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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**

10.00 AM, TUESDAY, 18 AUGUST 2020

DAY 1

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

COMMISSIONER SACKVILLE: Good morning, everybody. As with all our hearings, we commence with an Acknowledgement of Country. I wish to acknowledge the Gadigal People of the Eora Nation, the traditional custodians of this land, and pay my respects to Elders past, present and emerging, as well as to all First Nations people viewing this public hearing and First Nations members of the Royal Commission staff.

This is the 5th public hearing of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. It is the fourth to hear evidence on a particular topic within the Royal Commission's Terms of Reference. The hearing that commences today will examine the impact of the COVID-19 pandemic on people with disability and the response of the Commonwealth government in particular to the pandemic as it has affected people with disability.

Ordinarily, of course, any member of the community is free to attend and observe a public hearing of a Royal Commission. But these are not ordinary times. We will be conducting the public hearing this week but it will be a virtual hearing. For reasons of safety during the COVID-19 pandemic, no member of the general community can be present in the hearing room. We, therefore, cannot follow the usual practice of extending a welcome to members of the public in attendance at the hearing, but I can and I do extend a warm welcome on behalf of the Royal Commission to everyone who is following or who will follow these proceedings on the live stream or in some other way.

I would like, briefly, to explain how the virtual hearing will be conducted. We do have a hearing room, which is a courtroom within premises occupied by the Fair Work Commission in Sydney. We are using the courtroom with the kind permission of that body. Commissioner Barbara Bennett PSM is with me in the room. Commissioner Rhonda Galbally AC, like so many Victorians, is locked down in her home in Melbourne, but she is participating in the hearing by audio-visual link. Thus, three Commissioners will be hearing the evidence during the course of this week.

Two Senior Counsel will be assisting the Royal Commission at the hearing. Ms Kate Eastman SC is present in the hearing room, and Dr Kerri Mellifont QC is participating by audio-visual link from Brisbane. Some members of the Royal Commission staff are also in the hearing room or nearby. Others are contributing to the conduct of the hearing from remote locations. Legal representatives for the parties that have been given leave to participate in the hearing will appear by audio-visual link and they will announce their appearances a little later.

During this hearing we expect to receive evidence from about 36 witnesses over the course of four hearing days. The witnesses will include 12 people with disability, and they will recount their experiences during the pandemic. We shall also be hearing from advocates, disability representative organisations, academics, other experts, representatives of the Commonwealth and its agencies, and service providers. It is a very crowded agenda. Counsel Assisting will shortly provide

further details in their opening statement about the nature of the evidence the witnesses are likely to give during the week. Almost all witnesses will give evidence by video link or by way of pre-recorded video. Witnesses will give evidence from various places in Australia and, in one case, from overseas.

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As I have already noted, the proceedings can be followed on the webcast, which is available on the home page of the Royal Commission's website.

10 As with all our hearings, an Auslan-English interpretation will be visible at all times on the webcast and our excellent Auslan interpreters will be working from both Sydney and Brisbane.

The conduct of a hearing of this scope and complexity is an extremely challenging undertaking. It takes a great deal of careful preparation and planning.
15 Notwithstanding the meticulous planning by our very competent and dedicated staff and from the experts from Law In Order, it is always possible that something could go wrong with the technology and sometimes, perhaps, adjustments will have to be made to the schedule. We, therefore, ask in advance for patience and understanding if delays do occur or adjustments have to be made.

20

Nobody could have anticipated when the Royal Commission was established in April 2019 that less than 12 months later we would have to suspend public activities because of the advent of a modern plague. Indeed, the disruption could not have been anticipated when in late 2019 we released a schedule of public hearings for the first half of 2020. All of these public hearings, bar one, and much else had to be postponed when the pandemic arrived. Despite the interruptions to the Royal Commission's program, we have made very substantial progress since the pandemic arrived. The details of the work we have undertaken during the first half of the year have been set out in the Second Progress Report, which was released last week, and is available on the website. It's not necessary to recount what is in that report, but there is one matter that deserves specific mention.

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The Royal Commission's Terms of Reference require an interim report to be presented to the Governor-General by 30 October 2020. The difficult circumstances that have prevailed since March will not prevent that deadline being met. The interim report will provide an important voice to people with disability who have been prepared to share their experiences with the Royal Commission and also to share their aspirations for the future. The Commissioners are deeply grateful to all people with disability who have recounted their experiences, as well as the staff of the Royal Commission who have shown great dedication and skill in overcoming the unprecedented obstacles that have been placed in their path.

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Royal Commissions have to respond to circumstances as they arise, no matter how unexpected or unprecedented they may be. Our fundamental responsibility is to inquire into violence against and abuse, neglect and exploitation of people with disability in all settings and contexts. This includes not only experiences that have occurred in the past, but those that occurred during the life of the Royal Commission.

45

The COVID-19 pandemic, as we all know, has affected virtually every Australian. The impact on the mental, physical health of the community and on the economic, social and educational life of the country has been great. We really do not know
5 when this will end. In one sense we are all in this together, but we have not all been affected equally. We have been made aware, all too aware of the terrible toll of the pandemic on people in aged care homes, particularly in New South Wales and Victoria. What has happened, and regrettably is continuing, is a national tragedy. The impact of the pandemic on people with disability may not have received the
10 same level of media coverage or public attention as the terrible loss of life in aged care facilities, but that does not diminish the severity or significance of the impact of the COVID-19 pandemic on people with disability.

There are about 4.4 million people with disability in Australia, of whom 2.4 million
15 are under the age of 65. Some 365,000 people with permanent and severe disabilities are participants in the National Disability Insurance Scheme, the NDIS. This means that under 10 per cent of all people with disability, and only about 15 per cent of people with disability under the age of 65, are participants in the NDIS.

20 Whatever may be uncertain about this pandemic, it was clear from the very outset that people with disability were likely to be disproportionately affected when compared with people without disability. People with disability often have multiple health conditions, often referred to as co-morbidities, or chronic conditions such as reduced lung capacity that increase the risk of infection and the chances of
25 a COVID-19 infection proving serious.

Many live in segregated settings or are dependent on carers or service providers for the essentials of life. Many are people with cognitive disability for whom disruption or lack of continuity in their lives can create high levels of anxiety and stress.
30

In the early weeks of the pandemic, we received numerous calls to our hotline and also submissions that provided often harrowing accounts of the experiences of people with disability during the pandemic. We were told of abrupt isolation and denial of social contacts; sudden interruptions to or loss of essential support services; inability
35 to access medications, health care or even adequate supplies of food; a lack of protective equipment for carers and people with disability themselves, thereby exposing them to the risk of infection; financial hardship; and extremely high levels of stress and anxiety among people with disability and their families.

40 We heard too of the problems of isolation, lack of access to information and loss of services experienced by people with disability from First Nations and culturally and linguistically diverse communities.

These accounts of the impact of COVID-19 on people with disability demanded
45 an urgent response from the Royal Commission. We, therefore, published a Statement of Concern on 26 March 2020 drawing attention to the key issues of concern and calling on governments to develop specific strategies to ensure the

health and wellbeing of people with disability during the crisis.

5 The Royal Commission then released an Issues Paper on Emergency Planning and Responses which pointed to the threats to health and safety when people with disability are overlooked or left behind in emergencies, including the COVID-19 pandemic. Some 60 responses, many very detailed, have been received to the questions asked in that Issues Paper. In addition, the Royal Commissioners received many submissions raising issues about the adequacy of measures taken to preserve the health, safety and wellbeing of people with disability during the pandemic crisis.

10 The submissions and responses to Issues Paper have informed the content of this hearing.

15 The starting point for our consideration of the issues arising from the pandemic, as we shall hear today from the distinguished scholar Ms Rosemary Kayess, and later in the week from the United Nations Special Rapporteur on the rights of persons with disabilities, the starting point must be the terms of the Convention on the Rights of Persons with Disabilities, or the CRPD.

20 Article 11 of the CRPD obliges States Parties, of which Australia is one, to take:

All necessary measures to ensure the protection and safety of persons with disability in situations of risk, including humanitarian emergencies and the occurrence of natural disasters.

25 In addition, Article 25 requires States Parties to recognise that people with disability have the right to the enjoyment of the highest obtainable standard of health without discrimination on the basis of disability.

30 These provisions have to be read with Article 4(3) of the CRPD. This obliges States Parties in decision-making processes concerning issues relating to people with disability to consult closely with and actively involve people with disability through their representative organisations. These are important obligations which Australia, under international law, must comply with.

35 This hearing has, broadly speaking, four objectives: the first is to hear people with disability and their families recount their own experiences during the pandemic. Some of these stories will be distressing, but others will recount positive experiences of people with disability in the face of the serious challenges they have encountered; 40 secondly, to examine the response of the Commonwealth to the risks to health, safety and wellbeing of people with disability, tested against the Commonwealth's responsibilities under international law and specifically under the CRPD; thirdly, to identify measures the Commonwealth should have taken to protect the health, safety and wellbeing of people with disability during the pandemic, but which it did not 45 take. We shall also be concerned to identify measures that have had a positive impact on people with disability; fourthly, and most importantly, to recommend measures that will protect the health, safety and wellbeing of people with disability,

both during the remainder of this pandemic and in future emergencies.

5 We do not intend to wait until the Final Report is completed to prepare a report arising from the matters that will be investigated during this hearing. The current emergency may last a very long time. If new or revised laws, policies or practices are needed, subject to the Royal Commission observing the requirements of procedural fairness, we owe it to people with disability to put forward our recommendations as soon as possible. That is our intention.

10 Ms Eastman?

OPENING SUBMISSIONS BY MS EASTMAN SC

15

MS EASTMAN: Royal Commissioners, I appear with Dr Kerri Mellifont from Brisbane. We are Counsel Assisting the Royal Commission in this 5th Public Hearing.

20 We also acknowledge and pay our respects to the traditional custodians of the lands on which we are meeting today. We pay our respects to the First Nations Elders, past, present and emerging, as well as to all First Nations people watching the hearing today.

25 When this Royal Commission commenced in April 2019, it was not in anyone's contemplation that the Commission would have to conduct a hearing on the impact of a global health pandemic the likes of which have not been experienced since the Spanish flu in 1918. But over the past six months, all of us have carefully watched the daily numbers of infections, we've learnt to socially distance and we now all
30 understand the meaning of flattening the curve.

As at 17 August 2020, over 500,000 tests have been conducted in Australia. There have been 23,599 confirmed cases of COVID-19. 421 people have died, of which 334 are in Victoria. The daily statistics tell us about the age and the sex of people
35 who have died, or who are infected. The daily statistics also tell us about the number of people admitted to hospital and those in intensive care units. But there is no data or statistics that tell us about the rates of infection or death for people with disability. There is no data or statistics that enable us as the community to understand or to assess the impact of COVID-19 on people with disability in Australia. This is
40 concerning.

The risks of COVID-19 for people with disability were recognised in Australia very early. One of the witnesses who will give evidence today will tell the Royal Commission that she anticipated the seriousness of the coronavirus in January 2020
45 and acted swiftly to acquire necessary supplies for her family. She will tell the Royal Commission that at that time masks were impossible to source. By 7 February 2020, the NDIS Quality and Safeguards Commission provided an alert. The alert warned

providers of the novel corona outbreak. By 17 February, the Commonwealth Department of Health released the Australian Health Sector Emergency Response Plan for novel coronavirus, called the COVID-19 Plan. The Royal Commission will hear more about the Plan through the witnesses attending the hearing this week.

5

The COVID-19 Plan was designed to guide the Australian health sector response. The COVID-19 Plan said this:

10 *At all levels planning will consider what is needed to protect the most vulnerable members of our communities and address the special needs groups, such as the aged care sector and Aboriginal and Torres Strait Islander people.*

There was no mention or reference in the COVID-19 Plan for people with disability. The Royal Commission will hear this week that people with disability and their advocates watched and waited to hear the Commonwealth government's plan for people with disability.

15

On 25 February this year, the Commonwealth Department of Health released its Emergency Response Plan for Communicable Disease Incidents of National Significance: National Arrangements. This plan was activated at the request of the Chief Medical Officer. This national Plan did not refer to the needs of people with disability. However, the Plan did note the importance of diverse communication strategies. Those strategies are said to have been necessary to be tailored to meet the needs ranging across our community, particularly those in vulnerable groups.

25

Some people with disability assumed the reference to "vulnerable groups" may have been a reference to them. Commissioners, you will hear during the course of the evidence this week that the lack of effective communication tailored to meet the needs of people with disability has been a significant and recurrent theme.

30

By 11 March, the World Health Organisation declared COVID-19 to be a pandemic. Four days later, leading disability researchers, Professor Anne Kavanagh, who will give evidence this week, and Professor Julian Trollor, who has provided a statement for this hearing, called on Australian governments to prepare a targeted response to COVID-19 for people with disability, their families and the disability service sector. They noted Australians with disability are a vulnerable population to COVID-19 because of the elevated risk of morbidity and death due to underlying health conditions. They said this:

35

40 *It is frightening because, first, the health sector is under prepared to meet the urgent needs of people with disability. Secondly, the disability service sector will not be able to meet the care needs of people with disability. And, thirdly, information on what to do is not easily accessible. For example, some people may not understand that there is disruption to their daily lives and routines.*

45

They called on the Government to prepare a targeted response, noting that the response had been developed for the aged care sector, but not the disability sector.

They noted both sectors may have similarities, including congregated settings, and a precariously employed and inadequately trained care force and the families and carers may face significant challenges in meeting the needs of people with disability in Australia.

5

By 2 April, the disability organisations together, and approximately about 70, issued an open letter to the National Cabinet imploring the Government to act saying, "now is the time to act on pandemic measures for people with disability." On the same day, an Advisory Committee on the COVID-19 Response for People with Disability was formed. The purpose of this group was to develop a Management and Operational Plan for People with Disability. The Advisory Committee was chaired by Mr Simon Cotterell from the Department of Health and he will give evidence later this week.

10
15 By 16 April, the Commonwealth issued the Management and Operational Plan for COVID-19 for People With Disability, and during the course of this hearing, Commissioners, you will hear about the impact of that plan on the lives of people with disability and the extent to which it has or has not addressed the needs of people with disability over the course of the pandemic.

20

This hearing will focus on the Commonwealth government's response and actions. It will examine the actions taken by the Department of Health and key agencies such as the NDIA and the NDIS Quality and Safeguards Commission.

25 Commissioners, you have deferred examining the responses of the States, Territories and local governments for a possible future hearing. As, Chair, you have indicated, we will hear evidence from witnesses who will give the Royal Commission an insight into how the pandemic has affected daily lives in every respect.

30 One part of the evidence that you will hear will be the increase of violence against women during the course of the pandemic. The Australian Institute of Criminology conducted a national survey. That survey included 11 per cent of participants being women identifying with disability. The results of the survey are frightening. One in four women with disability who were in a current relationship, 23 per cent, said they had experienced physical violence during COVID-19. One in six, 16 per cent, said they had experienced sexual violence during COVID-19. And two in five, 42 per cent, said they had experienced emotional, abusive, harassing or controlling behaviours during COVID-19. Three in four women with disability who reported domestic violence said it was either the first time it had happened in their relationship or the violence had escalated in frequency and severity over the six-month period of the pandemic. The survey results reveal that compared to other women, women with disability were significantly more likely to experience the onset or escalation of domestic violence during the initial stages of the pandemic.

40
45 The findings also reveal that the risk of domestic violence has not been evenly distributed. First Nations women, women from non-English speaking backgrounds, were more likely to have experienced recent domestic violence compared to

non-Indigenous women and women from English-speaking backgrounds.

Dr Mellifont.

5

OPENING SUBMISSIONS BY DR MELLIFONT QC

10 DR MELLIFONT: Thank you and good morning. This pandemic has given many
within Australia just a taste of what it is like to live in isolation and to be unable to
attend work or participate in the community. As one witness, Samantha Dwyer
observes, "Some people without disability have experienced social isolation for the
first time". To them she says, "Welcome to my world". Some people, who are
15 already isolated to a significant degree, have found further restrictions on their
interactions with people crushing to their physical and mental wellbeing.

I will now turn to a brief overview of some of the evidence you will hear this week.
You will hear from advocacy groups, including Mary Sayers from Children and
Young People with Disability Australia, and Damian Griffis and June Riemer from
20 the First Peoples Disability Network. They speak about the challenges faced by
them during the pandemic. Advocacy groups have been instrumental in providing
accessible and timely information.

25 Many advocacy groups have been inundated with calls for help, ranging from people
needing to get access to essential, personal requirements; people who simply could
not get access to incontinence pads; they couldn't get food; people who are trying to
navigate and understand the publicly available information; people wanting to know
what they can do to try and make sure that their child, a student with a disability, is
provided accessible education and is simply not left to fall so far behind there is no
30 hope of catching up.

You will also hear from Christian Astourian and Sarah Yahya, who will speak to the
particular challenges faced by some people within the culturally and linguistically
diverse communities in Australia. You will hear from a number of experts, including
35 Dr Jason Agostino, a general practitioner and epidemiologist who specialises in
health in First Nations communities and who will assist the Royal Commission in
understanding some of the particular health issues faced by First Nations people, how
access to support services have been compromised during the pandemic, and how
telehealth services need to have patient end support to be effective for First Nations
40 communities.

Mr Griffis and Ms Riemer will give evidence of the particular barriers faced by some
First Nations people with disability and will share with us their recommendations for
change, including a dedicated 1800 number for First Nations people with disability.
45

Ms Riemer make recommendations in terms of comprehensive mapping and data
collection. She asks the question, "How can we enact an emergency response plan to

support people with disability if we don't have correct data of disability needs?"

5 This hearing also marks the beginning of the examination of the level of
preparedness of service providers for an emergency such as this, the actions taken
during the pandemic and the challenges faced by service providers and their
interaction with Commonwealth government and agencies. Notifications to the
NDIS Quality and Safeguards Commission has revealed the enormous challenges
faced by service providers in accessing sufficient and appropriate quality PPE,
accessing rapid testing for their staff and customers, workforce issues and access to
10 information.

On Thursday, the Royal Commission will hear evidence from two service providers,
Aruma, and Life Without Barriers in those respects.

15 The evidence in this hearing exposes inadequacies in supporting the needs of people
with disability and inequities, the constant world for some people with disability and
how those difficulties can become exacerbated if focus is not given to the particular
needs of people with disability in emergency planning and execution. The Royal
Commission will hear evidence about the importance of a human rights, inclusive
20 and person-centred approach to planning for emergencies, including from Associate
Professor Michelle Villeneuve from the Centre for Disability Research and Policy
who will speak about the need for emergency action plans.

The Royal Commission will also hear evidence from an international perspective.
25 Catalina Devandas Aguilar, the United Nations Special Rapporteur on the rights of
persons with disability will give evidence that in conflict and emergency situations,
people with disability are often the most adversely affected, sustain
disproportionately higher rates of morbidity and mortality. Her evidence reflects the
themes emerging through other witnesses, that the pandemic is revealing and
30 deepening pre-existing inequality and exposing the structural discrimination and
exclusion experienced by people with disabilities.

We wish to note that those watching or later reading or watching the hearing from
our website, you might find some of the evidence to be deeply distressing. The
35 content of a hearing such as this can be very upsetting and viewers might wish to
take such steps as are available to them to have support around them. The
Commission has counsellors and support services who are made up of social workers
and counsellors and support people who are able to provide help to people engaging
with the Commission. Blue Knot provides short-term professional counselling and
40 support, a gateway to frontline counselling services, advocacy and legal support
services, information and referrals about other useful services and psycho-education.
They have an extensive nation-wide referral network to support people. Their phone
number is 1800 421 468.

45 I turn then to protection for witnesses. There are provisions of the *Royal
Commissions Act* which have the very clear objective of protecting witnesses who
give evidence before the Commission, in particular, we note section 6(m) which

provides that:

5 *Any person, that is any person, who uses, causes or inflicts any violence, punishment, damage, loss or disadvantage to any person on account of that person having appeared as a witness before the Royal Commission, or giving evidence to the Royal Commission or producing documents to the Royal Commission, commits an indictable offence. The maximum penalty is imprisonment.*

10 We note the breadth of what that prohibition prevents extends to any damage, loss or disadvantage. So it is important that any person who might be minded to engage in such conduct, whether in person or by use of social media or any other cause, are extremely mindful of that very important legislative provision which makes it an offence.

15 Commissioners, we now turn to appearances for those parties with leave to appear.

20 COMMISSIONER SACKVILLE: Yes, could I ask those parties who do have leave to appear to announce their appearances, please.

25 MS MORGAN: May it please the Commission. Kate Morgan. I appear for the Commonwealth with Mr Dighton, who is appearing from Brisbane.

30 COMMISSIONER SACKVILLE: Thank you, Ms Morgan.

35 MS MORGAN: Thank you, Commissioners.

40 COMMISSIONER SACKVILLE: Are there other appearances?

45 MR CHESTERMAN: Commissioners, Scott Chesterman. I appear on behalf of the state of Victoria.

50 COMMISSIONER SACKVILLE: Thank you, Mr Chesterman. Are there any other appearances? I understand that Aruma Services and Life Without Barriers have been granted leave to appear. They may be appearing by legal representatives later in the proceedings.

55 MS EASTMAN: Yes. Commissioners, if I could turn to the first witness, Nicole Lee.

60 COMMISSIONER SACKVILLE: Ms Lee will be appearing remotely, I take it?

65 MS EASTMAN: Good morning, Ms Lee, how are you?

70 WITNESS: Good.

MS EASTMAN: Can I, first of all, ask if you will take an affirmation?

WITNESS: Yes.

5

NICOLE LEE, AFFIRMED

10 **EXAMINATION BY MS EASTMAN SC**

COMMISSIONER SACKVILLE: Thank you, Ms Lee.

15 MS EASTMAN: So your name is Nicole Lee?

A. Yes.

Q. And you are an advocate?

20

A. Yes, I am.

Q. And you prepared a statement for the Royal Commission dated 10 August?

25 A. Yes, I did.

Q. Are the contents of that statement true?

A. Yes, they are.

30

MS EASTMAN: Commissioners, you will find a copy of the statement in the tender bundle, volume B, behind tab 1. If it is convenient, Commissioners, I will ask you in due course to mark the statement as Exhibit 5.18.

35

EXHIBIT #5.18, STATEMENT OF NICOLE LEE, DATED 10 AUGUST 2020

MS EASTMAN: Ms Lee, can I start with a little bit about you. You say in
40 paragraph 3 of your statement that you are a disabled woman and family violence
survivor and advocate, and you focus on family violence perpetrated against women
with disability or who depend on carers and family members for support. You
yourself experienced a decade of abuse at the hands of your former husband and you
45 now use your lived experience of family violence to speak out for those who do not
have a voice.

A. Yes, I do.

Q. You prepared a detailed statement addressing the impact of family violence. I want to turn to that in a moment. But could I ask you to jump a little bit ahead in your statement to paragraph 30.

5

A. Yes.

Q. You say in the statement there that:

10 *The media often describe people with disability as "vulnerable"*

A. Yes.

Q. And you find that language to be problematic; why is that?

15

A. The media quite regularly declares people with disabilities as being vulnerable whether it is due to the pandemic or whether it's due to violence we've experienced, especially --- that's been more heightened recently with the death of Ann Marie Smith, with the impact of COVID and people being at greater risk of experiencing negative impacts due to COVID. But we repeatedly are classed as being

20 "vulnerable" and myself and other disabled people, advocates, friends around me also find that this language is very problematic and creates a lot of stigma surrounding our position in the world, especially in the middle of what we are experiencing right now.

25

Q. And in your statement I think you give some examples about some media commentary in July about the impact of the pandemic on people who might be perceived to be vulnerable and you say in your statement that this gives you a sense, as a person with disability, that you might be dispensable?

30

A. Yes.

Q. Why has the language around vulnerability caused you to have that feeling?

35

A. Well, the language around vulnerability has caused us to have that feeling because there has been repeated conversations around the impact of the economy and that disabled people either need to lock themselves in, and there has been comments over social media, especially here in Melbourne since stage 4 lockdown, around that if you are vulnerable to dying, you need to accept your fate and die, and that we are expendable, we are not seen the same as everybody else. There has been this lack of compassion that has been brought about by this language by people who, and I can understand, yes, they are angry, upset, scared around the impact on their livelihoods and their jobs, but we are talking about the loss of our lives. This also then crosses over into the aged care sector where people have less compassion if the person is

40 older that dies of COVID. Nobody should be dying of COVID.

45

Q. You say in the statement that this language is "the othering of people with

disability", so it has the effect of disconnecting people with disability and those who do not have disability.

A. Yes.

5

Q. And that has an ongoing impact in the sense of both value to the community and sense of dignity; is that right?

A. Yes, absolutely.

10

Q. You say in your statement that language like this might be something contributing to a greater risk of violence, and I want to explore that topic with you.

A. Yes.

15

Q. So one of the many roles and work that you do is that you are a board member of Safe Steps Family Violence Response Centre based in Victoria; is that right?

A. Yes, that's right.

20

Q. Can you tell us a little bit about the Safe Steps Family Violence Response Centre?

25

A. Safe Steps Family Violence Response Centre is essentially an emergency phone line that people experiencing violence can call to --- they do everything from risk assessments and will take action if that risk assessment is deemed as high risk. They are essentially a refuge service here in Victoria. And so at the moment they are putting women and children in hotels who are in very high risk situations of family violence escalating or family violence deaths. Part of this service is also that they coordinate the Disability Family Violence Initiative Fund down here in Victoria which gives somebody with disability who is trying to flee violence access to immediate funds for them to be able to flee that violence. So you've got the intersecting forms of somebody leaving violence already being quite difficult and then you had in disability and you've got more hurdles again. So they manage that fund at this point in time. They triage people on the basis of risk and manage where people go, what's the most appropriate refuge and as such, yes.

30

35

Q. And you've observed in your statement that during the COVID-19 pandemic that that has increased the risk for people with disability experiencing family violence?

40

I'm looking at paragraph 7 of your statement, and you say there that:

45

Violent partners are more likely to be working at home and potentially increasing the frequency of violence perpetrated. The health and economic impacts of the pandemic are also likely to heighten stress levels within already violent households.

A. Yes.

Q. So we've seen in the material that will be before the Royal Commission that there is a recent report of a survey undertaken by the Australian Institute of Criminology which documents increasing and, indeed, alarming levels of reports of family violence. One of the issues that you wanted to raise is the dynamic of the relationship that both causes violence and also creates the situation where women experiencing violence feel that they are not able to get help.

10 A. Yes.

Q. You've documented this in paragraphs 9 and 10 of your statement. Can I ask you just to explain to the Royal Commission, when you talk about being cut off from support networks, and the inability to leave, particularly during a pandemic, what those consequences might be?

15 A. Well, all of those --- in the past for people with a disability, the nature of coercive control is to completely isolate you from your family and friend networks, which is ---

20 Q. Ms Lee, I am just going to interrupt you. Because, and this is a bit of a learning experience on this new network, I think both of us need to slow down. Our Auslan interpreters are working furiously to keep up.

A. Sorry. The nature of violence and coercive control is to isolate you from your friends, family and support networks. What the pandemic has also, and what we've read in what has come out, which is women are already experiencing --- disabled women are already experiencing violence at three times the rate of that of able-bodied women for extended periods of time and more severely than other women. The pandemic, also at the moment --- our access to all of those touch points out in the community that we had at our disposal before, if you had supports coming in, whether it is something as simple as taking a client to the supermarket and removing them from the house where it is safe to be able to ask questions around safety. At the moment, if a support worker is coming into the house with a violent partner here it is not safe to ask a client those questions around: what is going on at home? Are you okay? Is everything safe? Those opportunities to have those conversations have been taken away from us. All of those touch points, and this is from my own experience in the past was around being able to leave the house with the support worker to go to the supermarket, being able to go to the GP on my own and have that conversation. OTs, physios, all of those things where you are physically in a safe position, away from where somebody can overhear anything to be able to have those conversations or to raise alarm and ask for support. Now they have been taken away from us. I don't know whether you are going to touch on telehealth later. Do you want me to do that now?

45 Q. I will, because I want to ask you in the context of the lockdown that you are experiencing in Victoria at the present time, what safeguards exist and what alternative safeguards are available? We might move to that, but I wanted to, before

I do that, ask you about something you have set out in paragraph 12 of your statement, and you say that:

5 *During COVID-19, calls to Safe Steps dropped significantly. This reduction in calls coincided with lockdowns in Victoria*

A. Yes.

10 Q. You say this means that it is “potentially no longer safe for women experiencing family violence to call for help when they are in the same family.”

A. Yes.

15 Q. That is an indication that the usual safeguards are not operating as effectively as they would outside the pandemic period.

20 A. So partners are no longer going to work, you are no longer in a space where you are away from the home where it is safe to make a phone call like that where somebody isn't going to overhear. It means that phone calls become very dangerous or just not able to happen whatsoever.

Q. So what safeguards are available at the present point in time?

25 A. Well, in regards to reaching out, face to face, things like the pandemic being used as a reason to not allow somebody to leave the home. There is no chance of going to a police station to report violence. There is no chance of making a phone call to any of these services. And some of the things that have been put in place which Safe Steps had to do very, very quickly was a web chat service was made available that we had to develop and put out live for the community to use.

30

Q. Can I pause you there.

A. Yes.

35 Q. I think we can actually get up on the screen the website so that we can see the chat function. If you can take us through how that might work in practice.

Can we put up on the screen, please.

40 As soon as I might speak, it will probably come up on the screen. As we are waiting for it to come up, because I think it would be helpful to see how it would work in practice.

A. Yes.

45

Q. The purpose of the web chat function is to allow somebody who might be able to get on to the internet to actually have a talk to somebody online ---

A. Yes.

5 Q. --- by typing in things. Here we go. Can you see that up on the screen?

A. Yes. It is a bit unclear on my end.

10 Q. There is a number of --- we'll wait for that to have a little more clarity. On that screen you will be able to go into the top left-hand corner and go down to the web chat function.

A. Yes, which gives you other information in there as well. Mind you, all of these websites are developed with a quick exit in case somebody is in danger.

15 Q. Right?

A. That's pretty standard with any family violence web page.

20 Q. So what it would mean in practice is that if somebody had a concern about experiencing violence, and they were worried about making a telephone call, they could jump on to this website and they could have a chat. So, in effect, you type in what your particular concerns are and then somebody will come and have a conversation with you that might allow a person to get some advice about what the options might be ---

25 A. Yes.

30 Q. --- to know whether they could leave their home in circumstances under a lockdown to find a safe refuge. Is that right?

A. That's right. Also if it is identified as high risk that they can offer the person to send the police to their home, to escalate things, to intervening to keep that person safe as well via that web chat so that they are looking for red flags in the conversation as well with somebody.

35 Q. You said in your statement that the web chat service has opened up opportunities for Deaf and persons who are hard of hearing in the community who wouldn't ordinarily have access to telephone services?

40 A. Yes.

45 Q. But you do have a concern about the extent to which this service is currently accessible for people with low literacy and people with cognitive disability. Is that right?

A. Yes, that's right. Or severe anxiety. I would not have been able to navigate the web chat service at the position I was when I was experiencing violence.

Q. And how is this particular service funded?

5 A. This is funded via Safe Steps directly who are funded by the Victorian Government.

Q. So this is a State Government initiative, not a Commonwealth Government initiative?

10 A. Yes, State Government initiative. They had to develop and get out to use very, very quickly because we were in the midst of a crisis and there was no time to do broad community consultation. There was no time to refine it completely when they needed a service to be able to access the community again safely when the phone
15 calls had dropped so drastically and they have never dropped like that before, is my understanding from the conversations I've had within Safe Steps.

Q. And we know that for people with disability, that only a small proportion of people with disability are participants in the NDIA. In your statement, though, you make the comment that it is your view that the NDIA is not well equipped to have
20 outreach ---

A. Yes.

25 Q. --- to people experiencing family violence.

A. Yes.

Q. And this is a matter of concern to you. Can you help us here at the Royal Commission just to understand what those particular concerns are? So this probably
30 is what is the expectation of the NDIA in such circumstances and what are your expectations in terms of how those needs could be met?

A. Well, you know, the expectation is you can't be cold-calling people and asking those questions for all of those reasons why that web chat was developed; it is not
35 safe to ask risk assessment questions on the phone when you have no oversight as to who is in the room with the person. You are either going to put the person in danger if they do answer correctly and are overheard, which has the potential to lead to escalating violence, potential murders, but then also you are leaving somebody in a position where they are most likely not going to tell the truth because the violent
40 person is in the room, standing beside them and then they are classed and ticked on the NDIA's end of things that the person said they were safe so therefore they've done their job. We need physical outreach to people to be able to physically assess the home, the situation, the body language of people, the dynamics in that house to understand whether that person is safe. We are not always in a position to be honest.
45 And we will give them the answer that we need to give that keeps us safe within the home that doesn't raise alarm bells. So, you know, the expectation is to go cold-calling which they did at the beginning of the pandemic, participants that they

thought were in vulnerable situations or at risk of experiencing violence, or had in the past, is just completely not appropriate and not good enough and leaving people in positions where they are going to be experiencing levels of violence. That outreach service whilst, yes, we are in the middle of the pandemic, they need to find
5 a way and they need to be going out and visibly sighting people. Ann Marie is a very good example. If there had been phone calls made, was there any capacity for her or the people around her to be honest? And if somebody had visibly laid eyes on her, it would have been a very, very different story and maybe that woman would be here and maybe other people would be here, or at least saved from being exposed to more
10 violence until they are able to leave their homes and reach out for help.

Q. So this now takes me to the telehealth.

15 A. Yes.

Q. This is an initiative developed during the course of the pandemic and relatively early on in the pandemic.

20 A. Yes.

Q. And at paragraph 24 of your statement you say:

The increased use of and availability of telehealth is fantastic

25 A. Yes.

Q. So this might be one of the positives of the COVID-19 pandemic. Can you tell us, what is it about the telehealth service that is working?

30 A. Well, it's opened up a lot of our worlds to access services that we didn't have the capacity to before. So reduced mobility access to transport has meant we are able to access health services and specialists that we didn't have the capacity to have access to in the past. In that regard, for people who are house-bound or people who don't have access to that kind of transport, it has completely opened up their worlds to
35 access services they weren't able to before. But with that comes, again, the stuff that we've spoken about, this is a very double-edged sword as well.

Q. The next thing I want to ask you about is financial support for women experiencing family violence during the pandemic, and in your statement you deal
40 with an initiative from the Victorian Department of Health and Human Services, but I want you just to talk about the importance of funding and how women in such situations may be able to access funding and what the impact of the lack of funding is in these circumstances?

45 A. Okay, so in Victoria we do have access to emergency ring-fenced funding which is purely for people with disabilities or families of children with disabilities to access in order to be able to escape violence. So you can make a refuge as accessible as you

want, but unless somebody has access to support workers or access to equipment to be able to go to that refuge and stay safe is massively decreased. The NDIS has repeatedly told us they are not a crisis service and they will not respond in a crisis. But for somebody leaving violence you can't wait for a plan review, you can't wait for access to the NDIS. If you need to leave that home, you need to leave that home that day. The nature of violence and coercive control again is cutting you off from family and friends, cutting you off from services and networks around you. It could be around limiting the amount of support you are able to access under the NDIS as a way of controlling you and retaining you in the home under their control and continue to enact violence or exploit you. And what this fund does is it takes away that avenue from a perpetrator and those funds are vital. I accessed it twice. Without access to that money, and, again, this is only a Victorian initiative, without access to that fund when police removed my violent husband from the home, who was eventually charged and served a jail sentence for what he was doing, when they removed him, nobody put anything in place to take over that caring position. I had nobody around us, two children and we were failing. It wasn't until I went to health protection and said, "I need to do something or I need to invite this violent man home, it's not what I want to do, but we are not surviving". I would not be here today if that fund was not available. I would have asked him to come home, I would have lost my children, and I don't think I would have been able to live through all of those things. What that funding did was it gave me access to a support worker that came in that day. I hadn't showered for eight weeks. That support worker was able to give me a shower. I was able to feed my dog, I was able to get my children to school, I was able to live independently in my home without having to rely on the only person in my life who was perpetrating violence against me. This is the difference, access to funds that day, without condition, makes for women with disabilities. There is no point putting someone in a refuge if they don't have the means to support themselves to stay in that refuge. The funding gives people the means to escape that they need. We need extra support leaving than able-bodied women and this funding is what does it. Like I said, I accessed that funding twice. Without it, I would not be here. I would not have been able to leave and things would have turned out drastically different. What really distresses me the most about all of this is the fact this is only a Victorian initiative. We have to continually fight the Victorian State Government to continue to extend this funding as it was hoped that the NDIS and the NDIA would take up this gap and they haven't. And the fact that women in other states don't have access to this, so how many women need to leave and want to leave but physically can't due to the barriers to accessing support is incredibly distressing and a huge, huge problem when we talk about violence perpetrated against disabled women. One of the things we do know is that disabled women reach out for help less than able-bodied women, even though we are three times more likely to experience violence than our able counterparts. What that screams to me is, one, being identified what your experience is, violence, two, having the means once you have identified that when you've been disconnected from all of your support networks and then, four, continue to be supported to remain independent without having to rely on somebody who perpetrates violence against you.

Q. Ms Lee, my final question, and the Commissioners may have some questions is if

there is one thing that you would like to see done now during the course of the pandemic that would make a difference, what would that be?

5 A. For me the main thing is the family violence services need dedicated funding from the Federal Government so that things like our web chat that we developed through Safe Steps can be made accessible to everyone so that we can make Easy Read formats and Easy Read versions of those web chat services so that all the messaging that is going out there at the moment, there is lots of messaging being out there that is targeted to able-bodied women, nothing is really being targeted in
10 multiple different ways with Auslan interpreting, with Easy Read messaging as well so that all women can see these messages, understand these messages, know that they apply to them and know the ways in which they can reach out for help. And then when they do reach out for help that all of those networks, whether it be via the phone or via a web chat is actually delivered to them in ways in which they can
15 access and communicate and voice their concerns with what is happening to them, because at the moment that web chat is far too wordy, they developed what they could, when they could with the funding they had. Services need funding to be able to reach out to the disability community. We don't want separate services or separate initiatives, we want those initiatives to be made accessible to all of us so we all have
20 pathways to accessing support networks. And I would also implore the Commission to speak to the Federal Government around having emergency funding ring-fenced just for disabled women to access supports while they wait for plan reviews on their NDIS so they can escape, be somewhere safe and be supported and remain safe whilst they wait for their NDIS to be reviewed and adjusted to meet their changing
25 needs. We can't wait six months. That could be the difference between life and death. We can't wait six weeks, we can't wait two weeks. That funding needs to be made available and I think they are fairly easy and straightforward initiatives that the Federal Government could be doing, given to the family violence sector, dedicated for: how do we reach the disability community, how do we get messages to them,
30 what have we got in place and how are they not working for them.

Q. Thank you, Ms Lee.

35 A. Thank you.

MS EASTMAN: Commissioners?

40 COMMISSIONER SACKVILLE: Thank you, I will ask Commissioner Bennett whether she has any questions and Commissioner Galbally whether she has any questions.

COMMISSIONER GALBALLY: No, thank you.

45 COMMISSIONER SACKVILLE: In that case, thank you very much. Thank you, Ms Lee for preparing your statement and for giving evidence, particularly remotely. We very much appreciate your attendance and your evidence. Thank you very much.

A. Thank you, your Honour.

THE WITNESS WITHDREW

5

MS EASTMAN: Commissioners, the next witness is Tammy Milne.

10 COMMISSIONER SACKVILLE: Thank you. Let us hope that Ms Milne will miraculously appear. Thank you, Ms Milne, for appearing. We will ask you, please, to take the oath or affirmation as the case may be.

TAMMY MILNE, AFFIRMED

15

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

20

EXAMINATION BY MS EASTMAN SC

25 MS EASTMAN: Good morning, Ms Milne.

A. Good morning.

Q. Can I confirm that you are Tammy Milne?

30 A. Yes, I am Tammy Milne.

Q. And you are an educational interpreter and I will ask you about that in a moment?

35 A. Yes.

Q. And you live in North West Tasmania?

A. I do, yes.

40 Q. And your address has been provided to the Royal Commission, that's right?

A. Yes.

45 Q. You prepared a statement for the Royal Commission dated 3 August. Are the contents of that statement true?

A. Absolutely, yes.

MS EASTMAN: Commissioners, you will find a copy of the statement in part A of the tender bundle behind tab 1 and I will ask Commissioners could you mark the statement Exhibit 5.1.

5

COMMISSIONER SACKVILLE: Yes, thank you.

EXHIBIT #5.1, STATEMENT OF TAMMY MILNE, DATED 3 AUGUST 2020

10

MS EASTMAN: I want to ask you about your role as an educational interpreter. You've recently resigned from that position.

15 A. Yes.

Q. But you say in your statement that your work over almost 35 years, is that right, has been facilitating communication between Deaf students and their learning contemporaries and teachers and other staff using Auslan and translating English to Auslan and vice versa?

20

A. Yes. So I've worked --- I've had a number of positions in the department over the 33 years or whatever. So for 17 years I was an educational interpreter when I first started. Then I took maternity leave, retrained and became a librarian and then I trained again and got a Diploma of Education, taught for eight weeks and then in the last 12 months I've taken back up becoming --- I've been working again as an educational interpreter. Yes, so, yes.

25

Q. And you live with a disability, is that right?

30

A. I certainly do. Yes. So I've had arthrogrophosis multiplex congenita since I was born. More than that. Like, it's in utero. It means in utero the muscles around my bones didn't grow. So muscles are supposed to grow in pairs, mine didn't grow in pairs. So one would be fully functioning and yet the other side, the matching set of muscles maybe didn't have as much growth and that meant my bones were crooked, came out crooked so that affects my feet and my legs and my hips and my shoulders and I also have paralysed vocal chords which may or may not be attributed to the arthrogrophosis multiplex congenita.

35

Q. You know this hearing is about focusing on the impact of the COVID-19 pandemic on people with disability ---

40

A. Yes.

Q. --- and you've said it probably all in one sentence, in paragraph 8, and that is that you have found the pandemic to be a surreal experience and you say it's like living in a science-fiction film?

45

5 A. Absolutely. In March I was in Sydney for a launch of a Women with Disability event and the pandemic had just sort of hit the rest of the world and was a little bit in the news in Australia, and then I came home and by 13 March it was everywhere, being talked about, and sort of we --- North West Tasmania went into lockdown fairly soon after that. It was like --- I just couldn't believe that something that had happened. It was (click) just like that. You expect something that is going to affect the whole world to be a war or, you know, I guess global warming, but it is --- this thing that has affected the whole world and it affected my world is coronavirus.

10 Q. Some might say living in the beautiful North West coast of Tasmania that it is a beautiful place to live, but you've said in your statement that you felt you became the test case for the country because it's the case, isn't it, that there was a hard lockdown in North West Tasmania due to a particular localised outbreak?

15 A. Yes.

20 Q. And that hard lockdown meant you had to stay at home and you could only leave home for exercise and essential items and services. And in that hard lockdown as a person with disability, you relied very heavily on outside support to get food, to cook food and to provide your daily care; is that right?

A. Exactly. Yes.

25 Q. You have a service provider and a support worker who comes six days a week ---

A. Yes.

30 Q. --- for a few hours in the afternoon to help prepare the evening meal ---

A. Yes.

Q. --- attend to personal hygiene issues and just to assist if any problems arise?

35 A. Absolutely, yes.

40 Q. So, during this hard lockdown, there was a problem one Friday afternoon. You were expecting your support worker to attend and the support worker hadn't arrived by 4.30 in the afternoon. You thought something must have come up but you didn't know what was happening. Can you pick up the story from that point in time?

45 A. Yes, sure. So she didn't come and, like, dinner for us is 6 o'clock and we're thinking, "Oh dear, what is going to happen now?" I didn't want to ring her and see what is going on because it's not really my responsibility to ring my provider. It is their responsibility to let me know. So at 7 o'clock that night, Friday night, I got a call from the service provider saying that my support worker had been put in a situation where she had --- may have been exposed to COVID. So the people in

her home and herself were isolating until the results of that testing came back.

Q. What did that mean for you?

5 A. Well, for me, it was like..... It was once again surreal. I had been isolating and
doing all the right things, not going out, you know, staying home. My husband has
a chronic illness as well. He had been staying home. And potentially we had been
exposed to COVID but we hadn't done anything to bring it on ourselves if you know
10 what I mean. It had just been --- it sort of invaded into our home without our
consent, if you like. We had no control over it coming in because potentially it could
come in with the support worker.

Q. Is it the case that you went for four days without a support worker and had to rely
15 on friends to assist in terms of cooking and the basic needs over that four-day period?

A. Yes. So I have a friend who was able to come in and pick up where my support
worker had left off, if you like, cook and run out and get takeaway and just basically
doing the job that my support worker would have done if she'd been here. But he's
a friend. Like, he's not a support worker. We were just lucky that he was available
20 to do that and that I had the resources to find a friend who could support me. What if
I didn't have a friend? What if I was totally isolated from the community with no
contacts? What would have happened to us then?

Q. And that's one of your concerns, isn't it, that if something happens to the support
25 worker, what alternatives are available and did anybody give you any information
about alternatives, other than calling on the goodwill of your friends?

A. No. No. There was no alternatives. Nowhere to go. I was just --- and at that
time in that high stress situation where we are thinking, "Oh, my gosh, potentially
30 we've got COVID", to have my friend come and be that support and to sort of, I don't
know, it was like dragging ourselves through those four days. Sludging through mud
waiting for something to happen, you know, you haven't got COVID, we're all good.
Just always on our minds, in the back of our minds, what if, what if, what if, yes.
What if is basically if Phillip and I got COVID we'd be dead. It's not like we could
35 survive because of our complex medical issues.

Q. One of the matters that you wanted to look into was to get access to personal
protective equipment. I think we are now all used to what PPE means, but back in
that hard lockdown in mid-April in North West Tasmania, what could you do to
40 access any PPE? You talk about this in your statement at paragraphs 22 and 23.
What did you do to try and access PPE?

A. Well, I rang the COVID helpline to find out where I could get PPE. Of course
they told me that I should contact the NDIS. But it was a weekend so I couldn't. So
45 I waited. I actually got on and went down to --- I rang a few chemists to see if we
could get PPE through the chemist, face masks and hand sanitiser and gloves. No,
they don't have them. So basically there was nowhere I could get it. I just couldn't

get PPE anywhere. I think it was later on that I found out that a place near me makes them and so I ordered some and they came to us, but that was like weeks later.

Q. Did you have to make your own investigations ---

5

A. Yes, I did.

Q. --- or was there a website or information to know where to go?

10 A. No, I saw Prime Minister Scott Morrison saying that PPE was being provided and I was like, "Hello, where is mine?" There was none. Strangely enough, though, a couple of weeks later a yellow manila [sic] envelope turned up in the mail with five home-made face masks in it and I think that was my husband's care provider that had sent those out. It was weird. They had no provenance. We didn't know the
15 authenticity, or provenance of them, were they medically fit for purpose or where they just --- yes, who knows if they would work Yes, they were these cloth --- they were pretty, but did they work?

Q. I want to turn to a different topic now and that is community attitudes. This is
20 a matter that you talk about in your statement at paragraph 30 and following. You've observed some interesting things during the course of the pandemic. You say in the statement that it has:

25 *..... illustrated to me the lack of understanding in the community of what people with disability go through or the complexity of disability.*

I want you just to tell the Royal Commission about the impact attitudes have had on you and what you have observed during the course of the pandemic?

30 A. Wow, it's been like the curtain has been pulled back on ableism, I guess, and it is out there for everyone to see --- well, the people with disabilities to have it brought home to them just how we are perceived in the community. The lack of understanding that the community has for people who have complex disabilities like you get an instruction, do this, do this. Yes, but I can't do that because I can't walk.
35 Oh, yeah, okay, is there a way around that? So it's like, I don't know --- look, I will just read this:

40 *The pandemic has really illustrated to me the lack of understanding in the community of what people with disability go through or the complexity of disability. While at an event, one person got up and said to a full room of people that he thought one of the major problems in tackling the pandemic would be getting people with disabilities to wash their hands. I was absolutely gobsmacked that he would take that view.*

45 So people with complex disabilities, dealing with lots and lots of medical issues and this one person believed that one of the ways that we could basically protect ourselves was to wash our hands. We can wash our hands. What about the myriad

of other people that come into our homes and have been out in the community having contact with hundreds of other people and yet the onus was on us, who don't see anyone, isolated in our homes, to wash our hands? I was just spun out at that. I think going down town later with my mask on and on my motor scooter I felt like --- I felt a bit --- it was like an advertisement for the pandemic, I guess. Person on a scooter with a face mask. Oh, my gosh, this coronavirus is real, people are actually wearing face masks in our community so I was looked at with suspicion: why are you wearing a face mask? Do you have coronavirus? That sort of thing. So, yeah, it was really hard. And I guess it brought home to me that even though in the year 2020 we've made huge leaps and bounds with disability and integration and full participation, there is still a lot under the surface that we need to scratch away and see.

15 Q. You've said in your statement, this is paragraph 46:

I have come to realise that I have had to adapt throughout my whole life to participant in society and it's not fair. Society should make allowances for me rather than me having burn out from all the energy I use to try and participate.

20 And the pandemic has really highlighted that for you. Is that right?

A. Yeah, absolutely.

25 Q. Could I ask you, my final question is: if there is one thing for you in the beautiful North West Tasmania that would make a difference, what would it be?

A. Oh, blue sky thinking, coronavirus instantly goes away and then we don't have to worry about it.

30 Q. Apart from that?

A. I guess in terms of disability support we need better networking, better access to information and that doesn't --- so there's scaffolding of information. It's all very well for the bureaucrats to have the information, but that information needs to filter down to everyone, managers, support workers, participants, everybody needs to be on the same page so that we know what is going on. I'm the person that the disability --- that the NDIS --- I'm it. Without my disability and all the other hundreds of people, thousands of people with disabilities, this NDIS wouldn't exist and I guess we are the people that you need to be mindful of that that is what --- that the intrinsic thing about the NDIS is people with disabilities. It's us. It's us here in our homes. It's us being looked at as valuable and important people in the community. Like, I've worked for 33 years in the education department. I've contributed, I've paid taxes, I've raised a family, I've participated to the fullest extent that most people do, with a disability. So I've worked twice as hard to do what people without disabilities have done and now all I'm asking is for some consideration, I guess, that you think about just exactly how hard it is for me to do things and if you think about it, there may be adjustments, better adjustments must be

made and I won't have to ask, they will just happen.

Q. Thank you, Ms Milne. I will ask the Commissioners if they have any questions.

5 COMMISSIONER SACKVILLE: Yes, Commissioner Bennett? Commissioner Galbally, do you have a question?

10 COMMISSIONER GALBALLY: I would like to ask about the situation at work. I'm aware that we skipped over that and I just thought it was such a pity that you had to resign because there wasn't appropriate accommodation, reasonable accommodation made for you. I wonder if you could just tell us that bit.

15 MS EASTMAN: Commissioner Galbally, sorry to jump in there, that was a topic that is covered in the written statement but we weren't going to explore this morning.

COMMISSIONER GALBALLY: Can I ask a question about it or would you rather leave it until another time?

20 MS EASTMAN: Can I leave that to another time. Thank you.

COMMISSIONER GALBALLY: Okay.

MS EASTMAN: Thank you, Commissioners. That is Ms Milne's evidence.

25 COMMISSIONER SACKVILLE: I wanted to ask one question, of course with your permission.

MS EASTMAN: Of course.

30

QUESTIONS BY THE COMMISSION

35 COMMISSIONER SACKVILLE: You mention, Ms Milne, that on the Friday night the carer didn't turn up.

A. Yes.

40 COMMISSIONER SACKVILLE: What did you hear, if anything, from the service provider?

A. At 7 o'clock that night the service provider rang and said that she wouldn't be coming in and it was because of the family situation that she had been supposed to COVID, potentially had been exposed to COVID.

45

COMMISSIONER SACKVILLE: But you didn't know when the service would resume, as it were?

A. No.

5 COMMISSIONER SACKVILLE: Okay. Thank you very much for your statement and thank you very much for giving evidence from beautiful North West Tasmania. It's been very helpful.

A. Okay. No worries.

10 COMMISSIONER SACKVILLE: Thank you very much.

A. Thank you.

15 **THE WITNESS WITHDREW**

MS EASTMAN: Thank you. Commissioners, that takes us to the morning tea adjournment. I see it is 11.25 now. If we can adjourn and resume at 11.45.

20 COMMISSIONER SACKVILLE: Thank you. Yes, we will take the adjournment and resume at 11.45 promptly. Thank you.

25 **ADJOURNED** [11.33 AM]

RESUMED [11.46 AM]

30 COMMISSIONER SACKVILLE: Yes, Ms Eastman.

MS EASTMAN: Commissioners, the next witness is Ms Kayess.

35 COMMISSIONER SACKVILLE: Ms Kayess, thank you very much for coming to give evidence today. I will ask for the oath or affirmation to be administered to you.

40 **ROSEMARY KAYESS, AFFIRMED**

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

45 **EXAMINATION BY MS EASTMAN SC**

MS EASTMAN: Good morning, Ms Kayess.

A. Good morning.

5

Q. If you need a break at any time during the evidence today, please let us know and we can accommodate any short break as we go along.

A. Thank you. I would appreciate that.

10

Q. So you are not new to giving evidence in the Royal Commission. You gave evidence to the Royal Commission at the public hearing in Melbourne in December, but for people who may not have heard your evidence on that occasion, can I ask you to confirm that you are Rosemary Kayess?

15

A. I am.

Q. And you are an academic at the University of New South Wales in Sydney?

20

A. That's correct.

Q. And you prepared a statement for the Royal Commission hearing in December and you've also prepared a statement for this hearing of the Royal Commission; is that right?

25

A. That's correct.

Q. Is the content of your statement true?

30

A. To the best of my knowledge, yes.

MS EASTMAN: Commissioners, you will see with Ms Kayess' statement that there are a number of documents referred to it. Just bear with me as I take you to the relevant reference points. A copy of the statement can be found in part B of the tender bundle at tab 2. I will ask you Commissioners to mark the statement as exhibit 5.19.

35

COMMISSIONER SACKVILLE: Yes, thank you.

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EXHIBIT #5.19, STATEMENT OF MS ROSEMARY KAYESS

MS EASTMAN: There are some annexures to the statement which are found in tab 3 and 4 of part B and there are also some further annexures in part D of the tender bundle at tabs 1 through to 33. They collectively will be marked as exhibits 5.19.1 through to 5.19.35.

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**EXHIBIT #5.19.1 THROUGH TO 5.19.35, ANNEXURES TO MS KAYESS'
STATEMENT**

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MS EASTMAN: Thank you, Ms Kayess, for bearing with me on that. Now, you are a senior lecturer at the Faculty of Law at the University of New South Wales?

10 A. That's correct.

Q. And you lecture in discrimination law, international human rights law, disability law and policy?

15 A. Yes, that's correct.

Q. And you've been a lecturer at UNSW since 2005?

A. That is also correct.

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Q. You are also a Senior Research Fellow at the Social Policy Research Centre at the University of New South Wales?

A. Yes, I am.

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Q. You have served as a long-term chairperson of the Australian Centre for Disability Law?

A. That's correct.

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Q. You have been a director of the Human Rights and Disability Project at the Australian Human Rights Centre?

A. That's correct.

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Q. And last year you were awarded the Australian Human Rights Commission's human rights medal for the recognition of your work in international law for people with disability?

40 A. Yes, I was.

Q. I've surprised you there because you didn't include that in your CV.

A. No.

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Q. Congratulations on that award.

A. Thank you very much.

Q. Now, with respect to this statement that you prepared for the Royal Commission, part of the matters that you comment on you do so in your capacity as the Vice Chair
5 of the UN Committee on the Rights of Peoples with Disability. Is that right?

A. That's correct. I'm authorised to give my evidence as the --- in my role as Vice Chairperson of the Committee.

10 Q. And during the course of your evidence this morning, if you are speaking in a personal capacity, you will make that clear; is that right?

A. That's correct.

15 Q. Have you got a copy of your statement with you?

A. I do.

Q. I might at various points refer to particular paragraphs of the statement, and if we
20 need to look at any documents, we'll do so. And I want to examine the relevant international human rights law framework and relevant human rights with you in a moment. But I thought I might start by asking you about some matters that you've set out in your statement at paragraphs 21 to 23 and this touches on the issue of
25 community attitudes. So with your indulgence, I will start with these parts of your statement.

A. Certainly. I just needed to get those paragraphs up.

Q. Thanks for bearing with me. You say in your statement:
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*In the early days of the pandemic, mainstream media and the Government's coverage of the COVID-19 outbreak in Australia tended to focus on the view that for most people the COVID-19 virus was a mild flu and that those at risk were older people and those with preexisting health conditions, including
35 people with disability.*

And you observed that the tenor of the media reporting and the Government's messaging, together with general community attitudes reinforce the pervasive and unconscious ableism and ageism that you say is inherent throughout society and
40 social institutions where older people and people with disability are less valued, not viewed as part of the general community and, therefore, expendable. And you say that the COVID-19 messaging is still evident today.

Now, you have a particular view about the use of the word "vulnerable" to describe
45 people with disability. Can I ask you what is the difficulty about using the expression "vulnerable" to describe people with disability, particularly during this time of a pandemic?

5 A. Well, it comes back to the inherent view of disability as deficit, and so people are
seen as less and as not able and in need of care or treatment or protection in some
way. And so it denies the dignity of the human being, it denies the personal
resilience that that person may have, it denies the capabilities that that individual
holds. And so by that reference of being inherently vulnerable you are in some ways
denying the humanness of that person and defining them only in terms of their
disability, so the physical manifestations of their disability. And so that deficit
defines the individual. And so you don't look beyond the deficit to see what
10 capabilities, and the whole of the person.

Q. How do we overcome that?

15 A. I think we need to recognise that the concept that we have of humanness is a very
narrow concept and that we need to embrace impairment in all its forms. That's the
central argument about CRPD, is that impairment needs to be recognised within the
standard of human dignity. And so that we are humans, regardless of where we sit
on the impairment spectrum because impairment is inherent to being human.

20 Q. If we use language such as "vulnerable", what impact does that have then on how
we might approach the development of policies for people with disability if the
assumption is that people with disability are inherently vulnerable, which you say is
not the case?

25 A. We look at a very narrow aspect of the human. So what we do is we look at their
disability only and not the individual and so the disability suggests that they need
supports in these mechanisms and that they are vulnerable without those supports.
And so what gets built around people are service systems that deal with one small
aspect of the person, but don't look at the person as a whole. And it doesn't
30 necessarily measure that up against their human dignity as a person as a whole. And
what it does is it continually reinforces that they need something special when their
supports get monetised in a way that they are all delivered in the same way, yet the
individual --- and the individual gets lost.

35 Q. Can I take you now back to the beginning of your statement, which is your
discussion about a human rights-based approach during the time of an emergency?
People who followed the work of the Royal Commission at Public Hearing 3 would
have heard your very detailed evidence explaining the operation of the Convention,
the CRPD. So I don't need you to repeat the evidence that you gave on that occasion,
40 but if we do need to trespass back into some of those areas, please do so.

A. Yes.

45 Q. But I want to focus on what are the particular human rights that arise for people
with disability during the time of the pandemic? And you've referred in your
statement to Article 11 of the CRPD. Let's hope that our systems work well. I might
put the text of Article 11 up on the screen. We'll back track on that. We might use

your statement. I think we had the very excellent thematic report on the application of Article 11 and you and I might spend the rest of the day discussing that, but for those following the work of the Royal Commission, could we focus just on Article 11. So that requires that in "Situations of risk and humanitarian emergencies" that the States, the countries that have ratified this convention, take, in accordance with their obligations under international law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.

10 And at a UN level, Article 11 has been interpreted to cover pandemics and emergencies of the kind that we face with COVID-19; that's right?

15 A. Yes, that is correct.

Q. And that very good document that came up on the screen before, the Thematic Study on the Rights of Persons with Disabilities under Article 11, you have referred to in paragraph 6 of your statement. And that report provides some content, some practical examples as to how a State party, including Australia, might meet the obligations under Article 11. So can I walk through a couple of the examples that are set out in that thematic report with you that you have ---

A. Certainly.

25 Q. --- included in your statements?

The first is "reform of policies and practices in the context of situations of risk and humanitarian emergencies under the CRPD". So, pausing there, in terms of reform of policies and practices, is that looking at particular policies or particular practices that are responsive to a situation of risk or emergency?

30 A. It would be seen as broader than that. It would be seen as, yes, reforming their policies and practice in the context of situations of risk and humanitarian emergencies so you need to make sure that existing Disaster Risk Reduction strategies are inclusive of people with disability so that they are factored into the response mechanisms. But it may also stretch broader, that when you get to reviewing and reforming, that you look at the broader triggers of risk. And so what is emerging in the COVID situation is the situation with congregate settings and the heightened risk of transmission of anyone in those situations. So you may need to reform broader policies and practices that increase risk in situations of emergencies.

40 Q. The next one you set out in the statement is to "ensure effective management and dissemination of accessible information at all time stages of emergency". Do we take it by that that this right in the CRPD is not just looking at an acute point in a conflict, but that during the course of emergencies there may be different stages and there needs to be relevant information ---

A. Definitely.

Q. --- referable to each particular stage of an emergency?

5 A. Definitely. I mean, it goes without saying that unless everybody in situations of risk are all well prepared, then you are creating an unnecessary vulnerability to the broader population, especially when you are talking about something like COVID-19, unless essentially everybody is actively working to cut down transmission rates, then we are all at risk, regardless of our personal status.

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Q. Some of the other items that are set out in your statement, I will come back to in terms of looking at particular Australian responses, but in the rest of this part of your statement you also highlight the importance of not just looking at Article 11 in isolation, but this article and this human rights has to pick up a whole range of other human rights in the Convention and you talk about this as cross-cutting; is that right?

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A. Yes. The State obligations, the articles that establish State obligations as opposed to individual rights have the --- are a mechanism by which individual rights are enlivened. So Article 11 does not provide an individual --- doesn't give a statement of rights to individuals. They don't bear rights under Article 11. But what it does is it enlivens the rights, the other individual rights within the Convention. So, the right to life; Article 11 is about facilitating the right to life. Article 11 also has a relationship with Article 21 in terms of the right for information, accessible information. But it also needs to be able to be seen in terms of the reduction of risk and violation of other rights such as autonomy set out in Article 12, or articles 14, 15 and 16 in terms of security and liberty of the person. And so the use of physical restraints to stop people from participating in the community to reduce transmission is a violation of their rights and there needs to be other ways of doing it that are within a human rights framework.

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Q. When you gave evidence back in December at a public hearing in Melbourne, we discussed the obligations of Australia to provide reports to the UN committee and the work of the UN committee reviewing Australia's reports about how Australia is travelling with compliance with the Convention obligations. And the committee has reviewed the Australian reports, and particularly the Australian response to its obligations under Article 11. And in your statement you say at paragraph 14 that.

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40 *..... the Committee has called upon Australia to consult with people with disabilities to establish nationally consistent emergency management standards to be implemented across all three levels of government, ensure inclusivity across diverse disabilities and cover all phases of emergency management preparation*

45 These recommendations were made before anyone had COVID-19 in contemplation, but you have noted that the Committee made a recommendation to Australia that it work in close collaboration with representative organisations of persons with disability to establish a fully accessible and inclusive mechanism to engage with

persons with a disability in the implementation and monitoring of something called the Sendai Framework. That is paragraph 15 of your statement. So the Sendai Framework for Disaster Risk Reduction, you've set out in some detail the operational framework in paragraphs 17 through to 19. You say, coming back to 16, that the COVID-19 pandemic has revealed that the CRPD has not been fully comprehensively implemented by States Parties and Australia has not fully implemented the concluding observations of the UN committee. And you say that it appears that the normative content of the CRPD has not informed its response to COVID-19. So the question I have is, why? Why do you hold that view?

A. Personally, I'm not speaking on behalf of my colleagues on the Committee here, personally I believe it is because there is a view within Government to a large respect that because we have the NDIS, disability is sorted. Everything is okay. And to a large extent, disability is invisible within Australian society in many ways. And a lot of that comes from the fact that people with disability are invisible within Australian society in many ways. Many people live very sheltered and isolated lives because of the nature of their residential settings. They don't have the resources or the accessibility to be out and about. We all know the incredibly low employment rate of people with disability. So people with disability are not visible within the society. And so I think it is a combination of those three that disability just gets left off the list.

Q. So you've looked specifically at some of the major policy announcements of the Commonwealth in responding to COVID-19 in your statement. And the first one that you address in paragraph 24 is the mid-February 2020, and I think this was 17 February, the Australian Health Sector Emergency Response Plan for Novel Coronavirus (COVID-19). This was developed by the Australian Health Protection Principal Committee which you identify as the key decision-making body comprised of State and Territory and I think also Commonwealth chief health officers. And you say that under that plan there was no targeted focus on people with disability or specific actions to ensure inclusion in risk mitigation and protection measures. And you form that view because of the absence of express references to people with disability in that document; is that right?

A. Yes, I do.

Q. And so was it the case that in the following months from the announcement of that plan it was your view that there was no active or coordinated plan for people with disability in response to the COVID-19 pandemic and you give a range of examples in paragraph 25 about people with disability having little or no targeted accessible information, information about physical distancing and information in appropriate form, so sign language interpretation, Easy Read materials, and the like. So is the effect of this period of time that it prompted the disability advocacy community to have to take some action? Is that right? And were you involved in that at all?

A. Definitely. On the sides. I won't take it away from the activists, they were

responding to the situation that they were all living in at the time and we were all living in at the time. They saw the need for urgent action to happen. They sought my advice on a few things but they pulled together and developed a response to the lack of information and focused on disability.

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Q. By 16 April this year the Commonwealth Department of Health published what is the Management and Operational Plan for People with Disability as part of the Australian Health Sector Emergency Response Plan. And you note that that plan recognises Australia's obligations to uphold the CRPD and also refers to the National Disability Strategy, that's the 2010–2020 document. But you have some concerns about this particular plan which was developed. The Government might say, "Well, we set up an Advisory Committee, we had people with disability contributing to an Advisory Committee, we listened to what people with disability had to say", do you have a view about this plan and the way in which the plan was developed?

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A. I think it is very difficult --- the plan was developed late in the process and so there was lots of information that people with disability themselves had about what was happening. And for me the high level nature of this plan, and to a certain extent it needs to be very much a framing document and there would be other plans that would fall out of it, such as implementation plans, probably at State level and community level, but I think that if you look at the make-up of the advisory group, it is questionable to the extent that people with disability were able to frame the issues as their issues and get to some of the really key points that were beyond service issues.

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Q. So the Government might say this to you, that the Advisory Committee was established on 2 April, it wanted to move very quickly and by 16 April, out of that process, came the plan. And what do you say about, well, if there was an urgency, the Government needed to act quickly and how does that fit in with a relevant human rights response?

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A. In hindsight, it should have started earlier. Okay, so they responded and then they needed it to act quickly. I think what they needed to start from is not just an NDIS perspective, but a much broader perspective and I think they needed to structure the plan in a way that was accessible to people with disability to understand what it was saying about what was happening. There still wasn't a lot of clarity that came out of that plan for people with disability.

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Q. You observe in your statement at paragraph 35 that the pandemic and the exclusion of people with disability from the February emergency response plan that the omission, that was a specific reference to people with disability, had the effect of causing significant fear and anxiety and, indeed, confusion among people with disability and so that, again, urged some of the disability advocacy groups to write an open letter to the Cabinet. And you were also involved in writing a public statement about a real concern that had developed in the disability community that people with disability may not get access to critical care at critical points in time. Did this arise because looking at what may have been happening overseas in terms of

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rationing on critical care that there was a concern that what would Australia do if there were no spaces in intensive care units or a shortage of ventilators? Can I ask you about this planning aspect from a human rights perspective and planning when you manage that type of fear within the community?

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A. From a human rights perspective, many of the proposals that were, and some of them were not just proposals, some were actually put into action, we saw documentation from Canada, from England, that highlighted the ways that decisions were going to be made about critical care triage and some of them were being made on blatant arbitrary diagnostic status with no clinical reference whatsoever. So no recognition of a person's right to equality in the standard of health care that was available. So based primarily on their diagnostic status, they would not receive critical care.

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15 Q. That caused you personally as an educated, working woman with expertise in human rights law, even these circumstances caused you to feel under siege and not in control of your situation and also worried about what access you might have to health care, is that right?

20 A. Look, personally, for the first couple of weeks of March when I require --- I have personal support people that work with me. I'm extremely lucky that I was able to reduce my transmission risk somewhat because the people who work for me only work for me. So I was able to feel as if we could manage that a bit better. It was not as if I could not have people coming into my home, but that the people who were coming into my home I had a clear understanding of who they were associating with at the same time. And there wasn't several other people that they were supporting, which is very common within disability support services, personal care in individuals' homes. So that was one, but we couldn't access personal protective equipment. Getting masks was nigh on impossible, so the ability to work on the process where you just work as if your support person has the virus. They are masked at all times once they are within a 2 metre or 1.5 metre area of you. That, you know, hygiene, we couldn't get sanitiser. Luckily, I have people in my family with chemistry degrees, and they told me to buy some pure alcohol, get some ethanol, break it down with 300 ml of water and use that as a surface-area sanitiser, but this stuff was not readily available easily and there was no information about how I support my support people and how they were to feel as if they were able to support me. So even getting food became difficult. Not getting food itself, but shopping for various things, and we all know the situation with toilet paper. But what was the greatest struggle was when the triage stuff started to happen. Now, I'm a person with a spinal cord injury. I have a very high level of spinal cord injury. I have a history of bronchitis and have had pneumonia and it is my Achilles heel. It seriously is my Achilles heel. To be very blunt, COVID scares the fuck out of me, Kate, it really does.

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45 Q. Do you still have that fear now, the fear has not waned at all?

A. No, it is still in the background. It's not in the forefront of my mind but it still

lingers there in the background. In March it was consuming me. Now, as I have said, it is in the background. When the triage stuff started to come out, as I say, and I've said in a couple of settings, I professionally deal with human rights and abuses and violations, I write about the interaction of law and ableism but here in my very privileged life I was being quite viscerally shown that I was dispensable, I was expendable, that because of my status I would not get a clinical assessment and equal treatment in access to health care.

Q. In the time that we've got left this morning, and there is so much in your statement --- Commissioners, I can't cover everything in Rosemary Kayess' statement, I just want to ask you about a number of particular concerns that you've identified that you've heard during the course of the pandemic. So there are a large number of matters that you set out in paragraph 42. You say at paragraph 42.2:

The increasing use of restrictive practices, including physical, chemical and environmental restraints to enforce physical distancing and transmission risk, such as increases in medications, disabling mobility devices, restricting people from going to work and health appointments, confining people to their rooms for long periods of time.

Is a breach of human rights. And also you say:

The increased use of menstrual suppression of women and girls with disability due to the lack of availability of sanitary products caused by panic buying.

Both of those things may come as a surprise to the community that these are concerns coming to your attention. Can I ask you to comment on the concerns that have been raised with you in these two areas?

A. Unfortunately I remember a conversation with a colleague at the beginning of this that, you know, we saw this is going to be a big deal for congregate care and that there is going to be --- we nearly saw it coming. So it isn't as if we went looking for this stuff. We were hoping that it might have been a different situation, but --- and then when we saw the two guardianship decisions in New South Wales that extended --- actually extended restrictive practice mechanisms available to guardianship to be able to physically restrain people from leaving their house. I mean, this was at the stage where people could still go shopping and could still go out for exercise. There were reports and there were reports in the media about people having their assistive devices, so their mobility devices disabled so stopping them from going out of their premises. Then there started to come the concern from parents of people living in group homes that they were being confined to their rooms for long periods of time and that people didn't have access to devices to be able to contact family and friends and maintain social relationships or family relationships. For me, sadly, it was a little bit predictable but then people with disability started to report the impact financially from COVID in terms of the increased cost of things, the difficulty to get stuff. So you had to order it in and that costs more and people with disability weren't included in the COVID payment initially.

5 Q. Finally, I want to move to where do we go from here? And if a human rights approach is taken in addressing the ongoing COVID crisis, I want to just ask you a few questions about those parts of your statement and some recommendations that you make as to a human rights approach.

A. Certainly.

10 Q. So you identify in paragraph 47 the importance of a disability inclusive approach, but you also make the point that that should be informed by rigorous, disability inclusive research methods for the collection of disaggregated data and a robust evidence base. Are you aware of any collection of data concerning people with disability during the course of the COVID-19 pandemic?

15 A. No, I'm not aware of any specific. I'm aware of various academics doing a variety of research projects. I'm not aware of any actual prevalence type data that is around. I've not come across anything that has analysed the rate of COVID within the disability community or sector or any implications that has had within various service systems. There will be, I assume, some data that will come out of the NDIS
20 or the NDIA structure, but that's not, you know, necessarily guaranteed. And there has been no reporting of disaggregated data; disaggregated data in terms of disability in terms of COVID cases that I've seen.

25 Q. Now, you make a number of recommendations, if I can use that word, about how Australia could respond from a rights-based perspective and Commissioners, they are set out in some detail in paragraph 48 of the statement.

30 My final question, then, Ms Kayess, is that in terms of one thing that may make a difference at the present point in time to achieve a human rights-based approach that is disability inclusive, what would that be?

35 A. I think it is getting strong understanding of disability within the policy discourse. So I think that is about having strong engagement with people with disability and their representative organisations. I think it is about having a whole-of-government approach. So something that doesn't see disability just in a service context.
40 Something that doesn't understand the lives of people with disability just as a welfare service provision issue, that people with disability are defined by welfare issues and service system provision. So we need to move beyond a policy focus that is service enhancement and safeguards. That's what disability seems to get boiled down to all the time when people with disability have a broad spectrum of engagement across government policy portfolios. And, until that is recognised, people with disability will continue to be "confined", and I use that as a double-edged word, confined to service systems and specialised care and protection, which actually through this
45 process has created their vulnerability and heightened their risk, some might say exponentially.

Q. Thank you, Ms Kayess. I will now turn to the Commissioners if the

Commissioners have any questions.

COMMISSIONER SACKVILLE: I will ask first Commissioner Bennett?

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QUESTIONS BY THE COMMISSION

10 COMMISSIONER BENNETT: I -- not necessarily an answer for today, but I
wondered in your last paragraphs you recommended or suggested the establishment
of a disability inclusion office and then a strong watchdog and a changed relationship
with the ombudsman. The flip side is, what would we --- what could be gotten rid of
if you actually had less and stronger national entities? In the Commission we've
15 heard and seen submissions that we are getting information, having a decision
reviewed, being able to make a complaint is such a complex and multi-focused and
often referred to different organisations. It is neither the right issue nor the right
demographic or the wrong cohort. I wondered if you might just consider how you
might make what is a complex system of getting advice, information, review of
decision or complaints simpler and maybe come back to us on that?

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A. I would have to take that on notice, but one of the things I would say is that we
continue, I mean, we continue to focus on the NDIS. The NDIS represents
10 per cent of people with disability. So what was done for COVID was focus on
NDIS recipients. Now I know this because I personally am not an NDIS recipient.
25 So I know what it's like to be a person with a disability and not included in that
COVID framework. So all information went through NDIS structures and so if you
are not in that, you weren't getting the information. I mean, that came down to
something as bog simple as getting groceries. So to have them delivered you needed
the seven-digit NDIS number and if you didn't, you couldn't get your groceries
30 delivered. So that is one of the things that we need to recognise, is that impairment
in Australia doesn't stop with being an NDIS recipient.

COMMISSIONER SACKVILLE: Thank you. Commissioner Galbally?

35 COMMISSIONER GALBALLY: No, no questions, thanks.

COMMISSIONER SACKVILLE: Ms Kayess, thank you very much. You have
been of enormous assistance to the Royal Commission in a variety of roles, your
research, your evidence, and your contribution to other parts of the work of the
40 Commission have been very great indeed and we do appreciate it. Thank you for
your contribution today.

A. Thank you, Commissioner Sackville.

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THE WITNESS WITHDREW

MS EASTMAN: That concludes Ms Kayess' evidence.

Commissioners, the next witness has a pseudonym and will be identified as AAV.
5 Commissioners, while the witness is coming on, you will find a copy of her
statement in part A of the tender bundle behind tab 2. And I will ask you in due
course to identify that as exhibit 5.2, including the annexure at tab 3, which is 5.2.1.

10 **EXHIBIT #5.2, WITNESS STATEMENT OF AAV, DATED 6 AUGUST 2020**

MS EASTMAN: I can see that AAV is now joining us. Before I take any evidence
15 from AAV, or she gives an oath or affirmation, Commissioners, you made
a non-publication order on 12 August in relation to this witness and her four children.
The effect of the non-publication order means that there can be no publication of the
names or any identifying information of this witness or her children.

COMMISSIONER SACKVILLE: Thank you.
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AAV, I must call you that, we will now ask you, please, to take the oath or
affirmation and then Ms Eastman will ask you some questions. Thank you.

25 **AAV, AFFIRMED**

EXAMINATION BY MS EASTMAN SC

30 COMMISSIONER SACKVILLE: Thank you.

MS EASTMAN: Thank you.

35 I will call you AAV. I hope we can manage with the pseudonym. Thank you very
much for your participation in the Royal Commission hearing today. You have
provided your address and your details to the Royal Commission. And are you
a full-time carer. Is that right?

40 A. That's correct.

Q. You've made a statement dated 6 August. Are the contents of that statement
true?

45 A. Yes, they are.

Q. There is one matter you wanted to clarify at paragraph 57. We will get to that in

due course.

A. Okay.

5 Q. Can I start by asking you to tell the Royal Commission a little bit about yourself, your children and your present circumstances? The Commissioners have your statement that tells us that you are a full-time carer and you have four children between the age of 14 and 22 and each of your children have a disability of some kind; is that right?

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A. That's correct. Yes, that's right. I've got three on the autism spectrum, one of them also has a neurodegenerative condition and one of them, although not formally diagnosed on the autism spectrum, most likely is and he's suffering severe anxiety and depression and two of them are also suicidal.

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Q. You have no extended family or support in any way; is that right?

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A. That's correct. Both my parents are dead. My husband's mother died a long time ago. My husband's father is almost 90 and living in Victoria. And that's of great concern to us. My siblings are either overseas or interstate and are all in their 70s. And my brother's --- sorry, my husband's siblings are also interstate. So we are basically living here isolated from our extended family.

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Q. And you are a full-time carer for your eldest son, but I think you say in your statement, this:

I am not a stay at home mum. I'm a trapped at home mum and my family is trapped with me.

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A. That's correct.

Q. Does that give the Royal Commission a sense of what a day-to-day life is for you?

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A. Yes. If I'm going to leave the house to go and do any errands, I have to time it when there is somebody in the house, my husband or one of the other adult children that can at least make a phone call, I can't really go two hours out of the house, but even that is restrictive. Trying to organise appointments for the other children --- I describe it a bit like having a new born in the house where you have to arrange all your appointments and your outings and your activities around the activities of the most severely disabled, which in my case is my eldest son, who has both

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a neurodegenerative condition and ASD. So that is difficult.

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Q. You say in your statement that isolation and social distancing is your usual way of life, that your family is so restricted in what you can do, where you can go and that you just don't attend sporting matches, concerts, theatre, and festivals.

A. No.

Q. And so to the extent that the rest of the community has experienced isolation during COVID-19, that is your ordinary every day.

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A. That is day-to-day life. That is day-to-day life. I get a little irritated when I hear people complaining about it because I'm like, "You know guys, there are people living like this all the time", and you tend to --- you adapt, I suppose. My mother's generation was from World War II and I learnt a lot of adaption from her. You just get on. It is --- it's really hard --- I think it is hardest on the kids because they don't get asked out, they don't have the friendship route or the social groups, they don't get that time away from the home and from the stressors in the house. And I think that is probably what drives a lot of the suicidal ideation that the younger ones have. They are lonely. And they are just --- it is just heart breaking.

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Q. You say this to the Royal Commission, and I will read paragraph 13 of your statement:

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Even before COVID-19, we have been trapped in our house, no longer a home, but more a prison. I can't remember the last time the family laughed, played and was happy. We don't choose to live this way. For my family, it is a life sentence of isolation, despair and exhaustion.

25

A. Yes, that's completely correct. The angst and the upset and the tension in the house and the different dynamics in the house prevent that communal gathering and sharing and laughing and it just --- and because we can't get away together as a family, because --- even before COVID, because we can't get away as a family because of the restrictions of finding a location that is accessible both financially and physically, it means we don't have that break from the drudgery of getting up at dawn, doing all the things you have to do, doing the caring roles, doing the life, doing the job, going to bed late, getting up in the middle of the night again. All that is just relentless.

30

35

Q. I want to ask you about the impact of the pandemic on top of that all-day, everyday experience that you describe.

A. Yes.

40

Q. You anticipated the seriousness of the pandemic back in January this year.

A. Correct.

45

Q. And in January you decided that you needed to act swiftly to obtain necessary supplies and they are non-perishable food, prescription medications, basic equipment for physical therapies. And it is right, isn't it, that in January you identified masks as a particular important aspect of the personal protective equipment that you and your family needed; is that right?

A. Yes, that's right. And I started trying to access just to have a box of masks in the house for how or when we were going to need them. But it was difficult even then and I remember that there were already reports of mask shortages because it was on the back of all the bushfires and people were complaining about not having masks because of they had disappeared from shelves because of bushfires. And then COVID came in really strong and it became apparent that it was going to be even harder. I put an order in from Amazon, I think it was, but it didn't come and it didn't come and eventually the order was cancelled and I got the refund and I finished up hitting the sewing room with all my scraps and making --- spending a day sewing masks for family and friends and even sent some to my sister's family overseas.

Q. So I want to ask you about particular aspects of family life and the impact of COVID-19. So I will work through the statement. The first is that the home school, that was a change for two of your school aged children that they remained at home from 17 March.

A. That's correct.

Q. And this is partly to protect their older brother, but this resulted in a fairly significant change to their routine. And for a young person with autism, what has the impact of home-schooling meant for one of your children?

A. For any change of routine, anything that is different, you are immediately dealing with tension and upset and challenges and meltdowns just before you even start. So I've learnt over the years it was really important to have routine, strict routines, even the same time that we were getting up in the morning, and the same time for breakfast and the only thing was --- it was a perpetual casual day. I didn't put them in uniform. And I got their timetable out and we stuck to the timetable like glue. And before --- the last day of school, before I knew I was going to be bringing them home, I made them clean out their lockers, we went to their lockers, we cleaned out their lockers and we made sure we had everything we needed. I contacted the school and I said, "This is the situation, we are staying home, I'm teaching them from home, please send through anything you have." To be fair, they actually did a really good job in that. They were really helpful. They have a system of connecting. As the pandemic increased, they tried some web conferences but my severely --- my disabled --- my autistic son who was in year 9 really didn't manage that at all because it was two-dimensional, I suppose, and there is too much else going on in the room to focus what is going on on the screen. I had to spend a lot of time sitting with him, working with him with his school work. I had to teach myself year 9 maths because it had been a very long time since I have done maths and I'm sure we didn't do that back when I did year 9 maths. So that was a challenge because I found that really frustrating, particularly as it was an area of maths I used to be good at. So that got me upset and uptight because I felt like I was letting him down. And I was really determined that he wasn't going to get behind, because I could see it is very easy to slip into: we're not doing the work, we are sitting on the computer game, and so --- he was hard work. He needed a lot of attention and teasing out of information.

I learnt that he had --- the knowledge is there, it's trying to --- he looks at a sheet which he has to work on and he can't decipher what has to be drawn out to put on the page. So trying to play 20 questions with him and tease out the information bit by bit was a huge challenge and draining, on top of my usual caring duties that I was
5 involved in with my eldest son, with getting him out of bed, getting him in the shower, showering him, dressing him, helping him with all his personal care needs, the lunches, the feeding, the whole thing. So that's going on as well. At the same time, I have another child at home doing year 12, who is a massively high achiever, who was constantly getting me to proofread psychology essays and research project
10 essays and English essays and thank God she didn't give me chemistry or biology. There was no time. There was no second in the day to think of anything other than that.

Q. So can I ask you, because one of the things you also say in your statement is that
15 you also had to manage a range of medical appointments?

A. Yes, that's right.

Q. Which would normally be in person, but some of them moved to online, but there
20 were still some issues for your eldest son to get to medical appointments while you are running the home school. How did you manage the medical appointments?

A. Well, some we cancelled and we're still trying to get rescheduled. Some moved
25 online with limited success. And the OT for my youngest moved online. It kind of worked but I had to be supervising pretty strictly, closely. The youngest also had a cardiology appointment because we were concerned he had a heart condition. That had to go on to a virtual meeting which clearly wasn't going to achieve anything and then we had to wait till later to go down to the hospital to get scans done. And
30 [REDACTED], the youngest, one of them, has terrible trouble with hearing audio stuff and so any online communication I have to translate. So, yes, it was --- all this is going on as well as --- and the other ones are having mental health appointments online as well. So in some ways it was good because I didn't have to drive an hour to get to the appointment and set up the extra care, but it is still the balancing act and the juggling act and every so often I would drop a ball.

35

Q. You've talked in your statement about the financial stress on the family during
this period of time, that you are not able to work and there is a single income
supporting the family, and you make some observations in your statement about the
financial assistance that has been available to carers for people such in your own
40 circumstances, and also being able to access the NDIS funding as family members. Can you tell us what has been the barriers or difficulties in terms of the financial stress and then access to relevant payments?

A. Oh, boy, where do I start? Sorry. Okay, yes, we are on a single income and my
45 husband's work has been hanging by a thread. He is a defence contractor and in February the contract came to an end. And at the end of February they extended it to the end of March. At the end of March they extended it to the end of April. And this

continued like this, gradually. So we never, ever knew how long he was going to be in employment until the day before it was due to finish. So that was a weight hanging over us. The adult children or late teenage children in the house who do work and were able to have their bit of independent income, that disappeared for them. One of them was doing some cleaning work for a disabled family and that family closed down services because of COVID. So she lost her employment. Another one is --- works at a local supermarket chain and this supermarket chain, the management did not provide screens for the checkout staff and she did not feel safe enough to continue working so she has basically not returned since March to work.

I cannot work at all because my eldest requires, because of his ASD, he is very, very, very strict about who will care for him and do personal care needs. He will only permit me to do any personal care or get him out of bed or shower him or toilet him or any of those personal needs. He will not allow anybody else. He will tolerate his father helping to do it, but I have to be there to supervise because otherwise arguments start out about how they are doing it. So there is no option of work. I can't even do volunteer work anymore.

So, we, at the beginning of this year when we were applying, around the time in January, I can't even remember now it was so long ago, we were doing his latest plan for the NDIS and we put in ---

Q. Sorry to interrupt you there, that's one thing that you want to clarify in the statement, is that right, in terms of the NDIS plan and the funding ---

A. Yes.

Q. --- for a wheelchair?

A. Yes.

Q. What do you want to change in the statement?

A. To clarify with that, when we --- when the plan initially came out, there was no funding to replace the wheelchair --- to update his wheelchair, which was top on his list. And we applied to make --- we made phone calls to chase that up and we eventually were told that "Yes, yes, it's all been changed, it's all good, you now have funding for a wheelchair", which at the time of making this application I took on faith, I suppose, making this statement I took on faith, and since then I have gone through the statement, gone through the plan, and there is funding to repair the wheelchair, there is funding to script a wheelchair, but there is no funding for a wheelchair.

Q. And that's the clarification you wanted to make to the statement?

A. Yes, I do.

Q. All right. So I'm conscious of the time and I am going to ask the Royal Commissioners for an indulgence of a few extra minutes beyond the allocated luncheon adjournment. But I wanted to ask you this, stepping back from the experience of COVID-19 over the last six months, is there one thing that would have
5 made a difference for you and your family in being able to navigate through this period of time?

A. One thing?

10 Q. You might say one thing is impossible and there are many things but --- (overspeaking) ---

A. Okay, I've had a couple of thoughts on this and there are probably two main things; one of them is the way that carers are being viewed by the government for
15 necessary funding. We have been compartmentalised, if you like, into not being very significant. We are called "informal support" which is clearly an accounting term. We --- hang on, I've got something I jotted down here because I want to get this right. A regular financial payment for the work carers do, respectful of what we are actually doing and the work we are doing. It will provide income, it will provide
20 self-esteem and self-worth and improve mental health. The NDIA needs to review its assumptions on what family carers are and how they administer regular payments to the caring full-time. Centrelink needs to look at income thresholds for couples and actually make them two single incomes or at least equate it to how many hours a carer is working and how many people they are actually caring for with a disability
25 in their family. Maybe make a scaled threshold of income because right now the income that we are allowed to earn is nothing. I get a carer's allowance of \$9 a day and that's it. And I'm working 24 hours a day. My --- the other thing that carers need to be --- all carers need to be given healthcare cards to take the pressure of our own health. Our health is coming from the same financial pool as a disabled family
30 member. The other thing that is really important, which would have made a difference, is the health workforce classification. This is a geographical map which designates who is in need depending on where they live. The problem is disability doesn't care where they live. It cares about being able to get out of the door, not being able to go to something convenient. We've so often been told that we are
35 either too far out from the GPO or we are too close to the GPO. It seems to depend on which way the money is flowing. But you can guarantee that we're always on the wrong side of it. And disabled families shouldn't have to worry about geographical boundaries or boundaries of any sort because every day is a challenge and a struggle for us. Every single day. So they are probably some of the most important things
40 that would make a difference. Don't forget us. We are working our butts off and we are being pushed aside all the time, because we don't pay income tax so, therefore, we don't count. I couldn't even get on to my super, because I can't get JobSeeker, because I can't apply for a job because I'm already working full time. We're forgotten. We're the forgotten members of this society, and I think Deloitte said we
45 are saving this country \$77 million, or something ridiculous, just the other day.

Q. So, AAV, I feel we've only touched the surface of your family's experience over

the last six months. We've got your very detailed written statement, but I wanted to thank you very much for your evidence today and at least opening the window into your experience and your family's experience over this time. I will just check with the Commissioners whether they have any questions.

5

COMMISSIONER SACKVILLE: Commissioner Galbally?

COMMISSIONER GALBALLY: No questions, thanks.

10 COMMISSIONER SACKVILLE: Thank you very much for your evidence, your statement and your evidence today. I'm sorry I can't refer to you by name, but thank you so much for your contribution to the Royal Commission.

A. Thank you very much.

15

MS EASTMAN: Thank you, AAV.

A. Thank you.

20

THE WITNESS WITHDREW

MS EASTMAN: Commissioners, that brings us to the luncheon adjournment and I think, Commissioners, you had planned to adjourn now until 2 pm.

25

COMMISSIONER SACKVILLE: All right, we will adjourn now until 2 pm. Thank you very much.

30

ADJOURNED

[1.05 PM]

RESUMED

[2.02 PM]

35

MS EASTMAN: Commissioner, I think for this afternoon we have a number of panels and the first two witnesses in a panel will be Mr Ross Joyce and Patrick McGee and they will take an affirmation.

40

COMMISSIONER SACKVILLE: Thank you.

ROSS JOYCE, AFFIRMED

45

PATRICK MCGEE, AFFIRMED

MR JOYCE: I do.

5 COMMISSIONER SACKVILLE: Can we hear Mr McGee?

MR MCGEE: My apologies, I do.

10 COMMISSIONER SACKVILLE: Thank you. Ms Eastman will now ask you some questions.

EXAMINATION BY MS EASTMAN SC

15

MS EASTMAN: Thank you Mr Joyce and Mr McGee for joining us this afternoon. You have prepared a joint statement for the Royal Commission and each of you have read the statement and can you confirm that with respect to your various contributions that the contents of the statement are true?

20

MR JOYCE: Yes, I can confirm that.

MR MCGEE: Yes, I can confirm that.

25

MS EASTMAN: Commissioners, I'm doing this a little out of the ordinary order. I just want to deal with the statement first. So, the statement, you will find a copy in tender bundle part B, behind tab 5. I will ask Commissioners to receive the statement into evidence and mark as exhibit 5.20.

30

EXHIBIT #5.20, JOINT STATEMENT OF ROSS JOYCE AND PATRICK MCGEE, DATED 20 AUGUST 2020

35

COMMISSIONER SACKVILLE: Yes, thank you.

40

MS EASTMAN: There are some annexures that will accompany the statement which will be marked 5.20.1 through to 5.20.5 and they are documents in tender bundle part B, behind tab 6 and 7, and in tender bundle part E behind tabs 1 to 3.

45

EXHIBIT #5.20.1 THROUGH TO 5.20.5, ANNEXURES TO JOINT STATEMENT OF ROSS JOYCE AND PATRICK MCGEE, DATED 20 AUGUST 2020

45

MS EASTMAN: There is one of the documents I will bring up on to the screen

during the course of evidence.

Thank you for bearing with me while I dealt with those formalities.

5 Mr Joyce, can I start with you. Your name is Ross Joyce?

MR JOYCE: Yes, correct.

10 MS EASTMAN: And you are the CEO of the Australian Federation of Disability Organisations, commonly referred to as AFDO; is that right?

MR JOYCE: That is correct.

15 MS EASTMAN: And, Mr McGee, your full name is Patrick McGee?

MR MCGEE: That is correct.

20 MS EASTMAN: And you are the National Manager, Policy, Advocacy and Research at AFDO?

MR MCGEE: That is correct.

25 MS EASTMAN: Now, you are going to give your evidence this afternoon and what I want to do is take you through a number of issues, and there is a lot of issues in your statement. So between the two of you, you may each wish to answer particular questions, but if I start by directing each of you to a particular topic, let's see how we go from there.

30 So, Mr Joyce, can I start with you. Can you tell the Royal Commission about AFDO, what its role is and what role it plays in terms of disability advocacy in Australia?

MR JOYCE: Yes, thank you.

35 AFDO is a Disabled People's Organisation, a DPO, as it is known as, a cross-disability representative organisation and we are the national voice representing people with disability in Australia. Our members are National and State disability advocacy organisations run by and for people with disability and their families representing Australians with disability.

40 Our vision is to achieve a community where people with disability can participate in all aspects of social, economic, political and cultural life. AFDO and our member organisations have a combined reach of over 3.8 million Australians, being people with disability, their families, supporters.

45 MS EASTMAN: Mr McGee, can I ask you about your role as the National Manager of Policy, Advocacy and Research. What does your job involve?

MR MCGEE: My role involves connecting the dots between --- from a research point of view and hearing from and networking with the disability community and people with disabilities particularly, and then representing those issues to
5 governments, primarily at the Commonwealth level, but sometimes at the State and Territory level. One of my key roles is to ensure that people with disabilities are actually provided with opportunities to speak for themselves and our job, therefore, would be to facilitate that access and to support them whilst they do --- whilst they speak for themselves.

10 MS EASTMAN: Thank you.

As you know, this hearing is focused on the impact of the COVID-19 pandemic on people with disability. Mr Joyce, is it correct that the disability sector became
15 concerned about the impact of the --- impending impact of the coronavirus in Australia for people with disability in early February?

MR JOYCE: That is correct.

20 MS EASTMAN: And are you aware of the NDIS Quality and Safeguards Commission issuing a provider alert on 7 February?

MR JOYCE: Yes, I certainly am, and we obviously also posted that out through our media sources as well.

25 MS EASTMAN: And in terms of that alert on 7 February, what does an NDIS Quality and Safeguards Commission alert mean in terms of your expectation of service providers or the information that the community needs to know and understand?

30 MR JOYCE: Well, our understanding would be that we would expect that service providers need to pay attention to that as part of their contractual obligations in providing any service and look after the health, safety and welfare of not only their staff, but of also any of the people with disability that they may be supporting.

35 MS EASTMAN: It's the case, isn't it, Mr Joyce, that the sector watched and waited to see what the Commonwealth's response would be for people with disability throughout February and into the early part of March; is that right?

40 MR JOYCE: Correct.

MS EASTMAN: And during the March period, what was AFDO hearing from the disability sector? What issues were arising?

45 MR JOYCE: Well, collectively, peaks through the sector --- we spoke with each other and thought, well, where is the representation happening for people with disability in the Government plans? We were quite concerned about that. We

became more concerned over it and then we thought we needed to take some action.

5 MS EASTMAN: Is the action that you took the open letter to the National Cabinet, that is referred to in paragraph 23 of your joint statement? So on 2 April a letter went to the National Cabinet. I think on my count there were 71 organisations, but a very significant number of organisations signed up to that letter. Can I ask you, what brought about the making of this letter and the contact to the National Cabinet?

10 MR JOYCE: Well, basically we saw that consideration for people with disability wasn't there in all the plans that were laid out at that point in time. So we thought there needed to be a mechanism and we thought the National Cabinet was the most appropriate way through the Prime Minister to actually raise the concerns from the sector and to say that we need consideration to be given in everything that the Governments are doing for people with disability.

15 MS EASTMAN: And that letter had a list of urgent actions and I hope that we can get up on the screen that part of the "urgent actions" document. So the document reference is FPD.999.001.006. Commissioners, this is part of tender bundle part E, volume 1, tab 1.

20 COMMISSIONER SACKVILLE: Thank you.

MS EASTMAN: So that worked. Slight breath there. Can I draw your attention to the urgent actions and there are ten urgent actions. Mr Joyce and Mr McGee, if you want to add to this, can you just walk us through why by 2 April you had identified, along with all the 69, 70 other disability organisations and advocacy groups, these as being the relevant urgent actions?

30 MR JOYCE: We had a number of meetings and you mentioned earlier about the Quality and Safeguards Commission issuing that provider alert, that certainly alerted us and if not slightly alarmed us as to what was going to happen there. So we collectively as a sector got together, worked through these, AFDO and all of its members signed off on that Statement of Concern and we did that collectively with quite a range of, as you mentioned, other peaks and key organisations that work on behalf of and for people with disability.

35 The essence of what was there, and you see that the very first one on that list is guaranteed continuity of supports for all people with disability. We became incredibly alarmed that there could be failure or other things of service providers and that relevant services for people with disability, and particularly those that need daily supports, may be in jeopardy, may not happen. We weren't sure what the workforce might do. The workforce may have decided, people could decide that they didn't feel safe in providing the supports, and we were very worried about who was going to continue on with that. Hence, they are in a bit of an order of how we rated them at the time. But they are all equally important in the statement and that became known as the 10 Point Plan.

MS EASTMAN: On the same day as your letter to --- open letter to the National Cabinet, the Commonwealth Department of Health established an Advisory Committee on health emergency response to coronavirus for People with Disability. Now that Committee is chaired by Mr Simon Cotterell, who will give evidence later in the week. Was AFDO part of the Advisory Committee?

MR JOYCE: No, AFDO wasn't but what we did as a sector, as sector peaks is we agreed with Jeff Smith, who is the Chief Executive Officer of People with Disability Australia as being our nominated representative on that. We weren't able to have multiple representatives there.

MS EASTMAN: But there was a meeting called a roundtable that was convened by the Commonwealth Department of Health on 7 April and you participated in that meeting?

MR JOYCE: Correct. Yes, I did.

MS EASTMAN: What can you tell the Royal Commission about the purpose of the 7 April meeting and whether any of the concerns identified in the 2 April letter were discussed during the course of that meeting?

MR JOYCE: Yes, those concerns were discussed in that meeting and I believe it was really called because of that purpose of us having sent that letter in. So we discussed those, we articulated what our concerns were, and the department officials, and there were numerous there, took note of those. That, I think, then started a process of us having a much greater involvement as representative organisations to ensure that the voice of people with disability was heard as part of the pandemic considerations.

MS EASTMAN: One of the functions of the Advisory Committee formed on 2 April was to develop a specific plan for people with disability. And you are aware, aren't you, that either on 16 or 17 April the Management and Operational Plan for COVID-19 for People with Disability was agreed and I think released to the community; is that right?

MR JOYCE: Correct. There was a draft Plan released at that time and our representative on the group was keeping us in touch and we had a number of meetings to discuss the contents of that Plan and suggest --- make suggestions to Jeff, which he would take back to the committee.

MS EASTMAN: And while that Plan was being developed, you were also involved in another public Statement of Concern being issued; is that right?

MR JOYCE: Correct.

MS EASTMAN: That was on 15 April. Again I will get this one up on screen as well. The document reference is FPD.9999.0001.0018. So this was the Statement of Concern and this was focused on human rights, disability and ethical

decision-making. And what prompted this Statement of Concern was a fear in the community that there may be health rationing and if people with disability required critical care, there was a concern that Australia might take an approach seen in other countries during the course of the COVID-19 pandemic; is that right?

5

MR JOYCE: That is absolutely correct. We were concerned about some of the things that had been relayed to us from other organisations overseas in a number of countries. Basically, you know, let's be blunt, it was to ensure that people with disability weren't just triaged out of appropriate medical care.

10

MS EASTMAN: And if we turn to the final page, which I think the document reference is 0023 of this document --- it might be a little earlier.

MR JOYCE: Yes, that's the reference.

15

MS EASTMAN: The final substantive page. So page number 0023, that is it?

So this framework for human rights principles for ethical decision-making, can you assist the Royal Commission in terms of how this was developed and what is the approach that you describe in human rights principles for ethical decision-making?

20

MR JOYCE: Yes, sure can. There are a number of organisations, once again through our sector meetings that we got together, and because of those concerns about what was happening in the overseas experience in a number of countries, we thought it was really important to have a document that reflected what is the correct framework for human rights principles and for ethical decision-making in terms of healthcare. For that we commissioned somebody to write that for us. We reviewed it, we all agreed on it, and we actually put money in to pay for all of that. That is the level of concern that we have. So, collectively, there were a range of organisations in it and they are mentioned in the document and we made sure that we then had a number of people, we contacted them, provided them with this and we sought their endorsement as people that have high standing in terms of human rights and in terms of ethical decision-making and in terms of medical decision-making as well.

25

30

MS EASTMAN: Have you received a response from either the Chief Medical Officer or the Commonwealth Department of Health to this Statement of Concern and the identification of human rights principles for ethical decision-making?

35

MR JOYCE: I'm not sure it was from either of those, but we certainly did receive confirmation back. Again, I think that came back through from the National Cabinet process. But I wouldn't be 100 per cent on that. But we certainly did have some feedback on that, that they had taken that and they were discussing it and putting it through the relevant areas across the health sector for them to look at and also consider.

40

45

MS EASTMAN: All right. Now I want to turn to some particular areas of concern that have arisen during the course of the pandemic. But before I do so, I just want to

come back to the Management and Operational Plan for COVID-19 for People with Disability. And from AFDO's experience, how has that plan been received and how have you seen that plan work in a practical setting for people with disability? I might ask each of you your views on that as the CEO and then also, Mr McGee, in your
5 role in terms of research and policy.

MR JOYCE: I think it was an important plan that was developed because it actually did focus on people with disability rather than just focus on generalised health concerns and issues. And, obviously, you still need to do that so there are a number
10 of plans that were developed. We were pretty pleased with the outcome in terms of it covering off on all the points that we thought were a priority for people with disability through this pandemic.

In terms of operationally how did that show itself through the healthcare system, I
15 would suggest from my perspective it is a bit of a mixed reaction. I don't think it was fully endorsed or locked in across all of the health systems that we have. So that would be my view on it at this point.

MS EASTMAN: Mr McGee, from the role that you have in policy and research,
20 what has been your sense of the reception of the plan?

MR MCGEE: Look, one of the key contextual issues that is being played out at the moment is the role of advocates in the disability sector, and the NDIA and other civil service systems have downplayed the role of advocates in relation to people with
25 disabilities. And their advocates are the key mechanism by which these sorts of plans actually mean something for people with disabilities on the ground. So it is very hard for us, given that there is this screening out of advocates in that disability process, to comment directly. But we would say that, as Mr Joyce was just saying, it is about whether or not the Plan moved from operation to implementation and I think
30 it is clear that it was hit and miss. Some States and Territories that have robust disability systems were able to implement the operation --- the Plan more comprehensively than others. If you look at the NT, it was less able to implement the plan than, say, Victoria, which was more able to implement the Plan.

35 MS EASTMAN: All right.

Now, I want to turn to a number of particular areas that you have identified in your joint statement. So bear with me while I jump around a little bit. I want to start with PPE, personal protective equipment. You have addressed this in your joint statement
40 at paragraph 71 and following. You say that the provision of PPE in the community was a significant issue for people with disabilities, their families and the service providers. I'm not sure who would like to address this question, but what have you seen evolve over the period of the pandemic in terms of the way in which the disability community have been able to access PPE? Who wants to take that
45 question?

MR JOYCE: It will be me because I actually wrote it. There are quite a number of

concerns and we are still concerned about where PPE is going. I suppose I can reflect on my experience having been through the H1N1 swine flu pandemic back in 2009 when I was in primary health care. PPE was an issue then, access to PPE supplies was an issue then, stockpile issues were an issue then, distribution was an issue then, does it start to sound familiar? Because that's exactly what we're experiencing again. I'm pretty disappointed that after nearly nigh on 10 years we still, as a country, have these issues, we didn't learn the lesson from H1N1, and we should have and we shouldn't have been having issues with all of those things right now.

People with disability feel very vulnerable in this situation. People with disability may have also other underlying health issues, so they can become incredibly alarmed. The supply to people with disability and also to the service providers who support people with disability needs to be given much more priority because you are talking about people that can actually have the most significant adverse health outcomes from the pandemic.

MS EASTMAN: What you say in this statement at paragraph 74 is:

The lack of training or approach developed to rapid upskilling on the use of PPE for people with disability, their families and support workers further impacted on the confidence and safety of all concerned.

What are you aware of in relation to available training and what you describe as rapid upskilling? What has been available over the course of the pandemic and from your knowledge, what is presently available in that respect?

MR JOYCE: There was a dearth of --- nothing available at the beginning and it's only in the last month or two that the Government has acted, there are training packages now up online. I think accessibility to some of those is an issue. You need to provide it in accessible formats. As we know, there are people with disability who may have an intellectual disability who may need other supports to help them understand the correct procedure in putting that on, taking PPE off and that side of it. You know, that's not covered anywhere. There are other concerns about, obviously, an assumption is that an online resource teaches you how to do it properly and we all know that that is not really the case. The best way of doing that, even for support workers, you have to have a practical hands-on approach to demonstrate how to correctly take on and off PPE to ensure that you are doing it correctly and you are not creating more of a risk.

MS EASTMAN: At paragraphs 107 to 109 of your joint statement, that is on page 21, you make some recommendations to the Commonwealth government in relation to PPE, equipment and training. Do you want to speak to those recommendations?

MR JOYCE: Yes, certainly. We've asked the Federal Government to undertake an urgent review of the operations and the response of the Federal Government PPE

stockpile during this pandemic. I'm hoping that the lessons that we need to have learned from this are taken into account seriously. We think it is about the delays in the agreed stock levels. I just thought --- my opinion is I found it unacceptable for the federal stockpile to say that they had a shortage, or they had given out a lot of supplies because of the bushfires. My understanding would be that you should be constantly topping up those supplies and not letting that situation occur. But I can't remember the exact number, I thought it was about 150,000 down or something. So I was a bit dismayed with that.

10 Delays in getting things out to those that request them, the fact that service providers in the disability sector weren't even recognised as able to access the PPE stockpile. It has principally been aimed at health and health professionals. And service providers that support people with disability in the sector weren't eligible to access that. We think that needs to change and there needs to be delivery to other sectors, not just the disability sector, but other sectors and areas that are affected and that are at a higher risk, aged care would spring to mind, obviously, as well. And that has to be not just for those working directly in aged care, but you'd be thinking it needs to apply for kitchen staff, it needs to apply for cleaning staff, for gardening staff. It doesn't matter who it is, we need to learn the lessons because if we have another --- well, 20 we're not through this pandemic yet. But, you know, there could be another one coming along in the next few years or sooner. Who knows? We need to make sure that we have adequate policies and procedures in place and guaranteed sources of supply for PPE and that everybody who could be potentially vulnerable has access to that, not just one area.

25 MS EASTMAN: Can I ---

MR MCGEE: If I could just contribute about the impact of that in two contexts. So in forensic disability units they are not classed as a health facility, so they were not provided with that priority access to PPE. In forensic disability units you have a higher level of people coming in and out of people's lives. They are the disability support workers and the forensic disability support workers and yet they were not able to access the priority stockpiles of PPEs. I think as well for people with disabilities themselves, the impact of not accessing PPE is isolation because what people with disabilities are extremely careful of is their own health. They have to be. And the impact of not being able to access PPE simply means people don't go out. And that leaves people very isolated and vulnerable.

MS EASTMAN: Mr McGee, you've given some evidence in the joint statement. You have been responsible for preparing that part of the statement dealing with forensic units at paragraphs 50 to 54. Can you tell the Royal Commission briefly what has been the issues arising during the pandemic for people with disability in forensic units?

45 MR MCGEE: I think that forensic disability units have been largely left out of any planning, either at the Commonwealth or the State and Territory levels. It's not to say that forensic disability units themselves haven't undertaken COVID-19 response

planning, but I think the high-level documents which have guided COVID-19 responses have failed to understand the context of forensic disability units, their existence even is sometimes missed and, therefore, they are not included in the response. We've got really significant issues with forensic disability units. These are
5 places where people with disabilities are detained for the purposes of treatment, and some of those peoples are at risk of harm to others and community safety is something that is of concern. And so what we've got in situations where forensic disability units did create COVID-19 plans is the question of how could they possibly be implemented? For example, work has been done on, you know, prisons and COVID-19 and there has been a call for the release of prisoners that were on
10 low-level sentences or nearing parole or had particular vulnerabilities, to take them out of the prisons and put them into the community. The question for forensic disability units is how could you do that with people who might be a risk of harm to others and may need significant high-level support? Because there is no place for people with disabilities to go to other than those forensic units. And we saw little
15 evidence of planning around COVID-19 in, say, the Northern Territory but we saw more evidence of it in places that had more robust and comprehensive forensic disability systems, such as Victoria.

20 I mean, COVID-19 has highlighted the fracturing of the forensic disability system. Most disability has gone up to the NDIS, but forensic disability remains a State and Territory Government program. And they are funded out of the State and Territory Government programs and so we have forensic disability units that used to sit in a disability services structure and now don't. And so things like coordination and
25 leadership, monitoring of rights breaches and the oversight by, say, community visitor programs have been called into question through COVID-19. It has highlighted that fracturing where people who are detained for the purposes of treatment, their rights might be overlooked. And we are seeing those sorts of things occur around the country. And when we approached the disability --- the Justice
30 Interface Principles Working Group at the beginning of the pandemic to help lead a national conversation on how to manage people in forensic disability units --- and those units are not just closed units, we're also talking about forensic disability in the community. So a closed congregate setting may be where you have a particular unit, it is a secure unit, but people with disabilities under forensic orders also live in
35 houses in the community, supported by people.

In Victoria, that system has largely weathered the transfer up to the NDIS and its retention at the State and Territory level. But in New South Wales the system has been largely dismantled and it is of great concern to us to understand how through
40 COVID-19 you could have a systemic and coordinated COVID-19 plan of response that everybody can follow.

MS EASTMAN: Thank you. I will jump in there because I'm conscious of the time and I want to make sure that we can cover the wide range of topics, but directly
45 linked to the nature of forensic units, as you said, is congregate and closed settings, this is a matter that you've identified in your joint statement in terms of people with disability gathered in group homes, in aged care centres and in Australian Disability

Enterprises which formerly were called sheltered workshops. You've addressed this in paragraphs 38 to 49 of the statement, noting that AFDO believes there has been no real policy consideration given to how supports could continue to be provided for people in these settings, and importantly, communication and support networks operating. So that is an ongoing concern, is it not, during the course of the pandemic?

MR JOYCE: Definitely. As Patrick mentioned earlier, the other real concern we have there is about people in those settings and particularly those in group homes or along that line, about their ability to actually connect in and communicate with their support networks. And the other issue that Patrick did raise earlier was about advocates and, they aren't considered a worker or a visitor in those settings ---

MS EASTMAN: What does that mean in terms of access to closed settings if there is a lockdown arrangement?

MR JOYCE: As an example, if an advocate has an existing client that they have been representing and they are in a congregate setting or even when they were in aged care and there was a lockdown, they weren't entitled to get access. So you are basically eliminating, again, another time when you have an external party that can actually check on, see that the person is safe, secure, that their rights are being respected, and you create a very closed environment. Again, that diminishes that person with disability from having that circle of support or circle of communication network, and we think that needs to be addressed and we think advocates need to be recognised as being workers and have access rights to those services and facilities.

MS EASTMAN: The final topic I want to ask you about is economic impact. You've addressed this at paragraph 55 and following of the statement. You say in paragraph 55 that you were:

Concerned to see that the NDIA placed a temporary 10 per cent increase to the price limit of some Core and Capacity Building supports for participants under the NDIS Price Guide, which service providers could charge. There was no similar increase provided in participant plans.

You talk about the impact of that approach, but you also deal in the statement in paragraph 56 with the Disability Support Pension and that was not included in the pandemic supplement payments. And you've also noticed that the consequence of that policy decision has had an impact. Who would like to speak briefly to the matters set out in paragraphs 55 and following of the statement in relation to economic impact?

MR MCGEE: I'm happy to respond.

I mean, the lack of inclusion of the DSP in the pandemic payment really sowed confusion in the disability sector and amongst people with disabilities. Some people on the DSP felt they should transfer across to JobSeeker when everybody agreed that

the DSP is the right mechanism, is the right payment for people with disabilities. Also people with disabilities who were applying for the DSP also suddenly were put in a place of questioning whether that was in fact the right application process to follow.

5

People with disabilities, the cost of disability, the cost of living with a disability, the NATSEM report of 2019 concluded that an extra \$100 per fortnight was needed to cover the cost of disability, and that if this was raised, if this was agreed to by the Federal Government, that the percentage of people living with disabilities, living
10 below the poverty line, would drop from 17.8 per cent to 9.7 per cent.

The lack of the pandemic supplement had a direct impact around accessing public transport. These are increased costs during a pandemic. Food products and their delivery, utility costs because you are at home more, an inability to access bulk price
15 foods as well as difficulty in obtaining medication, these are all financial impacts on people with disabilities and yet that financial impact didn't seem to be recognised by the Federal Government when it decided not to include the DSP in the pandemic supplement.

20 MS EASTMAN: All right.

So you've provided to the Royal Commission in your statement a series of recommendations. I won't go through those, but they are very clearly and comprehensively covered in the statement at paragraph 94 and following. I might at
25 this point ask the Commissioners whether they have any questions of either of you.

COMMISSIONER SACKVILLE: Commissioner Galbally?

30 **QUESTIONS BY THE COMMISSION**

COMMISSIONER GALBALLY: I would like to just pick up that last point about recommendations and ask Mr Joyce, what would be your comments on congregate
35 care and the issues you raise in paragraph 38 onwards?

MR JOYCE: Thank you, Commissioner.

I think part of what we are saying is one, we believe advocates should have the right
40 of entry into those congregate care settings and should be classed as a worker and there should be firm policies developed for how congregate care settings respond to a pandemic, an epidemic, or an emergency situation, and that should be really clear. That was part of the confusion. There weren't clear policies and procedures that they needed to adhere to as part of good operations and good governance and good risk
45 management. That wasn't there. So we believe that that needs to be developed. It needs to be government-endorsed and it needs to be put in there that this is how you need to be responding and these are the rights of people within your setting that you

need to respect.

COMMISSIONER GALBALLY: And what would those rights be?

5 MR JOYCE: Access to communicate and also to, dependent upon, obviously, what
the pandemic restrictions were for the rest of the community, but they should be in
line with anything that was applied from the health authorities that everybody else
could undertake. It should be exactly the same for people in those settings. There is
no right to be locking people into their rooms or into those settings.

10

COMMISSIONER GALBALLY: Thank you.

COMMISSIONER SACKVILLE: Thank you.

15 I have a couple of questions. One relates to the framework of human rights
principles for ethical decision-making. What specifically prompted that? What was
the experience in a foreign country, apparently, that created the concern here?

MR JOYCE: In a number of jurisdictions we would see that people with disability
20 were triaged out of emergency areas, were --- places were given to others over the
top of people with disability in order to have appropriate medical attention provided.

COMMISSIONER SACKVILLE: I understand the problem, but I'm wondering
where it was that you were specifically concerned about.

25

MR MCGEE: It was one country that specifically --- had a specific measurement of
who would get a medical responses.

COMMISSIONER SACKVILLE: All right. Thank you.

30

MR JOYCE: --- (overspeaking) ---

COMMISSIONER SACKVILLE: Which ones?

35 MR JOYCE: Italy and Spain.

MR MCGEE: There is a name for the measurement and we can provide that to the
Commission. It's just not present in my head right at this moment.

40 COMMISSIONER SACKVILLE: That's fine. Thank you.

I wanted to understand what you think about the current position concerning PPE?
You've explained what ought to have been done from the beginning and what should
happen with stockpiles. What is the current position, as at 17 August 2020?

45

MR JOYCE: The current position for those people with disability that are under the
NDIS plans, they pay for it out of their plans. Providers can now ask them to pay for

that out of their plans. We don't agree with that. We find that unacceptable. We believe that the service provider should be providing that level of safety for the work that they do. However, that's the current position with it. I believe the disability service providers can get access to the PPE stockpile now so that is good news.

5 However, it doesn't take into account people with disability that are maintaining and providing their own supports. So if they are paying for it themselves, they can't get access to that PPE stockpile the way service providers can as well. So I still believe there are quite a number of issues that need to be unpacked. We need some definite, better policy frameworks in there and we definitely need a better PPE supply chain
10 mechanism to ensure we can get that around to those people that really need it, and as we've said earlier, that's more than only the said workers.

COMMISSIONER SACKVILLE: Thank you very much. Thank you.

15 MS EASTMAN: Commissioners, that concludes the evidence of Mr Patrick McGee and Mr Ross Joyce. Thank you very much for your time this afternoon.

COMMISSIONER SACKVILLE: Thank you both for your statement and for giving evidence today. Thank you very much.

20

MR MCGEE: Thank you.

MR JOYCE: Thank you.

25

THE WITNESSES WITHDREW

MS EASTMAN: Commissioner, the next witnesses are another panel, Fiona
30 Downing and Eleanor Gibbs. I can see them on the screen. Perhaps we take their affirmations first.

FIONA DOWNING, AFFIRMED

35

MS DOWNING: Yes.

40 **ELEANOR GIBBS, AFFIRMED**

MS GIBBS: I do.

45

EXAMINATION BY MS EASTMAN SC

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

5 MS EASTMAN: Ms Gibbs, I might start with you. You will find a copy of Ms Gibbs' statement in tender bundle part B, tab 9. I will ask you, Commissioners, to receive that statement into evidence and mark it 5.22.

10 **EXHIBIT #5.22, STATEMENT OF ELEANOR GIBBS, DATED 12 AUGUST 2020**

COMMISSIONER SACKVILLE: Yes.

15

MS EASTMAN: There are some annexures I will ask you to mark at 5.22.1 to 5.22.5. That will be found in tender bundle E at tabs 4 to 8.

20 **EXHIBIT #5.22.1 TO 5.22.5, ANNEXURES TO MS GIBBS' STATEMENT**

MS EASTMAN: Ms Gibbs, can you confirm you are Eleanor Gibbs?

25 MS GIBBS: I am.

MS EASTMAN: And you are a media and communications professional?

MS GIBBS: I certainly am.

30

MS EASTMAN: And you currently work with People with Disability Australia and you are authorised to make a statement on behalf of PWDA; is that right?

MS GIBBS: That is correct.

35

MS EASTMAN: You've made a statement dated 12 August?

MS GIBBS: Yes.

40 MS EASTMAN: Are the contents of that statement true?

MS GIBBS: To the best of my knowledge, they are.

MS EASTMAN: Ms Downing, I turn to you.

45

You will find a copy of Ms Downing's statement in tender bundle part B, behind tab 8. I ask you to receive this statement into evidence and marked 5.21.

EXHIBIT #5.21, STATEMENT OF FIONA DOWNING, DATED 12 AUGUST 2020

5

MS EASTMAN: So you are Fiona Mary Downing?

MS DOWNING: Yes, that's correct.

10

MS EASTMAN: And are you a senior disability advocate with Disability Justice Australia?

MS DOWNING: Yes.

15

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

MS DOWNING: Yes.

20

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

MS DOWNING: Yes, they are.

MS EASTMAN: Thank you.

25

Let's see how we go on the panel. If there are questions that you want to jump in and both answer, please let me know.

30

Ms Gibbs, can I start with you? Many people following the course of the Royal Commission's proceedings this afternoon will know about PWDA, but I'm not going to assume that everybody does. Could you tell us a little bit about PWDA and its role and its functions as an advocacy body?

35

MS GIBBS: Certainly. PWDA stands for People with Disability Australia. We are a national peak organisation run by and for people with disability. We have a board who are people with disability, many of our senior staff, myself included ---

MS EASTMAN: Sorry, Ms Gibbs, I'm going to jump in here.

40

MS GIBBS: Sorry, I was talking too fast?

MS EASTMAN: As you know, I have the Auslan interpreters always reminding me to go slowly. This time you are faster than me. Can we slow down a little bit.

45

MS GIBBS: Indeed. Our board, and many of our staff, including our senior leadership team and myself are people with disability. We work with some of our colleagues under the umbrella of DPO Australia. So First Peoples Disability

Network and Women With Disabilities Australia and the National Ethnic Disability Alliance. We do both systemic and individual advocacy. We do training. We have projects. We work with people in group homes, in boarding houses. We have nearly 2,000 members who are all people with disability who regularly contribute to our organisation. So we have a deep connection with people with disability and we work across a variety of projects and programs.

MS EASTMAN: And the CEO of PWDA is Mr Jeff Smith and you may have heard the evidence just before you've come on that PWDA participated in the Commonwealth's advisory committee that was established on 2 April this year. Is that right?

MS GIBBS: I need to correct you on that. Our CEO, Jeff, has resigned due to a life threatening medical emergency in the last 24 hours. I just wanted to update you on that.

MS EASTMAN: Thank you. I'm sorry to hear that.

MS GIBBS: So am I.

He has done the vast majority of the committee work, particularly on COVID and has been the representative not just of PWDA but of the wider national DPO and DRO networks as Mr Joyce and AFDO have outlined in detail, which I was pleased to hear.

MS EASTMAN: Ms Downing, can I turn to you. You have worked as the senior disability advocate with Disability Justice Australia since May 2018. Can you tell the Royal Commission about the work of Disability Justice Australia and its particular role and function?

MS DOWNING: So Disability Justice Australia is also a Disabled People's Organisation, which is run by and for people with disability. Our board comprises of people with disability, our CEO has disabilities and nearly all of our staff and volunteers are people with disability or who have a close family member with disability. Disability Justice Australia is federally funded through the National Disability Advocacy Program to provide systemic advocacy at the state, federal and international levels, as well as individual and legal advocacy support to people with all types of disabilities and all ages.

We also receive funding to provide advocacy assistance for this Royal Commission and funding to assist with NDIS appeals. We also have NDIS project funding to build the capacity of our organisation, along with the capacity of people with disability by training them to deliver disability awareness training to Victoria Police recruits.

MS EASTMAN: Ms Gibbs, I will come back to you, and in your statement, in addition to speaking for PWDA, you wanted to share some of your personal

experiences at the onset of the pandemic and what has occurred for you during the course of the pandemic. These are matters that you've set out at paragraph 7 through to 11 of your statement. But can we hear your perspective and experience on the beginning of the pandemic and how you've navigated a range of issues?

5

MS GIBBS: Sure. I also wanted to note the evidence from Rosemary Kayess this morning. I was listening and agreed with some of her blunt comments, which I won't repeat. So I'm a disabled person. I am immunocompromised ---

10 MS EASTMAN: I have to slow you down. We've got time. There is no rush.

MS GIBBS: Apologies. I am immunocompromised so I'm in danger of both getting COVID-19 but because of my various impairments, if I get COVID-19 it will be extremely serious. So, for me, I went into lockdown before the community-wide lockdown on advice of my GP. And I found very quickly that the supports and the systems that I use to remain independent disintegrated completely. I found it impossible to get food, to get supplies, I found it difficult to get medication, my support person could not come so I was without disability support and it had very significant impacts not just on my physical health but also on my mental health. This is while doing my job and organising and translating information for people with disability about what was happening.

So it took nearly eight weeks for me to be able to find ways to get around things, to get different ways of getting food, to do all of that stuff, similar to what Rosemary said, I'm not on NDIS so I couldn't get groceries through the major supermarkets. But unlike half of people with disability, I don't live in poverty. I have a job, so I had the money to buy my way out of what happened. I could afford more expensive things and I could pay people to do some of this for me, but it was extremely distressing, incredibly scary and it was quite fast how those systems collapsed. And for people with disability, this was happening to many of us, and for what we were experiencing to be so invisible in the conversations from Government, the media, was extremely challenging at the same time.

MS EASTMAN: And PWDA was receiving a lot of information from the community generally of people's experiences, and you decided that you needed to do a survey to collect some data and see what was actually happening in the community. You say at paragraph 12 of your statement that the survey was undertaken, and people with disability talked about how alone and scared they had felt, and they had this fear of being left behind, the fear of being exposed and the fear of being abandoned. So you have published the results of the survey and if our technology works well, we might put up the key findings of the survey.

So, Commissioners, the document will be found in tender bundle part E, volume 1, behind tab 5, and the exhibit reference number, sorry, whatever that number is, EXP.0003.0003.0183. That's the beginning of the document and I want to turn to the page in the document of the report findings described as key findings.

Ms Gibbs, can you walk us through some of these key findings?

5 MS GIBBS: Certainly. Over 90 per cent of people with disability who responded to the survey said they faced increased expenses. So not just for food and groceries, but things like health care, interestingly internet and phone, but also hygiene and
10 sanitising equipment, including PPE. Many people with disability use hygiene and sanitising equipment as an everyday thing. So when everybody needed hand hygiene equipment, it became very difficult and expensive for people to get. But over
15 40 per cent of people also experienced having less support. So having their disability supports withdrawn or change, which was extremely concerning. That was people who both were --- have NDIS plans but also people who get their supports in other ways.

15 MS EASTMAN: Have you shared the results of these findings with the NDIA?

MS GIBBS: We have. We shared it with the NDIA, much of DSS and with all MPs and senators. One of the reasons we did the survey was we kept hearing from people with disability on one hand, we were hearing, "This is happening to us, and we are
20 having problems with getting access to essentials and we can't get supports". But what we were hearing from the NDIA and the Quality and Safeguards Commission was "We're not hearing any problems". So there was this significant disconnect between what people with disability were telling us, what they were coming to our advocates for, what they were telling us through our communication channels, and
25 what I was hearing from my friends and what was happening to me, and what we were hearing from the NDIA and that disconnect, this survey was part of our attempt to quantify this and to be able to demonstrate that this was more widespread than just the direct experience that we were having at PWDA.

30 MS EASTMAN: Ms Downing, can I turn to you. What has Disability Justice Australia been hearing during the course of the pandemic?

MS DOWNING: Some of the issues that El has raised have been similar to the experience of Disability Justice Australia. People with disability are terrified about
35 contracting COVID-19 from disability workers. Many people with disability are at greater risk of COVID-19 and they are worried about if they go into hospital, they are not going to receive the adequate care that they require. The general feeling is that the NDIS hasn't been set up to deal with emergency situations and the linkages with mainstream services like hospitals are still problematic. There is also still no provider of last resort for many people with complex disability. So there is just
40 a general sense that people feel forgotten. The media coverage in Melbourne has very much been focused around the aged care system, the school shutdowns and quarantine facilities and it's only in recent days that we are seeing a bit more coverage about the dangers of COVID-19 for people living in residential care.

45 So during the first wave in Melbourne, the sort of issues that were brought to our attention were about draconian measures in group homes where residents were subjected to restrictions that were far harsher than for other people in the community.

Last week a mother recorded to me that her son hasn't left his office of housing property since Christmas Day, nearly nine months ago, and he requires 24-hour care. So the support workers haven't taken him into the community.

5 There has also been a lot of issues around the use of PPE equipment for disability workers and council home help staff who also provide care for people with disability who are not on the NDIS. In one instance, a service provider refused an NDIS participant's request for all staff to wear PPE after nearly losing his life to pneumonia earlier in the year. The service provider's response to the participant's request was that wearing PPE was not a legislative requirement and that it was a choice for individual staff members. So the participant's right to choose whether staff members wore PPE when they were assisting him was just completely lost. And when you looked at the provider's policies around the use of PPE, it was clearly written from the perspective of how to protect staff rather than the residents. And we all now know from the statistics coming out of Victoria that the dangers around COVID-19 in disability services are generally from the staff rather than the residents. So even now that we've got legislative requirements to wear masks in the workplace, it is just clear that many of the disability support staff don't understand the rules or they don't recognise that disability accommodation is actually a workplace. In one video conference I saw a support worker who spent the whole meeting without a mask on and another worker came in and was within about 1 metre of each other and even after I raised concerns about this in the next meeting, once again they appeared without masks on.

25 So the other issues that have been raised to our attention is around testing, the Victorian Government has recently introduced home testing for people with disability. That should really be applauded but, you know, these measures should have come in months ago when the first wave hit. And people with disability have been voicing their concerns but it's just a general sense of across the community of people with disability not feeling like their voices are being heard.

30 MS EASTMAN: Have you seen a change in the people coming to seek services from Disability Justice Australia or the nature of the services that they are seeking over this period?

35 MS DOWNING: There is a lot more requests for advocacy that are specific around COVID-19 and just around concerns about not being able to receive the type of support that they require. We're really concerned about the lack of information that we have about how many people with disability are contracting COVID-19. That data is just not being released. I know --- I think it was Bill Shorten recently made a call to release that data, but to this date we still don't know how many people and even the amount of people that have tragically died, how many of them had disability.

45 The community visitor program in Victoria has been suspended and regulatory oversight bodies are just not conducting visits to disability residential services. So there is a real lack of information out there. This is the sort of thing that people are

approaching our service about. But we just don't know exactly how many people require advocacy but they are not seeking our assistance. There was one interstate advocate I know who reached out to some former clients and they found about 50 per cent of them required advocacy but because the advocacy sector is so
5 drastically underfunded, we just don't have the capacity to reach out to all the former clients and people we think might be in trouble. Unfortunately there has been no emergency funding for advocacy in Melbourne, despite the issues that have arisen and in fact this financial year we've had a cut to NDIS appeals funding. And this is right in the middle of the pandemic. So advocacy services are just constantly having to turn people away. People often can't even get their names on a waitlist because we
10 have to close our waitlist as a way of managing all the advocacy requests that are coming in.

MS EASTMAN: I wanted to ask both of you about the role of the disability
15 advocacy groups stepping in probably to do work they would not ordinarily do. You have stepped in, in terms of providing information in accessible ways. We've heard this and we will hear this through evidence in the course of the week. How do you fund taking on these additional responsibilities and what has it meant in terms of the workload of disability advocacy organisations during COVID-19?

20 El, do you want to respond to that and then Fiona I will come back to you?

MS GIBBS: Sure.

25 I'm talking in terms of my expertise in communications, the communications have been a real challenge in terms of trying to find out information relevant to people with disability and then being able to get that out to people with disability as quickly as possible in accessible formats. That has not happened generally from any level of government, particularly in the first few months. And as the public health orders
30 came through, trying to find out what they actually meant for people with disability who rely on support workers in particular and how that would actually work in the lockdowns and all of that kind of stuff was extremely difficult. So we did an enormous amount of work out of hours and there was --- we now have a brand new disability communications network because we got together, the comms people
35 from a variety of national and state disability advocacy organisations to work together to go, did you understand that, what does that mean, how do we do this? And we worked together on weekends, we worked after hours trying to make sure that we had information out as quickly as we could by as many channels as we could. As Fiona has said, it has been really challenging to reach people with disability
40 because for many people they have not had access to the regular places that they go and have often and we have certainly had this same experience, not been able to go outside at all. For people who live in any kind of congregate care, often they have not been offered opportunities to exercise and to try and get information to them has been extremely challenging and difficult.

45 We have proposed various outreach strategies but have not been resourced to do those pieces of work. The NDIA has done some outreach, but, again, that only

reaches the percentage of people with disability who have an NDIS plan. It doesn't reach some of the very significantly disadvantaged people who live in, say, assisted boarding houses and are not necessarily covered by the NDIS or have a phone or have any access but may have trusted organisations or workers that they rely on but during this pandemic would not have had access to.

So for a disability advocacy organisations, how we've funded it, we all have a lot of time in rebalances sitting there, and other work has had to be put aside because the immediate crisis for people with disability has been so great. So our individual advocates in particular have worked tirelessly while they have had their own challenges of working from home and working remotely to do that direct practice work to try and figure out things like the COVID app and how to download it, and how does someone access information when they have a shared phone that everybody uses or no access to the internet at all? I think the reliance on the internet and the phone as the only ways to get information have been significantly a disadvantage to lots of communities of people with disability.

I think that there needs to be a much better strategy around accessible and available and relevant information and not so much reliance on us to translate that into --- and find what the public health order for SA means and is it different to Tasmania and what does that mean for people trying to get groceries in Queensland, which is exactly what we were trying to do.

MS EASTMAN: Ms Downing, do you want to add anything to that in terms of DJA's experience during this period and the demands on funding?

MS DOWNING: In terms of services like ours, which is --- the majority of the funding is directed to individual advocacy. We are really relying on peak organisations and networking groups to get that information out because we simply don't have the funding to be doing a lot of outreach work and to be producing brochures. We're trying to service as many people with disabilities as we can. Across the state of Victoria there is a lot of advocates who are just burning out and we are getting great, experienced staff who can't keep up with the workload and having the outlook on advocacy funding so poor, it is really difficult to keep people's spirits up and to keep them engaged in their work. I think disability advocates work extremely hard, but there is just not enough funding there to provide that information. In terms of Melbourne when the hard lockdown was happening on the Housing Commission flats there was a real need to provide disability-specific information. I saw there was an Easy English brochure made for the Housing Commission residents, but as far as I know, that was the only information that was really given to those residents. I think when the outcome of the Victorian ombudsman investigation is revealed, it will show that there was real shortcomings in how the Government engaged with people in disability in that type of situation.

MS EASTMAN: I might turn to the commissioners at this point and ask the commissioners whether they have any questions of Ms Gibbs or Ms Downing.

COMMISSIONER SACKVILLE: Commissioner Galbally?

QUESTIONS BY THE COMMISSION

5

COMMISSIONER GALBALLY: Yes, I would like to ask Fiona Downing about the restrictions in group homes on people being able to take daily exercise. And also you mentioned that support workers weren't taking people living in the community for exercise. Like, that was a decision or how could that happen when that is allowed for everybody else and this is supposed to be their homes?

MS DOWNING: Commissioner, thank you for your question. I think one of the key shortcomings of the accommodation system at the moment is there is always dangers whenever you share supports, and service providers have been using a very risk-averse approach to their policies. For instance, if you have a group home of four to six residents and there is one resident who may have one respiratory issue, so, therefore, they will use the issue with that one resident to have a broad policy that covers all the residents that says, well, no one can leave the property, we can't have any support workers from any other agencies coming in because we really have to manage that risk. In one instance I was aware of a service provider said to me, "That person is really lucky, they get to go around the block in their wheelchair", and that was meant to be a really positive thing that this person was allowed to do, and I thought at this time when the first wave, for someone who was able to access the city, bars, restaurants, cafes all the time to be told that they are lucky to be able to go around the block in a wheelchair I think is just really shocking.

In the situation that you mentioned with the person who hasn't been out since Christmas, when you are working with people with complex disabilities, it is always difficult for a support provider to manage access in the community, and I think giving an extra reason about COVID it is even more, "Okay, hang on, that's another reason why we can't take this person out."

There is very little oversight of these issues. There really needs to be strong recommendations made so that people who are living in these facilities aren't hidden and their voices really are heard and that there really is a strong focus and move towards a human rights approach to housing people with disability.

COMMISSIONER GALBALLY: Could I have a follow-up question, please, about if they can't go out, then the internet and computers and phones and capacity building to help people use those, both you and Ms Gibbs made it sound like that is completely absent.

MS DOWNING: Commissioner, with all due respect, there has been a lot of service providers that have upgraded their internet, there has been a lot of people with disability who have used their NDIS funding to get tablets and had dongles used. So in many situations what we're told, but generally being told by service providers, is

that there has been an increase in residents' ability to access the internet and speak to people. But from our service we haven't had the funding there to go out and actually speak to people and see if that is actually the situation and without hearing from the voices of people with disability that they are able to use these services, I'm quite
5 sceptical about how much people are able to use video conferencing and other sort of technology.

MS GIBBS: We certainly know of people with disability who have been without phone and internet and have not been able to report that and only because of
10 an existing relationship with advocates have we found out what has been happening and been able to intervene and I know other advocacy organisations have had that. The complaints system that we have relies on people with disability making complaints, instead of being a proactive watchdog being able to investigate, and, as Fiona says, actually find out is this actually happening, are service providers actually
15 providing these things and providing alternatives to people if they can't do regular services, that's extremely difficult to know about and for people with disability who are significantly disadvantaged, expecting them --- the onus to be on them to make the complaint and to navigate a complaints system and to even know this isn't okay is really, you know, the power differential is quite great. It isn't really taken into
20 account in that system at the moment. That concerns me a great deal.

The other thing just to note is there are service providers who are saying to people with disability that you need to have a negative COVID test for us to return to services and return to providing you with support. It's been great to see accessible
25 testing available in Melbourne and in some places in Victoria, but we need that accessible testing available nationally. Because for people with disability who don't drive, for example, and don't want to go out into the community, or can't get out into the community, how do they get a negative COVID test to be able to get their supports to come back? So there are people who are in some really difficult
30 situations caused by the inaccessibility of the testing regime.

COMMISSIONER SACKVILLE: Thank you very much for your evidence, Ms Gibbs and Miss Downing, and thank you for your statement and coming today and sharing your experiences with us. Thank you.
35

THE WITNESSES WITHDREW

40 Ms Eastman, are we going to take a short break?

MS EASTMAN: We will take a short break. I need to reconstitute part of the hearing room. I had hoped to say to you that we could have 15 minutes but perhaps if I could ask you ---
45

COMMISSIONER SACKVILLE: We'll come back at 3.30.

MS EASTMAN: If we come back at 3.30, we may need to sit a little bit longer than the 4 pm adjournment time if that is convenient to the commissioners and those assisting the Royal Commission this afternoon.

5 COMMISSIONER SACKVILLE: That will be fine. Thank you.

ADJOURNED [3.19 PM]

10

RESUMED [3.31 PM]

COMMISSIONER SACKVILLE: Yes, Ms Eastman.

15

MS EASTMAN: Commissioners, our final witness this afternoon is Leonie Jackson, who I'm pleased to say is with us in person in the hearing room. And so Ms Jackson will take her affirmation.

20

LEONIE JACKSON, AFFIRMED

A. I do.

25

EXAMINATION BY MS EASTMAN SC

30 MS EASTMAN: Ms Jackson, you've prepared a statement for the Royal Commission.

A. Yes, that's correct.

35 Q. And you want to correct the date on it from 11 August to be 12 August?

A. Yes, that's correct.

40 Q. Commissioners, just to follow with the formalities of the location of the documents, Ms Jackson's statement is found in tender bundle part B, tab 10, and also accompanying the statement are the annexures in part B, tab 11 and tender bundle part E, tabs 9 to 15.

45 Could I ask the Commissioners to mark the statement exhibit 5.23 and annexures and accompanying material as 5.23.1 through to 5.23.5?

EXHIBIT #5.23, STATEMENT OF LEONIE JACKSON, DATED 12 AUGUST 2020

EXHIBIT #5.23.1 TO 5.23.35, ANNEXURES TO MS JACKSON'S STATEMENT

5 COMMISSIONER SACKVILLE: Yes.

MS EASTMAN: Thank you for bearing with me, Ms Jackson.

A. No problem at all.

10

Q. So your name is Leonie Mary Jackson?

A. Yes, that's correct.

15 Q. And you are the Executive Manager for Advocacy and Strategic Partnerships for the Deaf Society and Deaf Services Ltd?

A. Yes, that's right.

20 Q. And the contents of the statement that you've made on 12 August, the contents of the statement are correct; is that right?

A. Yes, that's right.

25 Q. I want to start with asking you about your role as the Executive Manager, Advocacy and Strategic Partnerships with the Deaf Society and Deaf Services Ltd.

A. Yes, that's fine.

30 Q. You've been in this role since May 2020?

A. Yes, that's correct.

35 Q. And what is the nature of your role and work as Executive Manager of Advocacy and Strategic Partnerships?

40 A. In that role it is to look at identifying gaps that are happening within the Deaf community in regards to the systems that they have and also working with a variety of stakeholders to ensure that we can set up solutions to make sure that there are better outcomes for Deaf people in the community and members.

45 Q. You say in your statement that the Deaf Society and Deaf Services Ltd are specialist service providers for Deaf, deafblind and hard of hearing people in Queensland, New South Wales and ACT?

A. Yes, that's right.

Q. The organisation has over 700 staff?

A. Yes, correct.

5 Q. And you work to support the vision and mission of Deaf people being empowered, connected and achieving; is that right?

A. Yes, it is. That's the vision of the organisation.

10 Q. I want to turn to the issues arising for the Deaf community during the COVID-19 pandemic.

A. Yes, it is a very important issue. Yes.

15 Q. At the Deaf Society you want to make sure everyone in the Deaf community understands what is happening.

A. We do, indeed, because we realise there are so many language and communication barriers for Deaf, hard of hearing and deafblind people and how they get access to information to support them throughout the pandemic.
20

Q. For a long time you have advocated for television broadcasts of emergency announcements to be provided with Auslan interpreters on the screen and that's part of an overall strategy to distribute information widely to the Deaf community.
25

A. That's correct, yes. It is extremely important.

Q. We've seen Auslan interpreters on the television screens during various media briefings during the COVID-19 period. Why has this been important?
30

A. It's important because throughout Australia in the Deaf community, they rely upon receiving information in Auslan to understand what is going on and that's why it is important for us as part of our overall strategy to ensure that we can connect with people and to disseminate information throughout the country about what is happening, particularly in states of emergency such as we are experiencing with the pandemic.
35

Q. Has the demand for Auslan interpreters placed any new or increasing demands on the Deaf Society?
40

A. Absolutely, yes, it certainly has because we provide interpreting on the television broadcasts throughout Queensland, New South Wales and the ACT and also federally. So we've had to recruit interpreters from other states in order to be able to provide a high quality interpreting service on the television broadcast on an ongoing basis.
45

Q. How are you meeting the demands?

5 A. Well, we are relying very much on a small pool of interpreters around Australia who are able to interpret in television broadcasts. They need to maintain professional training to ensure they understand what they are interpreting, to make sure that they are providing correct information all of the time. We provide them with ongoing support to this group of interpreters and we share information between the other interpreters within that group as well to ensure they are always up to date.

10 Q. And, other than the media briefings, what are the ways Deaf people can obtain information about COVID-19 and understanding the various rules and restrictions in place?

15 A. Well, within the Deaf community, we have a variety of subgroups, if you like. There are three major groups within the community, people who are bilingual who are able to communicate either in Auslan or English and move between both languages quite easily. They can get information that way. They can watch interpreters and understand and they can read English.

20 We have another group of people we refer to as monolingual Deaf people, meaning they rely on getting information in Auslan only, which means we need to ensure that we do something that we call unpacking information, so re-explaining information to ensure that they understand what it means for them.

25 The third group that I refer to is a group of Deaf people who have particular communication needs because they have an additional disability. We try to reach out to that group of people in particular and we prioritise them and give special training for people who are able to unpack information to ensure they understand what is happening in the time of the pandemic.

30 Q. In your statement you have identified a few areas where it has been difficult for the Deaf community to obtain information. Can I ask you about some of those areas.

35 A. Yes, certainly. I think that sometimes you can see interpreters on television broadcasts and government representatives use very sophisticated language that not many Deaf people can understand. We need, therefore, to unpack those terms for them, unpack the information to ensure they do understand it. Deaf people who rely on Auslan need to have concepts that are complex explained to them in much more simple language. We have staff members who are able to do that, to make sure they understand the importance of the information.

40

Q. Can I ask you about the use of masks, particularly accessing health care. And this is a matter you've addressed at paragraph 30 of your statement. Can you tell us a little bit about your experience of the use of masks and your engagement with the health system.

45

A. Yes, absolutely. I have two children. One is 12 and one is 9 years of age. Recently the 9-year-old became quite ill. So the GP said that I needed to take both of

the kids to the Children's Hospital to get them tested for coronavirus because the school wouldn't let them return until we knew the results of the test and that they did not in fact have coronavirus. So we went off to the Children's Hospital, myself and the two children. And it was a bit confronting, actually, because I walked in and saw
5 that everybody had a mask on. So for me as a Deaf person, I rely heavily on lip reading and facial expression to understand information. I can't rely solely on my hearing. I can't rely on audition to get the message completely. So I said by way of explanation, "I'm Deaf", and the doctor didn't really understand what to do so I said --- the doctor, who was female, said that if the three of us put masks on,
10 meaning myself and my two children, then the doctor would take her mask off and then she would put a shield on. I thought, fair enough, I would do that to be able to communicate with the doctor. But then I realised that I couldn't understand my own children with a mask on. They had a mask on. I had a mask on and I couldn't understand what was going on in the interaction. I felt a bit all at sea, actually.

15 Anyway, we had the test for coronavirus done and the doctor said, "Please give me a phone number where we can telephone you with the results of the test." I said, "Well, I'm Deaf, so I need to use the National Relay Service, so if you could please send me a text and I will call you back through the National Relay Service." She
20 said, "No, we can't do that, that's not possible. We must have a person who can hear who can answer the telephone, then we know the information will definitely get through", but I've been using this system for years and years and years and everything has been fine, I've never encountered a problem. I explained again this is how we communicate, and I had this interaction for about 30 minutes and it was late
25 at night and at the end I gave up because the kids were tired and hungry and I felt completely deflated by this experience. It was awful.

Q. To deal with situations such as this, the Deaf Society has taken it upon itself to develop some cards so that a person who is Deaf or hard of hearing can use some
30 cards that can be on their mobile phones to explain to a hearing person what the issues or concerns might be; is that right?

A. Yes, that's right. We at the Deaf Society felt we had to produce something, or develop a strategy to help Deaf people so that they don't have the same kind of
35 experience that I had. So we thought that these cards would help us because we know that doctors and other medical staff are required to wear a mask.

Q. So we're going to put the cards up on the screen. Ms Jackson, can I ask you to explain the cards as they come up.
40

A. Yes, certainly.

COMMISSIONER SACKVILLE: Can we make this legible?

45 MS EASTMAN: People who may be following the proceedings may not be aware that we have interpreters in Sydney, but also interpreters in Brisbane. And I think our interpreters in Brisbane can't see the screen. So we'll leave the Deaf Society

cards I think and keep going along.

COMMISSIONER SACKVILLE: And the Commissioners in Sydney can't read them either because they are blurred. So, carry on.

5

MS EASTMAN: Can I move to another topic, which is isolation.

A. Yes, for sure.

10 Q. And you have said during COVID-19 that many people in the Deaf community have experienced extreme isolation.

15 A. Yes, that's correct. Many Deaf people perhaps living in a home where they don't have good communication with their own family members. So, during the lockdown period, many Deaf people have not had access to what has been occurring around them. They haven't had internet access at home, perhaps, also, so they can feel what was once a very isolating experience in their own home far more isolating because they haven't had access to information.

20 Q. Now, in your statement, you describe the isolation of Deaf seniors. Can I ask you to tell the Royal Commission about the matters that you've set out in your statement at paragraphs 36 to 38.

25 A. Yes. With the Deaf seniors, primarily those over the age of 65, they may live on their own or within an aged care facility. Most of the time they are not computer literate, they don't have technological skills so they aren't able to maintain contact with their own adult children throughout this period of time. So it is very isolating. Also, during the pandemic, social groups that they would regularly meet with, perhaps on a fortnightly basis, had to be cancelled because of the pandemic and the
30 restrictions. So they are isolated and have no social outlet or company to enjoy.

One situation where we at the Deaf Society wanted to help a Deaf person who is a senior citizen, they had an old-fashioned type phone. It wasn't a smart phone, capable of modern access. So to access information during the lockdown on
35 coronavirus was difficult. We had to persuade this person to purchase a smartphone so that they then could access information online and know what was occurring in the community. However, many people like this cannot afford a smartphone. They live on a Disability Support Pension and affordability becomes prohibitive.

40 Q. What about the experience of younger Deaf people? You describe some circumstances that have come to your attention in paragraph 39 of the statements.

45 A. Yes. So, at the Deaf Society we organise courses for Deaf adults to provide them with access to a number of courses, for instance, literacy computer skills. Many of these Deaf people live with their elderly parents. This means they don't have access to the internet or can afford to access internet in their own home. There is also not a lot of communication occurring in their own home often because many parents of

Deaf children don't learn to sign so the communication is quite limited. There was one student who was attending the course at the Deaf Society. They didn't know what was happening. So during the class they had to be explained to what was occurring in the pandemic because they didn't have access at home. They didn't have a phone. And the only way they could understand the information regarding the pandemic was to physically present themselves to the Deaf Society and have one of the staff members explain information in a language suitable to them.

At that time we also had to lobby the NDIA to allow for some flexibility in this person's NDIS package to purchase some low-cost technology devices like an iPad so that they then could engage with us and engage with virtual services and also engage with other Deaf students in their class because otherwise they would have no ability to contact anybody outside their own home.

So we at the Deaf Society and Deaf Services Ltd have about 50 people who are in this cohort who don't have access and rely on an organisation, like the Deaf Society and Deaf Services, to be able to receive information and support during the pandemic.

Q. You also have to deal with experiences of people with very specialised communication needs and you've documented some of those examples in the statement.

A. Yes, that's correct.

Q. One person who we'll describe as Fiona is a deafblind woman in her early 60s.

A. Yes, that's correct.

Q. Due to her dementia and mobility issues she lives in an aged care facility.

A. Yes, that's right.

Q. Tell us what happened to Fiona during the early part of the pandemic?

A. I think early in April was when the Government was encouraging aged care facilities to ban external visitors within aged care facilities. So Fiona's aged care facility had notified the Deaf Society that visits were no longer possible and that our staff who could communicate with her, because she was Deaf, blind and had dementia, so you can imagine her needs were very specific. The communication factors were quite complex here. So it was important that staff were provided with training about Fiona's communications methods to understand what she was trying to say and to make sure that communication was in fact two-way with Fiona. The aged care facility had also banned Fiona from going out. And Fiona particularly enjoyed going out for outings and meeting up with people. Unfortunately this was no longer possible. After six weeks of lockdown without any communication we asked at a very bare minimum if we could please provide a person who could communicate

- with her, 30 minutes a day of contact, ensuring that this person would have PPE and would follow the correct procedures, have their flu vaccinations and have all that documentation in place. But the aged care facility um'ed and ah'ed about this. It was important to us because for six weeks Fiona had no idea why the lockdown was occurring and what was happening with coronavirus. You can imagine what affect it had on her mental health, six weeks of no communications, no awareness as to why she had no visitors and why all outings had stopped and why she had no communication with anybody.
- 5
- 10 Finally they permitted one of our members to go in and speak with her. It was very clear, at this stage her mental health had suffered a serious decline due to six weeks of no communication. The facility is now allowing visits daily, which is great, and we keep up that pressure and make sure this will continue to occur.
- 15 During the week beginning 27 July the aged care facility had decided that there would be no more outings or excursions and that Fiona would have to stay within the grounds of the facility. She received this news with great disappointment. She really, really enjoyed these outings.
- 20 Q. A number of people have made videos, and you have their consent to show some short videos of their experience during the COVID-19 period.
- A. Yes, that's right.
- 25 Q. We might show some of the videos. The first will be Naomie Hayman, a confident, bilingual person who works in a professional capacity as a literacy teacher for adult Deaf students. She has an 11-year-old son and she has made a video recording about her experiences of taking her son to the doctor. We'll play that one.
- 30

VIDEO OF NAOMIE HAYMAN BEGINS

- 35 MS HAYMAN: Hello. About a month ago I took my son, who is 11, to the doctor. My son was not well. When we arrived we found that we were not allowed into the reception area. So what we had to do was stay in the car and call reception, just to let them know that we were actually there in the car park. That was tricky. I can hear a little on the phone but not enough to fully understand and communicate. So my son
- 40 helped me make that phone call to let them know that we were there. He listened to the phone call and told me that the doctor would come to the car soon.

- We waited patiently and finally the doctor arrived, wearing a mask and donned in full PPE, obviously because of COVID-19. Now, I understand the need to protect themselves and also us. But I was stuck because I need to be able to lip-read to
- 45 communicate in this type of environment. I tried to use an app that would translate speech to text and generate captions for me to read but it didn't work. So I asked the

doctor if he could lower his mask. I explained that I was Deaf, I couldn't understand and I would need him to do that so that I could lip-read. The doctor seemed confused and shook his head, as to say no.

5 Instead, he turned to my son, who is only 11, and spoke to him. My son explained to
me what the doctor was saying. And I felt really frustrated. I'm the mother. I'm the
one who needs to communicate with the doctor, not my son. He's only 11. He's not
responsible for my communication or to communicate for me. Also, would he be
10 able to interpret 100 per cent accurately? No. He's only 11, he's not a professional
interpreter.

In that moment I felt inferior as a mother and as a Deaf person. I felt it wasn't right.
I wish the doctor had been more understanding, was willing to lower his mask a little
or perhaps write notes to me. But he did nothing. He immediately spoke to my son.
15 And that wasn't okay, it wasn't a good experience.

It would be good if there were masks made with perhaps a clear window to make the
lips visible. And there are also ways to call up an interpreter via smartphone. There
are also accurate speech to text captioning apps. Unfortunately, the one that I was
20 using at that time wasn't any good, the captions were not clear.

I felt like I didn't have access to general health services or health information from
my own GP, just because the pandemic dictates that the doctor has to wear a mask.
I really hope things improve in the future. Thank you.
25

VIDEO OF NAOMIE HAYMAN CONCLUDES

30 MS EASTMAN: You've also provided the Royal Commission with a short video
from Ms Desley Donnell about her experience of not being able to visit her Deaf
husband who lives in an aged care facility due to health issues. Can we show her
recording?

35 A. Yes, that's right.

VIDEO OF DESLEY DONNELL BEGINS

40 MS DONNELL: Hello, my name is Desley Lynn Donnell. I'm sharing my
experience with my husband, whose name is Kenneth, and his experiences in aged
care. We used to see each other face to face on a regular basis and that made us so
happy. However, when coronavirus hit the nursing home closed. We were stuck.
45 No one let me know at all what was going on so I went to the aged care facility and
I knocked on the door and I was looking through the glass. I wrote a note for my
husband to read and I gave it to the nurse by putting it under the door. I wanted my

husband to read that note. It said to please use FaceTime. But we only had five minutes and it wasn't enough time to explain what was happening.

5 He thought that I had deserted him, and that wasn't the case. It was only because of the coronavirus that I wasn't allowed to see him and we were stuck with that requirement.

10 After a great deal of perseverance, I got to see him but only through a glass window and the reflection was really strong, so it was hard to see each other sign. It wasn't very good.

15 Finally, we were allowed to meet by sitting across a table, 1.5m apart and we could talk just for 30 minutes once a week. That was not enough for us. Later we were finally allowed to see each other much more regularly face to face. It was a really difficult time. It was very stressful for me. And also my husband is the only deaf person in that aged care home, everyone else there can hear, so communication for him is a really big barrier.

20 I really hope that doesn't happen again. There are so many deaf people out there.

VIDEO OF DESLEY DONNELL CONCLUDES

25 MS EASTMAN: Ms Jackson, you also interviewed Sue Frank who is a Torres Strait Islander and she currently works for Deaf Services as a service access facilitator in Far North Queensland. She is based in Cairns. You had a very long interview with her and during that interview she told you about the experiences of First Nations people who are Deaf and deafblind in the Cape York Peninsula.

30 A. Yes, that's correct.

35 Q. We've taken a very small part of a longer interview, which will be part of the exhibits to your statement and will play part of your interview with Ms Franks.

A. Great. Thank you.

VIDEO OF SUE FRANK BEGINS

40

MS FRANK: There was another Deaf Indigenous person from the Cape York Peninsula and with him communication by SMS or video was just not enough. The video screen is really limited in size and the video was blurry and kept freezing because of the poor signal in that region. He became really frustrated and angry during the pandemic and I tried to tell him not to visit my office in Cairns. But it wasn't my choice, it was his. He was very assertive about it. I was very

apprehensive because it put me at risk when he visited my workplace.

5 The client came to me and wanted to know about his NDIS plan because he couldn't read it and just couldn't understand it. Then I understood that he had very limited sign communication and it just wasn't sufficient for his needs. He wanted to move from Cape York because they were bored and isolated at home. He had no help to help find a job, no health services, no support from his family. It was very sad, so he moved here and discovered Deaf Services, which was a really good fit for him. He's so much happier and he's improved a lot. You can see the difference between him now and how he was when he was living in Cape York.

VIDEO OF SUE FRANK CONCLUDES

15

MS EASTMAN: Ms Jackson, thank you very much for preparing and sharing those recordings with the Royal Commission. My final question to you is: what would make a difference to the Deaf community with respect to the mode or the manner of communication from Government during the course of the COVID-19 pandemic?

20

A. I think the Deaf people around Australia, like anybody else, any other person in the country, can be at risk in this period of the pandemic. They are very vulnerable, I think, because of their language and communication needs which are very specific. They have very limited access to information because, for example, most people get information from the internet, from radio or TV and for many Deaf people that is simply not accessible.

25

Sue brought up an excellent example in her interview with me to say that Indigenous Deaf Australians don't understand information on the television broadcasts because all of the interpreters are white, they are not Indigenous so their language use doesn't fit the sign language use that the Indigenous people use. It means that they have a heightened level of risk than do other Deaf people because they don't know what they should be doing, they don't know how to prepare safely or how to maintain their own safety and they put themselves at more risk and they also put others at risk through having continued contact with them. We've learnt from the Victorian experience that minority groups need to have access to information and support in their own language from a trusted group of people, a trusted group of leaders in their communities or organisations and my recommendation is that the Government works to establish a panel of expert people, which includes Deaf leaders, Deaf organisations, so that they can support the Government and advise the Government on how to ensure that their outreach is appropriate, how to contact the different kinds of people that I outlined in my statement who have a variety of communication needs, such as Deaf Indigenous people, who have their own communication requirements, which are quite different to a confident bilingual Deaf person like Naomie. Monolingual Deaf people constitute another group who require information from people they trust.

45

5 So I think it is really important that the Government establish some kind of advisory panel in order to provide a way in which to work with Deaf organisations and Deaf leaders to support them in their response to ensure they are providing the right information and supporting all Deaf people throughout Australia, no matter where they are.

Q. Ms Jackson, I've finished asking all my questions. I will just check whether any of the Commissioners have any questions.

10 COMMISSIONER SACKVILLE: Commissioner Galbally?

COMMISSIONER GALBALLY: No questions, thank you.

15 **QUESTIONS BY THE COMMISSION**

COMMISSIONER SACKVILLE: I would like to ask something to get a little bit of information if I could. Can I direct your attention to paragraph 18 of your statement, and also paragraph 44. In paragraph 18 you say that many Deaf people are not literate or have limited literacy. And in paragraph 44 you refer to monolingual people where Auslan is their only language. Why is it that there are many Deaf people who do not have, I assume you mean literacy in the English language?

25 A. Yes, it is the case.

COMMISSIONER SACKVILLE: Why is that?

30 A. Because of their educational background, because of the education system. The education system was not designed to fit their specific needs. Deaf people don't fit within our education system very well and mostly they don't have communication with their own families. So what that means is they are not able to learn in the same kinds of ways that other people do over time. It is an unfortunate fact. It is a reality for many Australian Deaf people. It is because of their education and how they were raised within their families with limited communication.

COMMISSIONER SACKVILLE: One of the issues we have to look at is that of inclusive education. And, as I understand that concept, Deaf children would be educated in mainstream schools and as part of the general education system, integrated, included within classes. Would that mean that over time the issue of Deaf people who have limited literacy would diminish?

45 A. Well, it's hard to say, and that's because in the field of Deaf education for many years, and I've been involved as an educator myself for more than 25 years, there is not a one size fits all solution for educating Deaf children. Some Deaf children do very well if they are educated in Auslan. They start to develop their skills in English after they develop Auslan first, or there are some other children who use spoken

language very well, they use amplification devices such as hearing aids, but there is not a 100 per cent guarantee that those devices will work. There is a great deal of diversity within the Deaf community. So education means --- a good education means a teacher is able to adapt to the needs of each student because everyone learns differently. With inclusive education, if that includes the ability for the teacher to adapt the way they teach to everybody in the classroom, then I think it can be successful in the long term for Deaf students, but we are not seeing that at the moment in regards to Deaf students.

10 COMMISSIONER SACKVILLE: Thank you.

Thank you very much for your statement and giving evidence and thank you very much for organising those videos as part of the evidence before the Royal Commission. Thank you for coming in today to this hearing room.

15 A. Thank you. It is my pleasure, Commissioner.

THE WITNESS WITHDREW

20 MS EASTMAN: Commissioners, that concludes the evidence this afternoon. I just have a few administrative matters to attend to. Perhaps if Ms Jackson is looking to leave the witness box, just give me a moment and I will attend to those matters.

25 Commissioners, there are a few documents that I need to tender arising from the evidence today. You will recall Ms Kayess gave evidence about the Sendai Framework for Disaster Risk Reduction and that document should have been included in the tender bundle. Can we now include that in the tender bundle and part of Ms Kayess's evidence, so it will be part of tender bundle part D, behind tab 33A and it is exhibit number 5.19.36.

EXHIBIT #5.19.36, SENDAI FRAMEWORK FOR DISASTER RISK REDUCTION

35 COMMISSIONER SACKVILLE: Yes.

40 MS EASTMAN: Secondly, in my observations this morning by way of opening, I referred to a publication of the Australian Institute of Criminology. That is a report for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with a Disability. It has been prepared by Hayley Boxall, Anthony Morgan and Rick Brown, entitled "Experiences of domestic violence among women with restrictive longTerm health conditions". I can tender that document, which will be part of tender bundle F, tab 173. If that could be marked as Exhibit 5.71.

EXHIBIT #5.71, DOCUMENT ENTITLED "EXPERIENCES OF DOMESTIC VIOLENCE AMONG WOMEN WITH RESTRICTIVE LONG-TERM HEALTH CONDITIONS"

5

MS EASTMAN: In relation to that document, I need to make a clarification and correction to something I said in opening this morning. I said that one in four, 23 per cent of women with disability had experienced physical violence during COVID-19. And what I should have said is that these are women with disability who were in a current relationship. So if that correction could be made to the transcript.

Then finally for today, we have a number of people who have provided witness statements to the Royal Commission who will not be attending in person to give evidence. And if it is convenient to deal with two of those statements this afternoon ---

COMMISSIONER SACKVILLE: Yes, certainly.

20

MS EASTMAN: The first is the statement of Clifford Stephens dated 12 August 2020 and his statement can be found in tender bundle A, tab 45.

He is a 73-year-old living in Melbourne with his family. His son acquired a severe disability in the early 1990s following neurosurgery. His son was then 18 years old. Mr Stephens has followed closely the work of the Royal Commission and provided to the Commission some submissions, including a very detailed submission in relation to the impact on his son during COVID-19.

Mr Stephens has helpfully provided a statement that summarises the key aspects of his submission. He identifies the difficulties of obtaining PPE and the battle, as he describes it, with a service provider over a number of months to ensure that his son was safe in his home.

He says in his statement that his primary concerns regarding COVID-19 and the disability sector are as follows: that there has been no federal funding to service providers for extra measures such temperature monitoring and purchasing PPE. He says that there has been no guidance from the Department of Health on assessing people with disability for vulnerability. He says the focus has always been on protecting workers, not people with disabilities. He identifies that service providers have poor communication about what measures they are taking and he considers that the service providers have a lax attitude to protecting people with disabilities, particularly when it comes to implementing measures.

The second statement that I will tender this afternoon is from a witness who is identified by pseudonym ABC and, Commissioners, you have made a non-publication order in relation to the identity of ABC.

ABC has two children, and her daughter has autism and ADHD and her son has autism, anxiety and depression. ABC also has an auto immune disease, Asperger's syndrome and anxiety. ABC's evidence talks about the impact of COVID-19 on her family, including the impact on her children in relation to accessing formal and informal supports, the burden of home schooling, particularly for young people with autism, and she has provided a very compelling statement for the Royal Commission, identifying that she and her family have experienced loneliness, and increased anxiety and despair during the course of the COVID-19 pandemic. So I also tender her statement.

Commissioners, her statement is in tender bundle A, behind tab 40 and I would ask you to mark her statement as Exhibit 5.15.

15

EXHIBIT #5.15, STATEMENT OF ABC, DATED 11 AUGUST 2020

COMMISSIONER SACKVILLE: Yes, thank you.

20

MS EASTMAN: I think that deals with all of the matters that I needed to advise you of this afternoon. So we can conclude the proceedings and then commence at 10 am tomorrow.

COMMISSIONER SACKVILLE: Thank you very much. Then the hearing will adjourn until 10 am tomorrow. Thank you very much for your assistance during the day, Ms Eastman.

30 **HEARING ADJOURNED UNTIL 10 AM, WEDNESDAY, 19 AUGUST 2020**

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