That guides all my work as Special Rapporteur. As I said, I support the States in implementing the treaty, especially in areas that are innovative, or where innovative introductions of the Convention.

45

Q. Yesterday the Royal Commission heard some evidence from Rosemary Kayess, the Vice Chair of the UN Committee on the Rights of People with Disabilities, and we asked her some questions about the operation of Article 11 of the Convention.
5 And you've said in your statement:

In conflict and emergency situations, persons with disabilities are often among the most adversely affected, sustaining disproportionately higher rates of morbidity and mortality.

10 You made this observation in your statement in the context of Article 11 of the Convention. Looking at the text of Article 11, and translating those rights into a practical perspective, can I ask you what, for you and your work, has been the practical perspective on the operation of Article 11?

15 A. Article 11 obliges the State Parties to take all necessary measures to guarantee the protection and safety of persons with disabilities in situations of risk, including, of course, humanitarian emergencies, natural disasters, and the current situation that we are facing. It is key, of course, to ensure that all national and local coordination
20 mechanisms also, as well as the preparedness and response plans to pandemics like the COVID-19 are inclusive of persons with disabilities and consider their rights.

It is important to remember that Article 11 cannot be read into a vacuum and that we need to read it in context with the whole Convention, including Article 5 on equality
25 and discrimination, so that persons with disabilities are not discriminated in the broader responses to emergencies.

Q. In your statement, looking at the planning and response to emergencies, you've said:

30 *.... policy development in relation to planning for and responding to emergencies should move away from the charitable and medical approaches, towards a human rights-based approach.*

35 Can I ask you, with respect to charitable and medical approaches in the context of planning and responding to emergencies, what are those approaches and why is it important to move away from them to a human rights-based approach?

40 A. Thank you. This is a very important question.

Prior to the human rights-based approach that has informed the Convention on the Rights on Persons with Disabilities, our groups were considered merely as recipients of charity protection treatment. That has changed with the Convention in the way that the treaty and the human rights-based approach consider persons with disabilities
45 as right holders, rather than as receivers of this care or protection in strong contradiction with what the charity or medical approach is, which focus on the impairment, perceive that the reality of persons with disabilities is only around their

impairment, that their needs are not going to be covered by the public policy, but that there are private burdens that should be covered either by charity or just focusing on their impairment.

5 So the charitable or medical approach focus basically on the impairments of the individual and their deficits and on the need to have those impairments fixed or cured. They don't see, or they see the challenges a person with disability face is because of the fault of the impairment, so it is an individual problem. In contrast, the social model, and the human rights-based model have focussed on how the barriers
10 that we have, the social barriers, the structural barriers, the lack of accessibility, are what cause the challenges of persons with disabilities to enjoy their rights.

The human-rights based approach also calls on societies to embrace diversity. So instead of trying to fix or correct persons with disabilities, to embrace their diversity
15 and to challenge what I think is the root cause of the main human rights violations of persons with disabilities, to challenge ableism, which is this perception or the value system that considers persons with disabilities and their experiences are less valuable.

20 Q. And you've said in this same paragraph that:

Persons with disabilities must be placed at the centre of all policy responses as agents and beneficiaries

25 So, can I ask you about this approach in terms of being at the centre of policy responses, but also what you mean by both "agents" and "beneficiaries"?

A. Of course nothing can be done without persons with disabilities and this is central to the CRPD. When I said that they must participate as agents and beneficiaries it
30 means they have to participate in the planning and implementation of all emergency responses— participate in a meaningful way, and they should also benefit from all the measures of the responses. Disability-inclusive responses and policies are critical to enable persons with disabilities to benefit and to participate on an equal basis with others, and particularly in emergency planning and response processes in those cases.

35 Their participation will enable further inclusion to make sure that they will not be left behind. This is something that is fundamental and that unfortunately we have been seeing in the COVID responses around the world that persons with disabilities were left behind. But in any case, what I meant was that persons with disabilities need to
40 be placed, and their organisations, this is important, they must participate in all the cycles of policy-making.

Q. Can I turn to COVID-19 and in your statement you've told the Royal
45 Commission that the COVID-19 pandemic is revealing and deepening pre-existing inequalities and exposing structural discrimination and exclusion experienced by people with disabilities.

I want to ask you about a few of the areas that you have identified in your statement. The first one is health. So in relation to these issues of inequality, structural discrimination or exclusion, in the COVID-19 pandemic, what has been the impact in the area of health?

5

A. Thank you. I do understand that the Commissioners have been hearing about the experiences of persons with disabilities with regard to COVID and what I've heard when it comes to the right to health or the impact on the health of persons with disabilities is that of course so far our community is experiencing greater risk of contracting and developing more severe symptoms, even dying from the virus and this, of course, is due to the barriers, barriers to implementing basic hygiene measures, such as hand washing when water and sanitation facilities are not accessible for persons with disabilities, difficulty in adhering to social distancing because of, for instance, the support needs that a person may have or because of institutionalisation. That has been another big issue. Also the need to touch things or obtain information from the environment. For example, when it comes to braille or public buildings or for physical support, and also because of barriers to accessing public health information we still see that unfortunately many Deaf people are not getting the information that they need because information is not made accessible in sign language or for persons with intellectual disabilities without access to information in Easy to Read or other relative formats.

So the risk that also persons with disabilities may have to their underlying health conditions is exponentially bigger due to these structural barriers on accessing health care and not to mention, of course, the important, and this perhaps is the final point, the strong discrimination that persons with disabilities have faced, even in very developed countries, when it came to the access to emergency health services, and this relates to the protocols on triage that denied access to persons with disabilities with regard to their quality of life assessments.

30

That is something of course that was reviewed in many cases by States, but was a grave and very, I think, important way to exemplify the structural barriers that persons with disabilities face, being denied access to ventilators or even to the emergency room.

35

Q. What about the area of education and other essential services?

A. Well, in the area of education --- in general persons with disabilities are disadvantaged by the socio-economic consequences of the COVID pandemic and by the responses that have emerged. In the area of education, for instance, pupils with disabilities were the least likely to benefit from distance learning solutions such as online learning and this is particularly important for those with intellectual disabilities. Support was not in place to accommodate the needs of these students. They face important barriers. One is the inaccessibility of the remote or distance learning systems, the lack of support, barriers in accessing the internet, inaccessible software and learning materials.

45

There is currently an increased risk that all the students with disabilities that are not attending school because of the lockdown will be excluded from education in the coming months and the gap will increase and, of course, this might heighten the risk of these students to be in segregated education or all the things that I mentioned before are also more likely to happen for students that are in segregated education settings that are against, of course, the Convention.

In the area of employment, for instance, persons with disabilities are more likely to lose their jobs. They experience greater difficulties in returning to work, and also have reduced access to social insurance. And this is important because it also affects the level of coverage benefits that you can receive from the social protection systems.

One big issue has been the disruption of services for persons with disabilities, including support services. What we have identified is that the support systems in many countries are very informal and because of that, services and supports such as personal assistants or sign language or psychosocial support were completely disrupted during confinement, leaving persons with disabilities in a very difficult situation.

Q. You've also expressed concern about people with disability in institutional settings. What concerns have come to your attention?

A. Well, the situation in institutions is one of the gravest, I think, outcomes of the pandemic. This is where it has been shown the levels of inequality and discrimination of persons with disabilities and how segregation is a grave source of discrimination that we need to stop. We require urgent efforts to end institutionalisation because despite their size, their names, their set-up, these institutions have some characteristics such as the small-group homes or social care homes in which persons with disabilities have to mandatorily share assistance with others, so limiting the possibility to have distance and also limiting their possibility of deciding who and how will provide this assistance. They are, of course, places of isolation, segregation, where they don't have control over the day-to-day decisions. They don't have control of with whom they like to live. They have routines, there is a paternalistic approach in service provision.

So in the context of COVID, the problem is that when persons with disabilities are detained in these facilities under the presumption of having an impairment or not being able to manage daily activities, or because they may need support to live in the community and that support is not being provided. So the problem with that is, of course, persons with disabilities were locked in places where they were more vulnerable to get the infection.

I want to extend that institutionalisation itself is also linked to the denial of basic rights, such as the legal capacity that needs to be revised because of the Convention on the Rights of Persons with Disabilities has already given back, or gave back the rights and legal capacity, full recognition of legal capacity to persons with

disabilities, but also because these institutions, even if they are nursing homes or psychiatric facilities where persons with disabilities are often sent or institutionalised, have become the hotspots of the pandemic. And we cannot deny the level or numbers of fatalities and infection rates in these places all around the world. Europe has been a big show case of this and it is quite worrisome. We have started a process to identify how and why this happened, but also what are the policy responses to avoid that from happening again because we have left persons with disabilities in traps.

10 Q. In your statement you also express concern about children, women and girls with disabilities being disproportionately at risk of gender-based violence, exploitation and abuse due to confinement measures. Why has this come to your attention as a matter of concern?

15 A. Well, this is important because of course the intersections between gender and disability need to be highlighted. Many women with disabilities are being forced to lock down at home with their abusers at the same time as services to support survivors are being disrupted or made inaccessible, right. So women with disabilities already face important challenges and the pandemic has exacerbated them.

20 We do think that during the lockdowns the shelter places become also --- I'm sorry, the shelter in place measures come with heightened risk of children witnessing or suffering violence and abuse because of the domestic violence that can happen in lockdowns. Also because there is violence by caregivers that lots of children
25 experience, and this is in the case of children, they are rarely in the position to report acts of violence, especially when there is no social care supervision or the children are locked down with only their caregiver. Yet at the time of increased needs, children no longer have the same access to, for instance, their teachers, to report abuses at home. Special police, such as social work and health workers, that are the
30 first responders, are overwhelmed with the crisis and they have changed priorities and are otherwise unable to help.

Also, civil society groups and other support groups that could help these children, or the women also, are affected by the lockdown or by the reallocation of resources.
35 Shelters might be full to address the needs of people that are homeless. So we have to close or have been --- these centres have been repurposed as health centres. So the disruption of services is quite evident in the case of violence.

40 Q. I wanted to move now to disability-inclusive approaches. On 15 April you expressed your concerns about the impact on people with disabilities in a letter that you published. And you said --- we might put the letter up on the screen, the document number is EXP.0027.0001.1384.

45 So, a few paragraphs into the letter you say, just after the middle of the page:

At this critical time, it is imperative to guarantee that all COVID-19 responses are disability-inclusive. This requires our joint efforts more than ever, guided

by a human rights-based approach, in strong consultation with persons with disabilities and their respective organisations.

5 I have that up on screen. And you say that you have worked with the World Health
Organization and other United Nations entities and organisations of persons with
disabilities to develop two practical guidance documents to address the rights of
persons with disabilities in the context of national responses to COVID-19. Then if
you go down a little more, there are two references, the first is to the World Health
10 Organisation disability considerations during the COVID-19, and the second is to the
disability-inclusive social protection response to COVID-19 crisis.

15 So, could I ask you, what was the reason to have to publish this letter in mid-April
this year? And then can I invite you to tell us about these practical guidance
mechanisms, the World Health Organisation and the disability-inclusive social
protection response?

20 A. Yes, thank you. The pandemic caught us unprepared, and I think that is
an understatement. In most cases what we were seeing was that the State responses
to COVID-19 were neither accessible nor inclusive of persons with disabilities. So
what we started witnessing was the lack of mainstreaming of disability in the target
actions, barriers on accessing public information and essential services; as I
mentioned before, the disruption of support services; how persons with disabilities in
general were an afterthought in the State responses to the pandemic; they were not
engaged in the decisions for persons with disabilities or their organisations and that
25 contributed to their further exclusion.

30 So my letter was important and was necessary to support the efforts for building
disability-inclusive COVID responses. Also because I saw it as a way of calling the
attention of States into a situation that perhaps was going --- that they were not aware
of the specific challenges that persons with disabilities were facing. Also, to give
them concrete ideas on how to make their responses inclusive. I think that when
everybody was dealing with so many priorities, it was important to be very concrete
and to be able to provide guidance on how to do it, what were the precise
interventions that were needed to avoid the situations that were being faced by
35 persons with disabilities in an effective way.

40 So, as you mention, we worked with the WHO to make sure that their considerations
on COVID-19 and persons with disabilities were issued and were issued under
a strong human rights-based approach. We included provisions about the triage, the
discrimination on the provision of health services but also about broader
consideration as to why persons with disabilities needed more guidance and
protocols to protect themselves and how to protect them from contracting the
infection.

45 We worked on the social protection guidelines also to make sure that the system
providing support and providing services and benefits for the general population
could include specific considerations for persons with disabilities or in the responses
and b

enefits that were being allocated, the needs of persons with disabilities to support, to have access to even food, were going to be taken into account.

5 I recommended to ensure the mainstreaming of the disability perspective in all
COVID-19 response and recovery, together of course with targeted actions --- and
this does in no way mean that when we talk about the twin-track approach, this does
not mean that we have a general response and then we have a segregated response for
persons with disabilities. In our case we are talking about making sure that the
10 mainstream responses include persons with disabilities in the first place and what is
needed is specific efforts within the bigger efforts will be devoted to cover or to talk
up the needs of persons with disabilities.

Also, of course, I recommended to ensure accessibility, accessibility of information,
15 facilities, services and programs in all of these COVID response and recovery. The
third point was also to ensure meaningful consultation and active participation of the
organisations of persons with disabilities in all stages of the pandemic response and
recovery and to establish accountability mechanisms to ensure that disability
inclusion in the COVID response is happening because if we don't measure how
20 persons with disabilities are being impacted from the pandemic, we are not going to
be able to measure how our policies are correct in the situation. So we really need to
be looking at what are we doing, what are the policies that we are trying to
incorporate to address the challenges persons with disabilities are facing, but also to
make sure that then we measure how these policies are actually benefitting or not
25 persons with disabilities, to be able to correct. And this I think is a fundamental part.

We also --- and I end with that --- contributed to the drafting of the
Secretary-General's policy brief on the situation of persons with disabilities and
COVID.

30 Q. Just while are you on the topic of measuring and evaluating, in your statement at
paragraph 32 you talk about the importance of measuring to help understand and
prepare for any future emergencies and disasters. And you say, in doing so,
providing data to inform how policies and responses are developed for the future is
important. Have you seen any practices internationally in terms of collecting data,
35 and how, if there has been any data collection, it has been used to examine the
COVID response to date for people with disabilities?

A. As I said, this is fundamental. Things are happening as we are speaking.
40 Countries are moving in the right direction. I have to say I see a global trend on that.
We see France, Peru and Spain that have introduced exceptions to confinement
measures, for instance for persons with disabilities. We've seen in your neighbour
New Zealand that the Ministry of Health provides accessible information, including
sign language. So we are seeing that all around the world --- Papua New Guinea also
45 is working with the UN system to improve counselling and gender-based violence
support in the context of COVID-19.

We are still lacking concrete examples of how this is being measured. And this is

why I wanted to stress that, although there is a response in saying, "Yes, we acknowledge that persons with disabilities need support, require support, and that we overlooked that support, that persons with disabilities have been an afterthought", I still haven't seen a very solid accountability mechanism or data collection on how we are actually correcting the situation and moving forward with a better system. And this is, I believe, fundamental to achieve success and to be prepared for the future. We have to make sure that we are learning from our mistakes and we'll never do this again to persons with disabilities.

5
10 Q. My final question --- and the Commissioners may have some questions --- is to ask you about looking forward. What should the community and governments do when we move out of the emergency or acute phase into recovery? What approaches should be taken to include people with disabilities in the planning and the policy response?

15 A. Thank you for that. And I believe that for me will be --- we need to look deeply at the Convention on the Rights of Persons with Disabilities. The Convention brings a complete paradigm shift in the way in which we should address the rights of persons with disabilities, the needs of persons with disabilities. We need to make
20 sure that whatever is being done at the level of public policy, it is done under a human rights framework. That is the only way in which the efforts are going to be sustainable, the efforts are going to be adequate and, more importantly, the efforts are not going to discriminate against persons with disabilities.

25 Because what the COVID has shown us is that the lack of a strong human rights-based framework to support the needs of persons with disabilities has resulted in inadequate responses when there are responses, or in the lack of responses or, even worse, in the discrimination and direct damage to persons with disabilities, like in the case of the triage policies or protocol. We need to bring back persons with
30 disabilities to the centre of the conversation, as the Convention asks us to do, to give them back their full citizenship, their full possibility of expressing their opinions and have legal impact of their opinions, to stop segregation, to make sure that we listen to their opinions directly and through the organisations of persons with disabilities. To stop segregation, services need to be provided for persons with disabilities on
35 an equal basis with others. And we need to work to make sure that the support that is needed, so that persons with disabilities can participate on an equal basis with others, is provided in the community, it is provided in the community and is of high quality.

40 Just yesterday I had this discussion with someone that said, "If you just do that, persons with disabilities are going to be unattended or neglected." Of course, this is never the aim. We should make sure that all the services are inclusive and of quality for persons with disabilities and, where needed, specific supports should be provided for persons with disabilities. And this is all what the Convention on the Rights of Persons with Disabilities is calling us to do.

45 We would not have to deal with many of the challenges that we are facing today, for instance in the area of education, if children were in the same school system; when

you have diverse school systems then it makes it harder for policy makers to know what to make in cases of emergency. And these minority, the segregated schools might just fall off the tracks, not being able to think and provide the support that children with disabilities need, as any other child.

5

So my recommendation is for the States to look closer at the Convention, to look at all the components of the Convention because of course everything is interdependent and we will not be able to succeed completely unless we look at it in a united way. I stop. I thank you very much for the opportunity and look forward to see or hear if the Commissioners have further questions.

10

MS EASTMAN: Thank you. Commissioners?

COMMISSIONER SACKVILLE: Commissioner Bennett?

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COMMISSIONER BENNETT: No questions, thank you.

COMMISSIONER SACKVILLE: Commissioner Galbally?

20

QUESTIONS BY THE COMMISSION

COMMISSIONER GALBALLY: Yes, I would like to ask particularly about your statement about the root causes of violence, abuse, neglect and exploitation, especially within the COVID-19 environment, being about segregation and institutionalisation. You talked about people with disabilities being left in traps, which I thought was a very evocative statement. So what countries are doing --- well, you might not be able --- but what are they doing that is really improving on this absolute risk?

25

30

A. Thank you very much, Madam Commissioner, for that question because, indeed, the biggest challenge has been in terms of persons in institutions. And I want to stress that even nursing homes where I will say the big majority of the residents are persons with disabilities as well, we tend to forget that the fatalities and the rates of infections in nursing homes also represent in big numbers the situations of persons with disabilities, because a lot of those residents are persons with disabilities themselves. And we need to look at that intersection.

35

One of my concerns, Madam Commissioner, is that the immediate reaction of some of the States has been basically to increase the protection or the measures of protection in the institutions, which is of course right, but to think that that measure is going to be the solution in the long term, like, making the conditions in the institutions more --- sanitising the institutions will be the solution, right. And I think that, that kind of approach has taken us back more than 60 years in the discussions on how to move away from institutionalisation if what we are going to do in response to COVID is to convert or reconvert some of these places in small clinics or into

45

hospitals, we are learning absolutely nothing from the experiences that we had. What we need to do is work out how we can support people with long-term care needs and how that support is provided in the community as long as possible in their homes under a human rights-based approach.

5

Some countries, I know that in Denmark for instance, they decided many years ago to phase out nursing homes. And due to the pandemic in Ireland, and this is a very interesting case that I would like to highlight, the Government has already stated their decision to rethink and reimagine the way in which long-term care services are being provided. And the Prime Minister has stated that they also want to look at complete de-institutionalisation of older people.

10

So, in short, my response would be the way forward is to move towards a process of de-institutionalisation, making sure that the support that persons with disabilities need, including those with long-term care needs, will be provided in the community, in the proximity, making sure that persons with disabilities can be safe and can stay at home if that is their desire.

15

COMMISSIONER SACKVILLE: Thank you very much.

20

Ms Devandas, thank you very much for coming and being prepared to give evidence today. We appreciate this, particularly in view of the very heavy demands on your time. We particularly appreciate your support in relation to the Statement of Concern that the Royal Commission issued. We are very grateful for that. And may we reiterate our congratulations to you personally for your appointment as Costa Rica's Ambassador to the United Nations. Perhaps we should be referring to you as Ambassador Devandas. Thank you very much.

25

A. Thank you very much, Mr Commissioner. My honour to be here.

30

THE WITNESS WITHDREW

MS EASTMAN: That completes the Special Rapporteur's evidence. I have a few small things to deal with and these are the tenders of the Special Rapporteur's evidence. A copy of her statement is in part B, tab 19. If you could mark the statement Exhibit 5.29.

40

EXHIBIT #5.29, STATEMENT OF CATALINA DEVANDAS AGUILAR, DATED 10 AUGUST 2020

COMMISSIONER SACKVILLE: Yes.

45

MS EASTMAN: There are annexures also included in part B of the tender bundle,

annexures 20 and 21. There are then the documents referred to in the Special Rapporteur's statement. They are found in part D of the tender bundle at tabs 71 to 96. So the annexures collectively will be marked 5.29.1 through to 5.29.28.

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EXHIBITS #5.29.1 TO #5.29.28, ANNEXURES TO STATEMENT OF CATALINA DEVANDAS AGUILAR

10 MS EASTMAN: The other matter, you will recall Commissioners earlier today that Ms Deane gave evidence about a survey that was undertaken by Every Australian
Counts and she said that the survey had been released today, she has provided to the
Royal Commission a copy of the survey and I wish to tender that into evidence as
well. If that could be received as part of the collection of documents that accompany
15 Ms Deane's evidence, so it will be inserted into the tender bundle in part E, at tab
19A and it will become exhibit 5.26.3 and I'll ensure that copies are available to all
of the Commissioners.

20 **EXHIBIT #5.26.3, ANNEXURE TO STATEMENT OF KIRSTEN DEANE**

That would otherwise conclude today's proceedings and tomorrow we've asked for
the Commissioners' indulgence to commence at 9.30 tomorrow morning.

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COMMISSIONER SACKVILLE: We're not working hard enough?! We'll be here at
9.30. Thank you very much. We'll adjourn until 9.30 tomorrow.

30 **HEARING ADJOURNED UNTIL 9.30 AM, THURSDAY, 20 AUGUST 2020**

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