



TRANSCRIPT OF PROCEEDINGS

THE HON RONALD SACKVILLE AO QC, Chair
THE HON ROSLYN GAY ATKINSON AO, Commissioner
MR ALASTAIR JAMES McEWIN AM, Commissioner

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

MELBOURNE

10.09 AM, FRIDAY, 6 DECEMBER 2019
Continued from 5.12.19

DAY 5

**MS K. EASTMAN SC, Senior Counsel Assisting, appears with MR A.B. FRASER and
MR M. HARDING SC**
MS F. ELLIS appears for Senior Practitioner Victoria

COMMISSIONER SACKVILLE: Yes. This is the final day of this week's hearing. I commence, as I have on the other days, by acknowledging the traditional custodians of the land on which we meet today, the Wurundjeri people of the Kulin Nation. I pay respects to their elders past and present and honour their young people who, one

5 day, will take their place as custodians. Yes, Ms Eastman.

MS EASTMAN SC: Good morning, Commissioners. This is the final day of the third public hearing of the Royal Commission. Our focus today will turn to two academics this morning. You will hear from Rosemary Kayess immediately. She's on video link from Sydney, and then Professor Christine Bigby. We'll then have a

10 short break and reconstitute with a panel. The panel members will talk about alternative options for group homes and alternative ways of addressing the accommodation concerns that we've heard during the week, and then our final witness will be Sam Peterson. So this might be an earlier day. I very much doubt that we will be continuing till 4 pm this afternoon. We're likely to finish in the

15 middle of the day. The precise timing, I will have to keep you up to date as the morning progresses.

COMMISSIONER SACKVILLE: I was hoping we'd get permission from you for an early mark.

MS EASTMAN SC: Maybe. There might be homework. So I just want to start with Rosemary Kayess. I just want to check that the video link will work. So those

20 following the Royal Commission proceedings via the internet and the webcast, so those who aren't in the room, this witness is appearing via video link from Sydney, and so we hope the technology works, and I've said I will speak very slowly to make sure that there's nothing lost in the communications between Melbourne and Sydney

25 this morning.

COMMISSIONER SACKVILLE: Thank you.

MS EASTMAN SC: So can I just check, first of all, whether Ms Kayess can hear me, and she's here on the screen in the Royal Commission.

MS R. KAYESS: Yes, Kate, I can hear you.

30 MS EASTMAN SC: Thank you. All right. So the first step is that we'll need to do an oath or affirmation. So that will be administered now. That's happening in Sydney. Thank you.

<ROSEMARY KAYESS, AFFIRMED

[10.12 am]

<EXAMINATION BY MS EASTMAN SC

COMMISSIONER SACKVILLE: Thank you very much.

MS EASTMAN SC: Thank you. So may I confirm that your name is Rosemary Kayess?

MS KAYESS: Yes, that's correct.

5 MS EASTMAN SC: And you are currently a Senior Lecturer at the Faculty of Law at the University of New South Wales?

MS KAYESS: That's correct.

MS EASTMAN SC: And that's a position that you've held since 2005?

MS KAYESS: That's correct.

10 MS EASTMAN SC: And you are also, presently, the Vice Chairperson of the Committee for the Rights of People with Disabilities established under the United Nations Convention on the Rights of Persons with Disability.

MS KAYESS: That is correct.

15 MS EASTMAN SC: And you assumed that position in March 2019. I think you were elected to the Committee with effect from 1 January, but, in March, you became the Vice Chairperson; is that right?

MS KAYESS: That's correct.

20 MS EASTMAN SC: And the capacity in which you're giving evidence this morning is based on your own education, training and experience, and you're not representing the views of your employer or in any other representative capacity in which you act?

MS KAYESS: That is correct.

25 MS EASTMAN SC: Commissioners, a copy of Ms Kayess' statement is found at tab 147 in the tender bundle with some additional material to tab 150. Ms Kayess, can I ask you to confirm that the contents of the statement are true and correct to the best of your knowledge and belief?

MS KAYESS: Yes, I can confirm that it is correct.

30 MS EASTMAN SC: Thank you. So over the course of the – sorry, apparently, your statement's now tab 146 with the accompanying material at 147 to 149. So thank you for that correction. Over the course of the week, there has been many references to the UN Convention and many references to rights and the rights of people with disability. We thought, this morning, it might be opportune to come back and reflect

on the Convention, the way in which the Convention operates, and the way in which the Convention deals, in particular, with Article 19. Then we're going to cover how we translate the Convention rights into an Australian setting, and your statement has covered all of these issues. So can I start with the Convention, and many people following this hearing may be familiar with the Convention, but many may – the Convention may be new. So can I start with a little explanation of the Convention. What can you tell us, Ms Kayess, about how the Convention came to be?

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MS KAYESS: The Convention has its genesis in the fact that whilst people with disabilities had coverage under international human rights law, there was not a process to act. The experience of people with disability, they continued to be highly represented in the levels of poverty in the world, and there was significant human rights violations continuing to come before the United Nations. It took several decades for the UN to develop a thematic Convention on the Rights of Persons with Disabilities, and, three times, a resolution went before the General Assembly before the General Assembly agreed to develop a convention. What the Convention did was translated all the existing human rights into the context of disability.

MS EASTMAN SC: Right. Can I pause there?

MS KAYESS: What – sorry.

MS EASTMAN SC: So just to – for the – to follow this, the work the United Nations does when it develops a Convention is to collect all of the members of the United Nations together and there's often a large conference, and then there'll be discussion and negotiation around what will be the content of the Convention. And when you talk about a thematic Convention, it's the case, isn't it, that, in the area of human rights, the United Nations has general conventions that pick up all of the relevant human rights. For example, the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights. So they're the general conventions. The thematic conventions are those that might be specific to particular issues. So we have, for example, a convention on the elimination of all forms of discrimination based on race. We have a convention dealing with discrimination against women. We have conventions dealing with torture. So they're the thematic conventions; is that right? And one of - - -

MS KAYESS: That is correct.

MS EASTMAN SC: - - - the areas that was missing was disability, and part of this was, wasn't it, because Article 26 of the International Convention on Civil and Political Rights had a whole range of grounds on which discrimination should not occur, but it didn't include disability. It just had something called "other status"; is that right?

MS KAYESS: That's sort of correct.

MS EASTMAN SC: All right. So tell - - -

MS KAYESS: Article 2 - - -

MS EASTMAN SC: - - - me how it's not quite correct?

MS KAYESS: Article 2 gives you the non-exhaustive list of areas in which the covenant covers, and so what it does is sets out a scope, but doesn't contain it to only
5 those areas in its fields. Article 26 opens the application of the covenant to all human rights, the fundamental freedoms, and brings in social, economic and cultural rights under the purview of being applicable before the law unto the Covenant.

MS EASTMAN SC: Yes. So when it comes to developing the Convention on the Rights of Person with Disabilities, this was intended to be a thematic convention that
10 did a little bit more than, perhaps, the earlier conventions, and that was to look at the specific nature of the way in which the rights of people with disability would apply in areas of public life and introduced important concepts such as reasonable accommodation; is that right?

MS KAYESS: That is correct. The Convention, whilst being a thematic
15 convention, is also understood as being a hybrid convention.

MS EASTMAN SC: What do you mean by hybrid convention?

MS KAYESS: So the Convention on the Elimination of All Forms of Racial Discrimination is understood to be a traditional human rights or non-discrimination model of a convention. So what it does is it articulates a definition of racial
20 discrimination and applies it to all human rights and fundamental freedoms. Now, ICERD has six substantive articles. CRPD, on the other hand, is considered a hybrid convention, in that, it has both a non-discriminate – sorry, non-discrimination model, but it also has substantive articles that have got prescriptive content for social development.

MS EASTMAN SC: Right. And Article - - -

MS KAYESS: So it's got 30 operative articles.

MS EASTMAN SC: 30 operative articles, and today - - -

MS KAYESS: Yes.

MS EASTMAN SC: - - - we're really going to focus just on one Article 19, but
30 before we get to that, I just want to deal with how the Convention works at the UN level. Sorry, I've just got a bit of background - - -

MS KAYESS: The Convention is a binding contract between a States party and the United Nations which is an intergovernmental body.

MS EASTMAN SC: And there's a - - -

MS KAYESS: That - - -
MS EASTMAN SC: - - - 181 States Parties to the Convention; is that right?
MS KAYESS: 181 States Parties to the Convention; that's correct.
MS EASTMAN SC: And Australia is one of those parties.
5 MS KAYESS: That is correct.
MS EASTMAN SC: And the Convention became operative for Australia in August
2008; is that right?
MS KAYESS: To a certain degree - - -
MS EASTMAN SC: All right.
10 MS KAYESS: - - - it came into force.
MS EASTMAN SC: All right. Now, in terms of, then, the monitoring of the
convention, the Convention itself establishes a Committee that's got a number of
functions. It's a little bit like a quasi-judicial body of independent experts, and
you're one of the members. So while you're nominated by Australia and elected,
15 you don't represent Australia on that Committee. You're independent; is that right?
MS KAYESS: That is correct.
MS EASTMAN SC: And how many members of the Committee are there?
MS KAYESS: There are 18 members.
MS EASTMAN SC: And the role of the Committee members – and if it's still the
20 practice of the UN, you do this on a voluntary basis with a modest stipend; is that
correct?
MS KAYESS: It's not a modest stipend. What they do is cover your travel and
your accommodation.
MS EASTMAN SC: And the rest is that you give your independent expert services
25 for the benefit of the international community; is that right?
MS KAYESS: That is correct.
MS EASTMAN SC: All right. So the members of the Committee meet twice a year
in Geneva?
MS KAYESS: That is correct.

MS EASTMAN SC: And the Committee has quite a heavy workload. So one of the functions of the Committee is to consider reports that are submitted by the States Parties?

MS KAYESS: Yes, periodic review is a major part of the work of the Committee.

5 MS EASTMAN SC: So the reports are called periodic reports and the States Parties are supposed to provide reports every five years or so, but, sometimes, you get combined reports covering a longer period; is that right?

MS KAYESS: That is correct. The first report is due two years after ratification, and then every four years.

10 MS EASTMAN SC: And so the way that the State Parties reports work is that the governments prepare a report, which is a little bit like an audit about how that particular state is complying with the Convention rights, and, often, in addition to the State Party reports, there are reports called shadow reports that various NGOs or civil society provide to the Committee. So for you, as Committee members, you've got
15 the official government report and you've also got a lot of background material in the shadow report. So you have to consider both those reports before you have, what is often called, a constructive dialogue, but, often, the States Parties feel that there's not a lot of construct around it, more criticism, but you have an engagement with the States Parties called constructive dialogue to discuss their reports and to ask them
20 questions often based on the shadow reports. Is that a general, very high-level summary of the work that the Committee does in relation to state reports?

MS KAYESS: That is correct.

MS EASTMAN SC: All right. And once the state report has been considered, the Committee's job is to give a little bit of a report card to the particular state, and
25 they're technically called concluding observations?

MS KAYESS: That is correct.

MS EASTMAN SC: And the practice of the UN Committees has been to give the states, initially, some good news about their progress, but then to highlight areas where the committee identifies concerns about a state's progress in implementing the
30 Convention rights. Is that a fair summary?

MS KAYESS: That is a fair summary. I mean, depending on the country and the type of progress, but also, the context of that particular country, it will also try to highlight opportunities that the State Party might be able to take up and implement.

MS EASTMAN SC: All right. One of the other functions of the Committee is to
35 prepare, what is called, a general comment or General Comments, and they serve, really, two purposes. I think, originally, the General Comments were designed to help States Parties understand the content of rights when they were preparing their

reports, but, over time, they've become – and I think you describe it as jurisprudence, but they've really become part of the commentary of the experts on the Committee in giving some content to the particular rights in the Convention. Is that a fair summary of a General Comment?

5 MS KAYESS: That's a fair summary of the - - -

MS EASTMAN SC: And the - - -

MS KAYESS: They're considered authoritative.

MS EASTMAN SC: And so when we're reading a convention right – for example, we're going to look at Article 19 – it's difficult to look at Article 19 without also
10 taking into account the General Comment, which is General Comment 5; is that right?

MS KAYESS: That is correct.

MS EASTMAN SC: Right. The third function of the Committee arises in a slightly different way, and that is for those States Parties that have also signed on to what is
15 called an Optional Protocol. So this is the add-on to the Convention. The Optional Protocol allows individuals within – and groups, I think – individuals and groups within the jurisdiction of the State Party – so that might either be in the territory of the State Party or subject to the laws of the State Party – to make a complaint to your Committee, and the UN language for a complaint is a communication; is that right?

20 MS KAYESS: That's correct. The Optional Protocol is a parallel treaty. So States Parties have to accede or sign up to the Optional Protocol and ratify, giving the treaty body jurisdiction to do international monitoring in terms of individual communications, but also inquiry procedures and state visits.

MS EASTMAN SC: All right. So there's 91 states parties that have signed up to
25 the Optional Protocol out of the 181?

MS KAYESS: That is correct.

MS EASTMAN SC: And Australia has also signed and ratified – and I use that expression, they're just the technical terms for making the international law work – but Australia has ratified the Optional Protocol on 30 July 2009.

30 MS KAYESS: That is correct.

MS EASTMAN SC: And so – so even though the Optional Protocol is there, that doesn't mean if I've got a complaint I can just ring you or ring the UN Committee.

MS KAYESS: No. No.

MS EASTMAN SC: So I have to exhaust all my local remedies.

MS KAYESS: Yes, all domestic remedies first.

MS EASTMAN SC: All domestic remedies. So if I want to bring a complaint to, say, my rights under Article 19 have been breached, I have to find all of the relevant
5 Australian legal remedies before I can go to the Committee, unless I can persuade the Committee that there is no local remedy to exhaust; is that right?

MS KAYESS: That is correct. If there is no effective remedy, and it's the definition of an "effective remedy" that is critical to admissibility.

MS EASTMAN SC: And if I can – I then have to satisfy two steps. So I would
10 have to persuade the committee that my complaint or the communication is admissible. So I'm complaining about something that's within the treaty. And if my complaint is admissible then the Committee will look at the merits of my complaint; is that right?

MS KAYESS: Yes. It's a two-step process. So admissibility is about whether all
15 domestic remedies have been exhausted, and also, obviously, that the – the state – the state is a States Party, and that there is a violation of – well, there is an actual right under the Convention.

MS EASTMAN SC: And there have been examples of Australian people with
20 disability who have lodged communications or complaints to the UN Committee and those complaints have been heard and determined. But it's a paper process, isn't it? You don't get to go to Geneva to present your case.

MS KAYESS: No, it - - -

MS EASTMAN SC: Which disappoints many lawyers.

MS KAYESS: No, it is a submission-based process.

MS EASTMAN SC: All right. I hope that just gives a very broad overview about
25 the mechanics about how the Convention works at an international level. Can we now turn - - -

COMMISSIONER SACKVILLE: Can I ask Ms Kayess a question, perhaps through
30 modesty or otherwise, your statement, I don't think, explains your role in the drafting of the Convention. Would you like to say something about that?

MS KAYESS: Thank you, Chair. I was a designated expert on the Australian
Government delegation during the negotiations between 2002 and 2006. During that process I facilitated the negotiations and wrote Article 24 on the right to education, but I was also involved with a lot of the other articles, but especially Article 12, the
35 scoping articles. So the interpretive articles which was highly contentious because it

was the debate about whether there should be a definition. So the way that disability is being conceptualised and scoped. So what – what is the population that the thematic Convention covers. And also Article 17, mental and physical integrity of the person. But needless to say on the delegation we had to engage with all Article development.

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COMMISSIONER SACKVILLE: Thank you.

MS EASTMAN SC: So the focus for this public hearing has been Article 19 of the Convention. And you have set out in the written statement what Article 19 means and its purpose. That's at paragraph 32 and following. But can I ask you to perhaps just tell us a little bit about, from your perspective and the work that you've done as an expert in this field, what does Article 19 actually mean from a human rights perspective?

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MS KAYESS: Article 19 is an interesting article. As I said before, the Convention is a hybrid Convention. Or you could say that Article 19 is a bit of a hybrid article. Most articles can be identified as either a civil and political right or a social, economic and cultural right. The genesis of Article 19 is based in Article 12 of the Covenant - - -

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MS EASTMAN SC: So that's in civil and political rights.

MS KAYESS: - - - on Civil and Political Rights. So it's based on the notion that everyone has the right to choose their residence.

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MS EASTMAN SC: Just pausing there that - - -

MS KAYESS: So - - -

MS EASTMAN SC: That Article 12 in the ICCPR is - - -

COMMISSIONER SACKVILLE: The ICCPR being the International Covenant on Civil and Political Rights.

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MS EASTMAN SC: - - - the International Covenant on Civil and Political Rights is – couches the freedom of movement, and the freedom to move in your own State, to come in and out of your own country but it also has that right of residence. So that's the concept of the Article 12 right about residence has been picked up in the Article 19 right. Is that – am I understanding that correctly? So you've picked up concept of residence but it's not a right of housing, is it?

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MS KAYESS: No, it is not a right of housing.

MS EASTMAN SC: Okay. So how does that work?

MS KAYESS: The right of housing has been traditionally found within adequate standard of living.

5 MS EASTMAN SC: So is Article 19 bringing together the hybrid themes of the concept of place of residence, of standard of living, and then the particular features of the Disability Convention around choice and around decision-making, and around personal control or self-determination; is that right?

MS KAYESS: Yes. It's basically trying to give people with disability – well, respecting the right of persons with disability to have on an equal basis with other – others the ability to choose where they live.

10 MS EASTMAN SC: Does equal basis mean identical or the same, or does it have a different concept?

MS KAYESS: It does have the sense that it should reflect the same opportunities and choices that others have.

MS EASTMAN SC: Right.

15 MS KAYESS: You wouldn't say it's the same because it wouldn't be the same for all people within the general population because of their individual context.

MS EASTMAN SC: Right. So sometimes I think when we talk about equality, we think of it as everybody being treated in an identical or same way. But for the Convention, the concept of equal basis has got some shades of meaning, doesn't it?

20 It might be treating people the same way but it also might be focusing on what's sometimes called substantive equality which is different treatment to achieve same outcomes or to achieve an outcome of equal basis; is that right?

MS KAYESS: That's correct.

25 MS EASTMAN SC: Right. So can we turn now to Article 19 and its translation at a practical level. And before going into the detail that you've addressed in paragraph 39, is it right that just because Australia has signed and ratified this Convention, and has international obligations, that doesn't mean that the rights in the Convention are automatically part of Australian law; is that right?

30 MS KAYESS: That's correct. Australia has Parliamentary sovereignty. So law in Australia is enacted from the Parliament.

MS EASTMAN SC: So if the rights that are in the Convention were to become part of the Australian law, it would require the Commonwealth Parliament or the State and Territory Parliaments to take the rights in the Convention and bring them into Australian law, sometimes called domestic law; is that right?

35 MS KAYESS: That is correct.

MS EASTMAN SC: And has that happened in Australia? Is there one law in Australia that has taken all of the Convention rights and made it part of Australian law?

MS KAYESS: No.

5 MS EASTMAN SC: No. Are there any laws in Australia that have taken part of the – parts or rights in the Convention and made them part of Australian law?

MS KAYESS: Not – not like, say, the Racial Discrimination Act has, which has literally lifted Article 1 of the Racial Discrimination – yes, the Racial Discrimination Convention.

10 MS EASTMAN SC: All right. The Disability Discrimination Act refers to the Convention but it doesn't translate the rights out of the Convention directly into that law; is that right?

MS KAYESS: No. It picks up several of the themes. Technically it doesn't work the same way. The DDA is – it picks up direct and indirect, and it picks up
15 reasonable accommodation, which are the three elements within the Convention, but it's not structured the same way.

MS EASTMAN SC: All right.

COMMISSIONER SACKVILLE: Can I just ask you, so that we can understand how the respective powers of the Commonwealth and States work, under the
20 Australian Constitution, the external affairs power conferred upon the Commonwealth Parliament permits the Commonwealth Parliament to enact legislation which implements Australia's obligations under international treaties; is that correct?

MS KAYESS: That is correct.

25 COMMISSIONER SACKVILLE: So that it is open to the Commonwealth Parliament to implement any conventions, international conventions to which Australia is a party, and that's what it has done in relation to the Convention for the Elimination of All Forms of Racial Discrimination.

MS KAYESS: That is correct.

30 MS EASTMAN SC: Right.

COMMISSIONER SACKVILLE: Here endeth the lesson on constitutional law.

MS EASTMAN SC: But even if the Convention is unincorporated, so it hasn't been translated into Australian law, it's still possible to use the Convention, isn't it?

MS KAYESS: It should be able to be taken on judicial notice.

MS EASTMAN SC: So judges can take the Convention into account. So it could be judges or tribunals or Royal Commissioners can take the Convention into account when they exercise discretion or they make decisions that those decisions can be
5 consistent with the rights in the Convention. That's possible, isn't it?

MS KAYESS: That is correct. There is nothing within the Australian legal jurisdictions that would preclude any judicial officer from not taking judicial notice of the Convention and the rights that we have signed up to, ratified.

MS EASTMAN SC: And the Convention can be taken into account by the
10 administrative branch of governments, either in making decisions that a discretion can be exercised to give effect to the rights or to act consistently with the rights in the Convention or also to develop policies and practices. That's open to the executive arm of government, be they policy makers, government departments and the like; is that right?

MS KAYESS: Yes, most definitely. The prescriptive normative content of the
15 Convention is to be indicative of what implementation should – what standards implementation should take.

MS EASTMAN SC: And it's not – the Convention is just not limited to
20 governments or court, is it, because we now see that there's a real move to using human rights conventions in framing how business operates. And there are guidelines about human rights and business, so human rights and corporations. So do you think that the Convention is also relevant to the work of corporations and businesses in Australia?

MS KAYESS: Yes. I certainly do.

MS EASTMAN SC: Right. And how could businesses and corporations look to the
25 Convention in terms of framing their policies and practices?

MS KAYESS: Well, it should be a guideline to understand their social obligations and social responsibilities, but also framing their internal policies and procedures in terms of equity, diversity and inclusion.

MS EASTMAN SC: So that sort of takes us directly into your statement where
30 when you talk about translating Article 19 into a practical application, you say in paragraph 39, in your opinion:

*The practical implementation of Article 19 requires a coordinated cross-
35 government strategy, such as the National Disability Strategy. And the purpose of the NDS is to make wider community inclusion of and more accessible to people with disability.*

So having told us that, can you just tell us a little bit about some of the ways in which the rights described in Article 19 can be implemented in a very practical way in Australia.

5 MS KAYESS: First and foremost there needs to be opportunity for people with disability to make choices about where they live. Practically in Australia, that is problematic because access to housing, affordable and accessible housing, is very limited. And we have little commitment to universal design in housing. And we have little commitment to mandated standards around housing, accessible housing.

10 MS EASTMAN SC: So how is Australia going with compliance, then, in meeting the Article 19 rights against what you've just described? That would make it very difficult to implement the Article 19 rights, wouldn't it?

MS KAYESS: It is very problematic. It translates to the experience for people with disability of not being able to come out of hospitals after traumatic injury. It means an over-reliance on – the deinstitutionalisation process not being a true
15 deinstitutionalisation process, but a reliance on an existing smaller conceptual framework – framework around institutions. The jurisprudence around Article 19 is very clear, that if a person does not have choice, and it shouldn't be a false binary choice, that mechanisms that tie bricks and mortar to support and don't give people those choice as to choose where they live are not acceptable.

20 MS EASTMAN SC: Why is that?

MS KAYESS: It comes back to the very enablers to marginalisation of people with disability. Conceptually, we have framed disability as difference and set up parallel systems across life domains. Those parallel systems have reinforced notions of deficit and difference, and that because people with disability are different, we can
25 have a different standard for how they – how life domains are framed for – for them.

MS EASTMAN SC: What do you mean by life domains? I think we've had some discussion during the week about that concept but it might be helpful to understand that from a rights-based perspective and the work coming from the UN Committee.

MS KAYESS: Well, like domains will be, I mean, very much how the fact that we
30 were talking about education a couple of weeks ago in Townsville. We are talking about group homes in Melbourne now. I know there will be a focus on justice at some point. It's these types of domains where segregated parallel systems have been established because social structures and administrative structures are not inclusive for people with disability.

35 MS EASTMAN SC: All right. The last thing I want to ask you about is how can Australia ensure compliance with Article 19. And at paragraph 73 of your statement you refer to the committee's concluding observations on Australia's periodic review. So this is a report card on Australia. And the Committee expressed concerns about the lack of mandated national access requirement for housing in the National

Construction Code, and recommended that Australia amend the federal law by including mandatory rules on access for all new and extensively modified housing. The Committee also made some particular comments about the application of Article 19 to group homes. And the Committee observed:

5 *The fact that specialist disability accommodation framework facilitates and encourages the establishment of residential institutions and will result in persons with disability having to live in particular living arrangements in order to access the NDIS support.*

10 And the Committee made some recommendations. Do you want to speak about the Committee's recommendations in relation to the group home issue and the NDIS? That's in paragraph 76.

MS KAYESS: Well, as I say there, there are mechanisms within the existing NDIS framework that allows for not only the maintenance of existing group homes but also the building of more group homes. If residents in there have a dominant agency that they use for the provision of care, whether it is being provided by the agency
15 managing the group homes, if somebody else moves into that group home and wants a different agency, nine times out of 10 they won't get that choice because it's not administratively possible because the service is being provided by another agency or the other residents within the facility. So even though, technically, people should be
20 able to get a choice, their choice is a kind of false choice because we don't have the stock of accessible and affordable housing, mainstream housing. So group homes become the default option. And it's up to the situation within that group home about whether they can have choice about who provides their service. And if it ends up being a choice of one agency for the whole group home, then they may not get a
25 choice about which actual person does work with them.

MS EASTMAN SC: Right. So that's separating the bricks and mortar from the support services.

MS KAYESS: Yes.

MS EASTMAN SC: There are many more questions that I would like to ask you, but I think time is against us. Is there anything in the matters that you've raised in
30 your statement that I haven't covered that you wanted to share with the Royal Commission on Article 19 and the implementation of those rights?

MS KAYESS: I think it's important that we understand that CRPD is about addressing segregation on the basis of disability. Specialist supports such as group
35 homes is part of those segregation on the basis of disability. And there is significant evidence that they are core enablers of leaving marginalised people at risk, for exploitation, violence and abuse. Now, as I said earlier, this occurs across all domains. And the fact that we are probably going to be talking about the same situation across education, across justice, and across health means that we need to

interrogate that segregation and what drives that segregation and how we break down and end that segregation.

MS EASTMAN SC: Thank you. I will just check if the Commissioners have got any questions?

5 COMMISSIONER SACKVILLE: You mentioned, Ms Kayess, the role that the Convention could take in the practices of business. Bearing in mind that business entities in recent years, at least some of them, have shown an interest in developing socially responsible policies – not all of them, but some – has there been any attempt to draft, for example, a charter that would guide business in relation to the rights
10 conferred by the Convention on the Rights of People with Disability?

MS KAYESS: Business and human rights is becoming a strong focus at the moment. And there is lots of work that's happening through what is called the charter procedure for the UN in terms of business and human rights. There is an independent expert that is about to be appointed underneath the Human Rights
15 Council. I am hoping that it will be a colleague of mine from here at the University of New South Wales – New South Wales Law School but I would say that one of the things that will come out of that special procedures will either be guidelines for a framework around business and human rights that will pick up the various conventions.

20 COMMISSIONER SACKVILLE: Is that something, do you think, that the Royal Commission could usefully explore?

MS KAYESS: Yes. I think it is. And I think it's not without the realm of – it's not - - -

COMMISSIONER SACKVILLE: Outside – outside - - -

25 MS KAYESS: I think it's quite within the realm of possibility for the Committee to also be looking at guidelines for business and human rights as it pertains to people with disability. Sorry, I'm trying to keep the feedback down and tripping over myself.

COMMISSIONER SACKVILLE: Thank you very much. Thank you very much,
30 Ms Kayess, for giving evidence and for preparing your statement. And I know from the work that you have done that your work has been extraordinarily influential in our understanding of the Convention. Thank you very much.

MS KAYESS: Thank you.

COMMISSIONER SACKVILLE: Thank you. Now, Ms Eastman, do we now
35 adjourn for a short period?

MS EASTMAN SC: If that's convenient. We started a little bit later just managing the technology.

COMMISSIONER SACKVILLE: Yes.

5 MS EASTMAN SC: Professor Bigby, who's our next witness, is here. If it's convenient, perhaps, to have a 15 minute adjournment, so a very quick morning tea and then Professor Bigby will be the next witness. Then we might have a very short adjournment to reconstitute for our panel, if that's convenient.

COMMISSIONER SACKVILLE: Well, we will do that.

MS EASTMAN SC: Thank you.

10 COMMISSIONER SACKVILLE: Thank you. Thank you again, Ms Kayess.

<THE WITNESS WITHDREW [11.00 am]

ADJOURNED [11.00 am]

RESUMED [11.22 am]

15 MS EASTMAN SC: Thank you. Commissioner, the next witness is Professor Christine Bigby, known as Chris Bigby, and she'll take, I think, an affirmation.

COMMISSIONER SACKVILLE: Thank you. If you wouldn't mind just following the instructions. Thank you very much.

<CHRISTINE BIGBY, AFFIRMED [11.22 am]

<EXAMINATION BY MS EASTMAN SC

20 COMMISSIONER SACKVILLE: Thank you, Professor Bigby. Please sit down. Thank you.

25 MS EASTMAN SC: A copy of Professor Bigby's statement is at tab 61 in the tender bundle, together with a copy of Professor Bigby's CV which is the very extensive 52-page CV with the Professor's publications behind tab 62, and then some accompanying articles at tab 63 and 64.

COMMISSIONER SACKVILLE: Yes.

MS EASTMAN SC: So, Professor Bigby, you are Christine Bigby?

PROF BIGBY: Yes, I am.

5 MS EASTMAN SC: And you are the Director, Living with Disability Research Centre.

PROF BIGBY: Yes.

MS EASTMAN SC: And that's based at La Trobe University.

PROF BIGBY: Yes.

10 MS EASTMAN SC: And you are also the Professor of Disability Research and Practice at La Trobe University.

PROF BIGBY: Yes.

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

PROF BIGBY: Yes.

15 MS EASTMAN SC: Okay. There's one correction to your statement, and that's at paragraph 5, and you wanted to correct the date of 16 – sorry, of March 2006 to make that March 2016. So if we make that correction?

PROF BIGBY: Yes. Thank you.

MS EASTMAN SC: And with that correction, the statement's true and correct.

PROF BIGBY: Yes.

20 MS EASTMAN SC: All right. So, Professor Bigby, can I – I want to start by asking you a little bit about your areas of research and your work over many years. The Royal Commissioners have your very extensive CV which indicates that you have been a researcher in this area for many years. So can we start by just explaining the nature of the work that you have done and your research methodology.

25 PROF BIGBY: Okay. So I've been researching group homes, which has been a major program of research along with a couple of others, since about 2000, and I sort of followed the cycle that you might expect of research, in starting with very qualitative, in depth ethnographic type work, and then building from that into key concepts, and then undertaking much larger scale studies. So I've used qualitative
30 mixed methods and large scale quantity statistical modelling.

And I guess it's important to say that a lot – most of the research that I'm going to talk about which is in group – in relation to group homes has used observation methods, structured observation, spending time trying to watch what's happening for people that live in group homes. And, primarily, that's because many of the people
5 who live in group homes are people with severe and profound intellectual disabilities who cannot tell you what their life is like. The only way you can find out about that is to watch and see, and the only way you can find out about what staff are doing is also to watch and see because staff will always overestimate and be optimistic about what they're doing. So that's been a major methodology that we've used over a long
10 time.

MS EASTMAN SC: Right. And - - -

COMMISSIONER SACKVILLE: What was your PhD in, if I may ask?

PROF BIGBY: My PhD was finished in 1996, and it was titled what Happens
15 When Parents Die, and it was a retrospective study looking back at a cohort of people who had always lived with their parents, but were now older with intellectual disabilities, and it looked at what had happened when their parents had died, and the effectiveness or otherwise of the planning that the parents had undertaken, and the types of transitions that people had had once they stopped living with their parents.

MS EASTMAN SC: Now, you've been following the hearing over the past week;
20 is that right? So I think you've been here or watching it on the broadcast.

PROF BIGBY: Yes.

MS EASTMAN SC: And some of the things that we are going to talk about, I'm going to ask you about, just some of your reflections on some of the issues arising in the hearing. So in your statement at paragraph 12, you say:

25 *There's approximately 17,000 people with intellectual disability who live in group homes across Australia, and they're still being built as the last institutions from that larger process of deinstitutionalisation has occurred.*

And then you make this observation, you say:

30 *While it may be argued other options are preferable, there is much less research on other models, and the reality is it will be many years before other options replace group homes.*

So you argue that:

35 *It's important to understand how to design and adapt group homes and provide support that will enable people to have a good quality of life, free from neglect and abuse.*

All right. And you've just heard the conversation with Rosemary Kayess in relation to the Article 19 issues around choice and the like. So do you want to say something – because you've prefaced the comments that you've made in your statement by noting that there is an argument that group homes should go and that there might be

5 alternative models or options available, but you say 'We don't have the research yet'. And you heard Colleen Pearce's evidence earlier this week also talking about what other options or what other alternatives may be available, but an alternative might not necessarily result in a better outcome. So do you want to say - - -

PROF BIGBY: Yes.

10 MS EASTMAN SC: - - - something more about that.

PROF BIGBY: So what we know from the research is that the model of group homes can have – can actually have very good outcomes for some people. It can also have very bad outcomes for other people. So it's variable, the outcomes. So having a small group home is a necessary – or having any sort of home is a necessary, but

15 not sufficient condition of having a good quality of life because it's the support that you get wherever you live that makes the significant difference, and the research that we've done shows that it's the quality of the support, rather than the bricks and mortar that really does make the difference. Obviously, there's other components to people's lives about the social connections that they have, but support is very

20 important to those things too.

So I would say that, when we're thinking about other models, we need to – we need to look at the research about those and, basically, the research that we've done shows people's – people's on average life, quality of life, in a group home is pretty mediocre, and it's pretty similar to the people we studied who lived in supported

25 living situations which are situations where people are their own tenants and they have drop-in support. So it's great to look at other options, but we have to look at the quality of the support that's being provided wherever somebody's living, and that's the sort of pivotal type of issue that you can influence. So what our research tries to do is to turn the visions that we have in the – in the right-spaced UN

30 Convention into what does that actually mean in practice on the ground for the people that are being supported. So it's a very different kind of research from the types of research that you've heard earlier in the week.

COMMISSIONER SACKVILLE: I suppose there is one view of the Convention that the rights conferred by Article 19 are inconsistent with the continuation of group

35 homes. Do you share that view?

PROF BIGBY: Not necessarily, no, because there may be some people who may choose to live with other people in – in a shared supported accommodation which is now the – the jargon for group homes. So there may be some people who wish to live in that situation, and as – and I think I said it's been the only option since we

40 started closing institutions, and the reality is it's going to be the only option for a long time to come. So while we might – while we might say, well, as a model, it's

flawed and I would argue with that, I think we have to pay attention to how we can actually make it as good as it possibly can be.

5 What we found was that there's – there's an overlap between people living in group homes and people living in drop-in support. There's about 30 per cent overlap in terms of people's capacity. So 30 per cent of the people that live in group homes could quite easily move out tomorrow if there was affordable housing and if they wanted to and if we could provide good quality support to them. Without any doubt, those people could move out because there's already people that are very similar to them living out in the community.

10 COMMISSIONER SACKVILLE: So the problem they face in terms of an exercise of choice is the absence of suitable accommodation into which they could move?

15 PROF BIGBY: I think that – I think that's – you could say that. There is an absence of options, but I think we've used the word "choice" a lot this week, and I think we need to interrogate what do we mean by "choice" and how do people with intellectual disabilities, particularly people with severe and profound intellectual disabilities make choices. People with severe and profound intellectual disabilities are people who don't use words to communicate, who have difficulty – who don't think in abstract terms, who don't think in language and who can't communicate, in the standard way, their choices. They – you have to work out what it is are their preferences through knowing them really well, through spending time with them, and through observing them.

20 If you've never lived in any other situation, how can you make a choice if you've never experienced that? So part of what's necessary in talking about choice for that group of people is to give them the experiences of living in other places and watching how they respond to that, and whether they prefer that or whether they're – whether they're lonely and don't like being on their own, whether they would prefer to live with two or three other people, but the only way you can know that is by giving people those experiences. Now, that's for a particular group of people with intellectual disabilities. There are people with more severe and profound disabilities. But many other people who live in group homes do have some sense of – of options, but, again, maybe – maybe not have experienced them, and so lots of people have moved out of group homes in Victoria over the last few years, and some have done that successfully, and some have done that with less success, and some have chosen to live with other people. So there isn't one answer, and I don't think – I don't think we should demonise group homes because it is a model that does work well for some people if you have the right type of support.

35 MS EASTMAN SC: You also want to make the point, as you do in paragraph 13 of your statement, and you say, at the outset, you want to make it clear that you are talking about:

...people with intellectual disabilities, particularly those with severe and profound intellectual disability who cannot direct their own support or express their own needs using words, and who require far more than attended care to live a good life.

5 And you've watched the Royal Commission and we – this – in – during the course of the Commission this week, we haven't had anyone with the level of intellectual disability that you're describing coming to the Royal Commission; is that right?

PROF BIGBY: Yes. I don't think you've – you've heard about that group of people because that group of people clearly can't speak for themselves and are reliant
10 on other people to do that, and these are people who are human the same as everybody else, but they have significant differences that need to be taken into account in terms of how they can be supported to exercise their rights.

MS EASTMAN SC: So how does the Royal Commission make sure that it can understand and to capture the interests of the cohort of people with intellectual
15 disability that you're talking about?

PROF BIGBY: So – and just to reiterate, these are people who need 24-hour support to be safe, but also need skilled support in order to be engaged in meaningful activities and social relationships. They're people who can't necessarily initiate their own social connections, but with the right quality of support, they can engage in
20 meaningful activity and they can engage in social relationships, but they might not look like the social relationships that we're used to. And I think what we need to do for that group of people is to be very clear that it's not about what I want for those people, what my values are for those people, what my preferences are. It's what does that person want and how can we tap into knowing that person well enough,
25 giving them enough experiences to be able to try and work out, from their perspective, what their preferences are.

And the only way you can really tap into that is through people who know them well, and that may be siblings, it may be parents, it may be long-term support workers that people have, and it may be researchers like me who go and spend a lot of time
30 watching people. So I think, in terms of listening to the voices of that group of people, it's really important to think about how do we tap into it, who can we listen to, what are the different takes on their life because the way I interpret what somebody may want from knowing them in a particular way may be quite different from the way a parent interprets them from knowing them from a parent point of
35 view. And so understanding and listening to their preferences needs to bring together the range of people that are involved in their life.

COMMISSIONER SACKVILLE: Can we assume that a parent, necessarily, is able accurately to reflect the views of the person with a disability?

PROF BIGBY: I don't think anybody is able to accurately – to represent - - -

COMMISSIONER SACKVILLE: Accurately.

PROF BIGBY: - - - the views of a person with disability. A parent will be able to give you their perspective. It's very hard, and we know from the research that we've done on supported decision-making, to put aside your own views and your own values and to step into somebody else's shoes and think about what it is they would want, not what it is I would want if I was in their shoes. So I think parents are – often, have a very, very good understanding of the person, but I think other people in the person's life, if there are other people, also have an understanding. So what I found in my PhD was that many siblings actually waited until their parents became very frail and sometimes had died, and then often stepped in and began to open up new life opportunities for their sibling with intellectual disability because they had a different perspective on the world from their parents, and that's not judging parents. It's recognising that people bring their own values and their own experiences when they interpret what the needs of people with disability are.

15 COMMISSIONER SACKVILLE: And their own generational understandings.

PROF BIGBY: Of course.

COMMISSIONER McEWIN: Professor, may I ask a question. You talked earlier just now about if a person with disability had the right support and the right services around them, they can lead meaningful lives. Why can't that description or environment you're describing be in their own home? Why must it be in a group home?

PROF BIGBY: I didn't say it must be in a group home.

COMMISSIONER SACKVILLE: Didn't say that.

MS EASTMAN SC: So, Commissioner, we're going to come to that.

25 COMMISSIONER McEWIN: Yes.

MS EASTMAN SC: If I can - - -

COMMISSIONER McEWIN: Okay. Yes. I was just going back - - -

MS EASTMAN SC: - - - ask you, perhaps, just - - -

COMMISSIONER McEWIN: - - - to a comment - - -

30 MS EASTMAN SC: - - - to hold that question - - -

COMMISSIONER McEWIN: Yes. Sure.

MS EASTMAN SC: - - - because we're going to come to those issues shortly if that's all right. Before we get to that issue, one of the papers that you provided to the Royal Commission is entitled Known Well by No One, and you looked at trends in informal social networks of middle aged and older people with intellectual disability
5 five years after moving to the community. And I know you don't have a copy in front of you, but just following on from the exchange with the Chair and the importance of having someone who knows you, the research that you did in relation to Known Well by No One raised a very interesting finding, and in that article – so this is behind tab 63, if the Commissioners want to follow me. In that article on the
10 second page, page 149, you said:

Residents living in small community-based services have been found to have larger social networks and more network members who are not staff, family or others with an intellectual disability compared to those in larger services.

Despite this reported advantage –

15 and then you cite some authority –

that the other researchers found that the median social network size of residents in smaller services, excluding staff, was three people, but this then comes to who knows you well.

And you say, reporting on that research:

20 *That 75 per cent of residents had six or fewer people in their network. 25 per cent had two or fewer people in their network, and 10 per cent had no one in their network.*

So I just draw your attention to that because that comes out of some of your research, and if we come back to the importance of knowing the person, if the only person who
25 knows you is somebody who is your support worker, how does that fit in with what you've described as the importance for the Royal Commission and probably for the community, generally, in understanding and knowing what the interests and choices might be of a person with intellectual disability in the cohort you're describing? So it's a long question, but I hope that - - -

30 PROF BIGBY: Right.

MS EASTMAN SC: - - - makes some sense.

PROF BIGBY: So in that – in that study, 62 per cent of people who were living in – in the small group homes in that study had no one who knew them well. They didn't have a family member and they didn't have any friends outside of other people with
35 intellectual disabilities that they lived with or that they maybe went to a day program with. The other interesting figure in that study was that, in a period of five years, we followed about 26 people and did some very in depth work with 11 houses, and there was only one house supervisor that was left after that period of time. And I – I went

to one of the houses consistently over that period of time, and I saw the house change from being a really beautiful place that was looked after by somebody who was a mother, and she played mother to these five people in the group home, and then the next house supervisor was a guy who saw it as a bachelor pad, and he changed the whole culture of the house and he became the sort of – the friend to those people. So the problem is when nobody knows you well, there's nobody to – to convey to staff, to convey to the parade of people that are coming through your life what your preferences are and what your history's been. So there's problems for that group of people wherever they're living, in that, we need to find a way of finding people to be friends or to be advocates in the long-term. This isn't short-term advocacy. This is having a long-term relationship with somebody outside the service system who becomes, in fact, a de facto family member, and we know it's incredibly hard to do that.

There's lots of volunteer programs and there's been some paid programs that have tried to recruit people to find those sorts of relationships, but it comes back to the need to look at building connections for people outside of the service system, but also focusing on the service system and making sure there's really good consistent skilled support on a day-to-day basis, but also that that's backed up by really good supervision and leadership of that practice at that frontline level, and then really good support at the organisational level for those sorts of things. So it's a multifaceted problem building relationships for people out in the community and making sure we've got good solid support for people wherever they're living. Does that answer the question to some extent?

MS EASTMAN SC: Yes, thank you. So I want to turn, now, to culture, and you deal with this starting at paragraph 14 of the statement. And you say:

Culture is often identified as the reason for poor practice and abuse, yet, it's rarely described in terms specific to group homes.

And I think you've heard, over the course of the week, that there's been much discussion about culture and the need to change culture, and this is part of a matter of research that you've undertaken where you've identified cultures in what you describe as underperforming group homes and also the cultures in better group homes. So I want to just explore that with you. In terms of the cultures in underperforming group homes, at paragraph 15, you identify five particular characteristics of underperforming group homes. Do you want to speak to that and explain to us how your research has identified these particular characteristics and what they mean from a practical perspective as well?

PROF BIGBY: So we – we derive these characteristics from the ground up. We worked shifts across weeks, across years in – in a number of group homes in Victoria. And we develop these concepts to try and characterise what – what the culture looked like. And we ended up with five dimensions. These were underperforming group homes because there were really poor outcomes for people

and we knew that from a larger survey that we'd done about the outcomes for those people.

MS EASTMAN SC: Just pausing, what – when you mean by outcomes, what do you mean? Quality of life abuse, neglect, exploitation, violence?

5 PROF BIGBY: When I use the word “outcomes” I then to mean outcomes in terms of the quality of life that people have which we tend to use sort of the eight domains of quality of life which are sort of central in the literature about people with intellectual disabilities, the work of Bob Schalock. So that tends to be the sort of benchmark.

10 COMMISSIONER SACKVILLE: What are those eight domains?

PROF BIGBY: The eight domains are actually listed further on in the statement. They're personal development, their physical well-being, self-determination, social inclusion, rights, emotional well-being, interpersonal relationships and material well-being.

15 MS EASTMAN SC: So this is pages 9 to 11 of the statement.

PROF BIGBY: And they - - -

COMMISSIONER SACKVILLE: I'm sorry if I've taken Senior Counsel out of the order she prefers.

MS EASTMAN SC: That's – we will get – we will backtrack and we will get there.

20 PROF BIGBY: And they map on very well, really, to the rights in the Convention. You can – you can align them. So in terms of the culture we ended up – we identified five domains, five dimensions of culture. In this first study we looked at the underperforming houses and looked at one end of that dimension. So the first one was there was a – there was a misalignment between the values of the staff in the
25 house who held power in that house with the mission of the wider organisation. So these were DHS houses that were set up when Kew was closed, and the – and the organisation was very clear that these were houses that were supposed to support social inclusion, social participation, and yet the staff who were in there who were in control – and often that wasn't the house supervisor that was in control, there was
30 often cliques of staff – they didn't see those values as being things that they could actually implement. They didn't understand those values and they didn't think they were realistic. So they were sort of out of sync with the bigger organisation. The second one was that people with intellectual disabilities were regarded by the staff as being “other”, as being not like us. And they used derogatory terms to
35 describe the residents, they called them – excuse me – “shitters and grabbers” in one case. They used separate crockery, separate cutlery for people so when I tried to, for example, get a drink using a cup, I was directed to, “No, no, no, that's what the

residents use. You need to use the crockery that's up on the top shelf." There were separate toilets, separate bathrooms for staff which actually were probably the most nicely decorated places in the house sometimes. They were very different from the residents. So the residents were seen as non-people.

5 Staff perceived their purpose for being there as being to look after people, being to look after their personal care and to take them out in the community. You may think that sounds all right but their role should have been about supporting people to be engaged in their own homes and to build relationships and participate in the community. So we saw people going out – "Let's go out", the staff would say, and
10 they would take somebody – a group of people usually five people, to a train station, you get on a train, you go for half an hour, get off, cross over, come back on the other side and that was your community outing. With absolutely no purpose, no interaction because there's five of you and a staff member.

The working practices in these houses were resident – were staff-centred. The
15 rosters and the activities were organised around the staff and to support staff needs. So staff would use their own values, "You know, it's – I don't like going out in the evenings when it's dark" so that meant nobody got to go out in the evenings. I remember one of the staff members saying there were – there was a Greek guy who lived in one of the houses and there was a discussion about how they might be able to
20 support him to go to one of the Greek community churches. And the staff member said, "You won't get me doing that. I don't go to church." So it was a sense of – it was what they wanted to do and what suited them rather than what suited the – the residents.

And then, finally, there was a resistance to change and a sort of lack of openness to –
25 to outsiders. So there was a sense that they didn't want to get new ideas. They didn't want to hear from people outside and they thought the people outside really were unrealistic about their expectations and things. So they were – there were lots of little satellites of these group homes, and we sort of coined the term "yes, buts" – they would say "Yes, that's a good idea but we can't do it at the moment because we
30 haven't got enough staff" or – so everything got – got put off and nothing changed. So that was what these underperforming – the culture in these underperforming houses was like. But they weren't all like that.

MS EASTMAN SC: All right. And you also used the same methodology to
examine the culture in what you describe as better group homes. And you start to
35 deal with this at paragraph 17 of your statement, and you also then set out five characteristics of a culture of better group homes. That's in paragraph 18. So do you want to speak to those and then we might put up on the screen the table that appears on page 7 of the statement, which lines up the underperforming and the better performing, and looks at how they might sort of work together where those lines are
40 that once crossed either makes you better performing or underperforming. All right. So let's do the characteristics of better performing group homes.

PROF BIGBY: And remembering that culture is about the way we do things here. So it's the way your house sort of operates. So we actively went and sought out – we asked the field, we asked the community visitors what were – where were the good group homes in Victoria that we could go and study because we were – we knew
5 there were places that were much better than the ones that we had seen. And we – we did the same thing. We worked on shifts, we spent a long time in the houses just watching what was going on, being non-participant observers at times and being workers at other times. And we found – we were recommended four houses. We spent time in the four houses and we decided after comparing the statistical data
10 about outcomes on quality of life measures that only three of those were better group homes.

And in these houses they were very, very different. And remember, this is the same model with the same type of funding but there was a very, very different culture. So in these good group homes in the better group homes there was strong leadership. So
15 in the house the house supervisor held the power and led. And the values of the house supervisor were aligned with the values of the organisation. And the other staff's values were aligned with the values of the leader in the house. And when the leader wasn't there, there was a sense of dispersed leadership. So they weren't relying on the leader to tell them what to do, they monitored each other's quality
20 because they all had a sense of what their mission was. So there was a real coherence and leadership in these – in the better group homes.

The staff had what they called a positive regard for residents. They acknowledged that they were – that they were the same overall sort of diverse humanity that everybody belongs to, but they also gave attention and recognised people's
25 differences. So they tailored the support that they provided to the different support needs that each individual had and recognised that for these people a lot of them needed very intensive personal care, as well as support to be engaged. So I think it goes back to what – what you were talking about with Rosemary; it wasn't about treating everybody the same as everybody else. It was about treating everybody as
30 an individual, as a human being, with emotions but with particular support needs. The third element was the sense that staff in these houses had a purpose, that it was to make the life for each person as they wanted it to be. So the staff would – knew people, they had long-term relationships with people, and they tried to adapt the support that they provided and the opportunities that they provided to what they saw
35 as what that person's preferences were. So the example that always stuck with me was one young woman, her sister was having a baby, and she had quite a close relationship with her sister, and the staff member went out of her way to say to the family and to the hospital and anybody else who was involved, "Please let me know as soon as she goes into hospital because this young woman will want to know. And
40 we want to be able to take her as soon as possible."

Now, the young woman hadn't said that but because the staff member knew, and other people in the house knew her so well, they were trying to make the life that she thought she wanted and offering her those opportunities. So you can see that

repeated lots and lots of times in these houses in that it was very tailored support. And so the purpose wasn't to look after people. The purpose was to make a good life for people. The good life that they wanted. The staff practices were person-centred, they weren't staff-centred. They were attentive to people's needs, they would check on people's needs. They would – for example, people with severe and profound disabilities often can't tell you when they're cold so they would check people – how warm people were, how cold they were, whether they – whether they were positioned well, without having to wait until the person – the person's behaviour conveyed that they were uncomfortable.

10 They were relational, so they had strong relationships with the people that they were supporting. They were flexible. And they were also characterised by moments of fun. And that's often the way that you can interact and really build a relationship with somebody with severe and profound intellectual disability by having an intensive interaction that turns into a moment of fun. And one of my PhD students

15 actually wrote her thesis and wrote a fantastic paper out of it called Hanging Out and Having Fun. And the support worker said to her, you know, "They're paying me to do this." So there are some people who are really skilled support workers who can tune into other people, and they get – they get enormous satisfaction out of those interactions, as is clear that the person with intellectual disability does.

20 COMMISSIONER SACKVILLE: One of the criticisms that we have heard of group homes is that it denies choice because when somebody comes into the home they have no choice as to the people with whom they live, and equally, quite often, the people who were already in the group home have no choice about who will join them in the group living environment. How do the better – the group homes with

25 better culture, how do they address that kind of difficulty?
PROF BIGBY: Our evidence shows, both from this cultural work and from the more – the larger-scale work that we've done that's done structured observations, is that for people with severe and profound intellectual disabilities they very rarely interact with each other, because they don't have the skills to do that, and they often

30 don't have the support to do that. So while I accept – and I am – it's often the case that there have been very mismatched people living in group homes, it's not always the case. And for some people, because of the type of life that they lead it really doesn't matter what the other people in the group home are doing as long as they're not interfering with them.

35 So group homes aren't supposed to be shared houses of a group of friends. They can be and the good group homes can be this and are this, the ones that we've seen and the ones in the UK where people can live independent lives. They don't have to do everything with everybody else in the group home. That's not necessarily a feature of – of group homes. It sometimes is but it doesn't have to be.

40 COMMISSIONER SACKVILLE: But don't they have to do some things with other people in the home?

PROF BIGBY: Well, actually not.

COMMISSIONER SACKVILLE: No?

PROF BIGBY: You don't have to eat with the other people that you live with.

COMMISSIONER SACKVILLE: No.

5 PROF BIGBY: You don't have to sleep with them, you don't have to shower with
them. You don't have to go out into the community with them. And the staffing
levels are often sufficient to enable one staff member to go out with one person into
the community and provide that support, while the other people may stay at home
and be supported in other ways. So I think it's – it's part of the culture in the – in the
10 poorer group homes that things are done in – on a group basis but it doesn't
necessarily have to be like that. You – and I'm painting a picture here of three
houses that we found, with some difficulty, that were really good quality and had
high – a really strong culture. So I think, in a sense, that demonstrates it's possible
with the right support and the right leadership.

15 And it may not work for everybody if you've got a really mismatched group of
people who are more able people who are will interfere with each other, then that
probably won't work. And just to finish off the fifth dimension of these group
homes was an openness to new ideas and to outsiders. So these homes welcomed
other people, people from the community, and they built relationships with their
20 neighbours and they – they were open to all sorts of new ideas and it was very
characteristic that they invited us in to come and do the research.

COMMISSIONER ATKINSON: The three group homes you're talking about, did
they all have the same service provider?

25 PROF BIGBY: Two of them were run by the same organisation and the – the third
one wasn't.

COMMISSIONER SACKVILLE: Is there any difficulty about identifying the
organisation?

PROF BIGBY: That would be up to the organisation. I'm sure they would be more
than willing to be identified but remember this – this research - - -

30 COMMISSIONER ATKINSON: These three might; the other five – the others
might not.

PROF BIGBY: But this research was done and published – the first paper was
published in 2012, the underperforming ones, and the higher performing one was
published in '15/16, but the work was done a couple of years before that, and what
35 we know from our larger scale study is that good practice is really fragile.

COMMISSIONER ATKINSON: It's vulnerable to change when the people change.

PROF BIGBY: I wouldn't say that. It's vulnerable to change when the senior managers take their eye off a focus on practice and when they don't pay attention to strong frontline practice leadership. So our evidence shows clearly that you can have
5 a really good group home with really strong quality support one year, and in the next year, that might change because the leadership in that house, the leadership in the organisation has changed. So if you went back to those houses now, I suspect you would still find these three would still be going really well, but it would be open to question. You would need to check that.

10 MS EASTMAN SC: That might be a convenient point to jump forward a little bit, and you, also, in your statement, deal with predictors for quality support in group homes. This is paragraph 22, and you discuss, in the paper, a practice called active support, and you set out, in the paper, some detail about the way in which that active support practice works, and then, at paragraph 28, what data comes out of the
15 research done in relation to active support. So, against that background, can I ask you just to give us a sense of what active support means, how it works, and then what I would like you to do is to look at the points in paragraph 28 which are the indicators of – of good active support and good practice.

PROF BIGBY: Okay. Can I – can I just say one thing before I do that.

20 MS EASTMAN SC: Of course, yes.

PROF BIGBY: So, following on from that work, the very intensive ethnographic work that we did about culture, one of my PhD students who has now finished, Dr Lincoln Humphreys, developed a scale of culture which now gives us a way of measuring culture – a much quicker easier way of measuring culture in group homes
25 than – than going out and spending a lot – a lot of time watching, and the initial research that we've done to look at the alignment between his measures of culture and – and good outcomes is – suggest – is very fine, what we found from the qualitative research. That you can measure culture and it is an indicator of outcomes so - - -

30 COMMISSIONER SACKVILLE: Even though you said, earlier, that in order to understand the preferences of people with profound disabilities within group homes, you need to spend time with them on the spot in order to understand their preferences?

PROF BIGBY: So in order to understand the individual's preferences, but in order
35 to understand the staff culture - - -

COMMISSIONER SACKVILLE: Yes.

PROF BIGBY: - - - you can get a sense of the culture from what the staff actually say and talk about. It's – and it actually lines up, then, almost as a proxy for the

outcomes for the person with disability, and that will become clearer when I talk about the active support.

COMMISSIONER SACKVILLE: Right.

5 PROF BIGBY: So active support is a – is an evidence-based practice that was developed in the UK when they emptied the institutions in the seventies, and it was developed from – again, from the ground up by looking at what was going on in the small group homes. It was developed primarily by Professor Jim Mansell, Eric Emerson, David Phelps who were the leading researchers in the UK at that time. So active support – there is a significant body of evidence now that says if staff use
10 active support, then the people they’re supporting will be more engaged. They will have more choice and they will have more control and they will exhibit less change in behaviour. And the definition of active support, it’s an enabling relationship between a staff member and the person they’re supporting that facilitates the person’s engagement in meaningful activity and social interactions.
15 So it’s the type of practice that people have touched on all week, and there’s a name for it and it’s got a rigorous body of research that underpins it. In the 2000s, this was imported to Australia, and various people did various trials of it and said, “Yes, yes, well it works,” and so a lot of organisations started to adopt active support. And we did our first study in – it was a long time ago. I can’t remember exactly when it was
20 published. It was published in 2013, and we looked at 33 group homes in Victoria from six organisations who said they were doing active support. Our qualitative work suggested they might not be doing it, and the quantitative study that we did showed that only one of those six organisations was doing active support. So, here, you have an evidence-based practice that is being adopted, but is not being
25 implemented well, and that led to our major research question that we’d been pursuing since 2009 which is what are the factors, then, that influence organisations being able to implement and sustain active support and, therefore, good practice. We know that use of practice called active support leads to good quality of life outcomes. So we were trying to work out what are the factors, then, that are the most important
30 things that group home managers and organisations need to focus on in order to ensure that there’s good staff practice. And this has been an enormous study that we’ve collected data using observational methods over a long period of time, and the analysis of the biggest dataset which was
35 461 people with intellectual disabilities, 134 services managed by 14 organisations from five different states in Australia allowed us to – to do statistical multilevel modelling, which was done by my colleague Dr Emma Bould, allowed us to predict what you need to have in place in order to do good active support and get good outcomes. And I’ll just tell you – I’ll just go through that list - - -
MS EASTMAN SC: So this is the - - -
40 PROF BIGBY: - - - which might be really helpful.

MS EASTMAN SC: This is the list on – which is up on the screen on paragraph 28, and this comes – and I think you’ve got a footnote, so this is research published this year; is that right?

5 PROF BIGBY: Yes. So we’ve just published four papers that give you these findings. So the first one is staff that are trained in active support. We put qualifications, we put all sorts of characteristics of staff into the equation. The only thing that came out as a predictor was training in active support. Staff who have strong practice leadership where the frontline staff are supported by a practice leader. Therefore, that means that they get regular coaching, observation/feedback about
10 their practice. There’s discussion of practice in team meetings and individual supervision. There’s planning, what’s going to happen on each shift, and there’s support to maintain a focus on people’s quality of life as the core of everything they do.

15 And when I talk about a practice leader, that’s usually the frontline manager, and it should be somebody who is close to the house. They don’t necessarily have to work in the house, but they need to spend a lot of time in the house. They may be responsible for two houses. It’s very hard to have strong practice leadership if you’re responsible for more than two houses. So practice leadership needs to be structured close to everyday practice. Staff need to have confidence in the management of their
20 organisation. Services should be supporting no more than six people under one roof, and services should be supporting people who are relatively homogeneous who have similar support needs, but don’t all have change in behaviour.

25 And at the organisational level, to have senior leaders who have a shared understanding of active support practice and recognise and value high quality practice. Into this equation, we put all sorts of variables about the size of the organisation, about the length of time they’ve been doing active support, about their diversity, about their geographic spread, about the quality of their paperwork, the quality of their job descriptions, the quality of their processes and practices, and none of that came out. The most – the only thing that came out at the organisational level
30 was the values and actions of the senior leaders. So people at the senior level who understood about good practice and reinforced that through the organisation so - - -

COMMISSIONER SACKVILLE: What does training in active support involve?

35 PROF BIGBY: It involves two days with a classroom training and a follow-up hands-on training with a skilled trainer who then supports the person who has learnt the skills to put those skills into practice. It is designed – so we actually designed a free online training module called “Every Moment Has Potential” which is used very extensively across Australia and elsewhere. It’s – active support is founded on really complicated psychological behavioural principles, but it’s translated into very simple concepts and practice that staff can see and can copy and can work out how to do.
40 So you don’t need – because most staff don’t have a high level of education in order to do active support, but you do need training, you do need hands-on training, and

you need continual reinforcement from a good practice leader to support you to continue to develop your practice.

5 COMMISSIONER SACKVILLE: So it takes a couple of days of classroom training, as it were, and then how long does the program require some kind of practical training in addition?

10 PROF BIGBY: It's interesting you say, "The program". What we recommend is that everybody has, at least, three hours of follow-up, where they're working, hands-on training with a skilled trainer, and then they continually get regular observation and feedback from their practice leader. So the skills in active support are something that you – you keep developing. What we – what we know is it's much harder for people to develop those skills in relation to people who have higher support needs than people who have lower support needs, and that's one of the things that the training needs to pay more attention to.

15 So it's not a very expensive form of training. It doesn't require a high level of literacy or conceptual ability, but what it does need is to be done when you enter into a service. So it's no good understanding at a conceptual level and being told, "These are the human rights that you have to enact during every day." Active support shows you how to do that in practice and what choice and control and what support to be engaged looks like in a practical way. Does that - - -

20 COMMISSIONER SACKVILLE: I understand, I think. I'm just wondering whether two and a half days is enough to produce these kinds of splendid results.

25 PROF BIGBY: I'm not saying the results are splendid. I'm saying the results are much better than if you don't have any training, and we know there is – there is, statistically, a relationship between the quality of active support that we've observed and the level of engagement of the people that are being supported.

COMMISSIONER SACKVILLE: Okay.

30 PROF BIGBY: Every staff member can provide better support. You keep developing these skills. What we're running into at the moment, though, is NDIS funding where organisations are saying to us, "There is no funding for two days of classroom training. There is no funding for hands-on training. We're just going to get staff to watch the video." So - - -

MS EASTMAN SC: Is that good enough?

PROF BIGBY: Sorry?

MS EASTMAN SC: Is that good enough - - -

35 PROF BIGBY: No.

MS EASTMAN SC: - - - watching the video?

PROF BIGBY: We designed the online training program as a resource to be used in classroom training, as a resource to be used by trainers, but what's happening is that organisations are being forced just to use that because they say they don't have funds to do anything else. So I would say that's the minimum, that – that there needs to be, and, obviously, practice leaders need to be trained – need to be really good practitioners in active support, and then they need to be trained in being practice leaders in how to observe and provide feedback and ensure consistency amongst the team of people that are providing the support.

10 COMMISSIONER SACKVILLE: Who provides the active support training?

PROF BIGBY: At the moment?

COMMISSIONER SACKVILLE: Yes.

PROF BIGBY: It's – I don't know how to answer that. So it's out there free online. Many organisations do in-house training.

15 COMMISSIONER SACKVILLE: I see. So it's available to anybody who wants to utilise it.

PROF BIGBY: Yes, it's there. It's for free.

COMMISSIONER SACKVILLE: Why then does NDIS funding come into it?

PROF BIGBY: So it's – it's an online training course.

20 COMMISSIONER SACKVILLE: Yes.

PROF BIGBY: So you would need funding, if you're an organisation, to have staff time to do that two days worth of classroom training using the resource. So you need backfill for the staff, and you need to pay the staff to come and do the training.

COMMISSIONER SACKVILLE: I see.

25 PROF BIGBY: I mean, ideally, you would say everybody should be trained before they get a job, and, quite honestly, I don't know why we don't do that. In Victoria, we've had Cert III and Cert IV as prerequisites, and yet, everybody says, "Well, they're rubbish, so why haven't we improved those?" So the whole issue about training is another question. But what we found is that it's not the qualifications of the staff or their alleged attitudes; it's the training that they've had in active support that makes the difference.

30 COMMISSIONER SACKVILLE: I see. Thank you.

MS EASTMAN SC: Can I turn to another topic now which is measuring the quality in group homes. So this is matters that you've dealt with at paragraph 36. So am I right in understanding what you say there is that governments have developed a whole range of standards for service providers to report against, and one of the
5 concerns that you've got is that the auditing processes and quality assurance systems are largely based on assumptions that if an organisation has policies and procedures that are directed to staff practice, then it will follow that there are good outcomes for residents. And you highlight that paperwork in the form of records, service policies, procedures have been shown to be poor indicators of the quality of services and do
10 not necessarily represent staff action. And so I want you just to expand on this. The Royal Commission has seen during the course of the week that organisations have lots of policies and do reviews and have had auditors coming in. And some of that is voluntarily undertaken but in some cases it's reporting against government standards. Is that sort of desktop review appropriate?

15 PROF BIGBY: Basically, no. The Victorian Government and then the – the Australian Government has had disability standards for quite a long time now. So the intention of those standards is fine but they're cast at a very high level. They're not cast in behavioural terms and they're not judged by going to look at what's happening. They're judged by whether you've got the policies and the practices in
20 place. We know from some analysis that one of my PhD students, Jade McEwen, published is that 81 per cent of the information collected in audits is drawn from paperwork. And so you may go to a large service, 81 per cent of the evidence is about the paperwork, and you might, if you're lucky, interview two or three people. Those are likely to be people that are hand-picked and that can communicate what
25 they think about the service. Asking service users what they think is often very problematic.

So basically, the way we've judged the quality of service is by the quality of the paperwork. And I think you've heard quite a lot of that this week. And we actually know from the work overseas, from the Winterbourne View disaster and from the
30 Victorian Parliamentary Inquiry into Abuse that organisations where there has been major abuse happening have actually passed their standards, their audits. So they're not really an indicator of anything other than nice paperwork. I have another PhD student who has now finished called Dr Claire Quilliam, and her PhD was about the use of paperwork in group homes. It was an amazing study that she did, look at how
35 staff use and manage paperwork.

And she has some amazing qualitative data where staff talk about – and she saw it happening – prefilling the paperwork in terms of what they think is going to happen on a shift, and then backfilling it some time later in terms of what they would have liked to have happened on that shift, what they think the organisation would have
40 wanted to happen rather than what actually happened. So paperwork is – is a really, really poor indicator of anything, really, and that's what we've relied on for many years.

And I think that's – that's the value of the work that we've been doing, is that those indicators I've given you in terms of the predictors of good active support are really now really good indicators of what you might look for in a service if you're looking for good quality outcomes. You need to both look at the practice and then you can

5 look at some of the characteristics that are in place in an organisation.
Characteristics that are known to be associated with good practice rather than assumptions based on paperwork.

MS EASTMAN SC: So you've said one of the matters that the Royal Commission might want to look at into the future and the work of the Royal Commission is the

10 establishment of an independent external monitoring service so that there can be the opportunity for observational tools rather than simply paper reviews; is that right?
PROF BIGBY: Yes. And we have – we have the National Disability Insurance Quality and Safeguarding Commission which is now responsible for monitoring the quality of services. So my recommendation would be that they – they need to look

15 very carefully at what it is they're auditing and the tools that they're using, and it should be based primarily on observation of practice of what's happening and some robust rigorous evidence about the other characteristics that are associated with good outcomes.
MS EASTMAN SC: All right. Now, I'm conscious time-wise. Is there – is there

20 anything else that you wanted to tell us in the context of having listened to the evidence over the course of the week, and that might pick up the question that Commissioner McEwin asked earlier. So this is the options and alternatives. But was there anything else that you wanted to add, and the other Commissioners may have some questions as well.

25 PROF BIGBY: So I think there's just a couple of things. Support – the quality of support is really important. The model is – is – is not necessarily flawed if you have good support but there are some people, clearly, with milder intellectual disabilities who would choose not to live there, being a group home, who would want to choose to with other people but we need to be careful about building new options.
30 We need to do the research about how do we get good support, drop-in support when people are living on their own or maybe with one other person – person; how do we get team work; how do we get good practice leadership for those staff who are providing that support. We know from the small pieces of research that we've done about drop-in support that people who live in those type of situations are often very

35 vulnerable to exploitation from outsiders. And actually, they're no better connected to the community than many of the people that live in group homes.
So I think there's another – there's two other solid pieces of work that the Commission needs to look at. One is around how do we build community connections and relationships for people with significant intellectual disabilities who
40 don't have strong resourceful families. How do we ensure that those people can exercise choice, that there's people that can support them to do that and to know

them well, and quite honestly, we've been investing money in trying to do community participation and trying to build relationships for the last 20 years and we haven't done it very successfully. It's been very ad hoc. We've got a program of research that's beginning to sort of unpack some of those things.

5 The other area obviously about an evidence-base to providing effective supported decision-making. We've heard a lot about how important that is. We need to have some evidence and we need to have some clear practice guidelines about how you do that. The other thing that I would say is that I think we need to be very careful about always following what I would say would be a politically correct line. We absolutely
10 have to listen to the voices of people with intellectual disability, of people with intellectual disabilities who have come to the Commission today. But I would urge the Commission to think about how do we hear – how do we figuratively hear the preferences and the life experiences of people with more severe and profound intellectual disabilities.

15 And for that group of people, as for other people, there are other sources of information that you need to look at. There are family members who know people really well. And there are researchers that spend a significant amount of hours watching what happens, trying to work out what's happening, and they too have something to contribute to this sort of trying to put together the mosaic of what's
20 happening and what the answers may be. So while having people with intellectual disabilities on the boards of organisations may be one strategy, it is only one strategy. We need – we need to be much more sophisticated in trying to work out how we can bring the perspective of a whole range of people with intellectual disabilities into our policy-making and into our governance and the delivery of
25 services, and I think that's – you know, that's the work that we need to work on over the next few years. We've moved to a position where it's accepted we need people's input but how do we get that in a realistic rather than a tokenistic way. Thank you.

COMMISSIONER McEWIN: Thank you, and you've addressed what I was asking earlier. I just want you to clarify one thing you just said. Be careful about following
30 a politically correct line. Could you just help me understand what you mean by "politically correct line" and to be careful.

PROF BIGBY: Okay. So I've been criticised – when I publish my research and when I talk about it, I've been criticised by – often people in the NDIS or in the advocacy movement that would say "Why are you talking about this? Why isn't
35 somebody with an intellectual disability talking about this research? And why weren't they involved in doing the research, in conceptualising the research?". And I would say that sometimes designing research, thinking about research questions, speaking on the radio, is – is not within the – not within the skill set of some people with intellectual disabilities. And that when we've done a piece of work that's
40 involved several hundred people with intellectual disabilities and spent a long time trying to work out what their life is like, to then ask one person with an intellectual disability who may not have experienced the same type of situation at all to talk about that research is tokenism. So that's what I mean by political correctness.

I think we need to be careful that we're not being tokenistic in order to appear to be following a line that has become very dominant at the moment. Now, I might be, you know, excommunicated from the disability field for saying that but that's my honest opinion, that we need to be – we need to do things in accordance with the
5 rights-based legislation but we need to tailor what we're doing very carefully to each of the people that we're involving, and we can't always rely on people with disabilities to – to understand and to know what the research questions are and what the research methodology is, because that's a really skilled understanding that you have to have.

10 And I give you the example of in the UK there was a researcher who – who was a fabulous researcher who started to research menopause for women with intellectual disabilities. And she said, "Nobody raised it". It wasn't on the agenda of any of the self-advocacy groups. It wasn't on the agenda of any of the women that she had spoken to because none of them had the words, and none of them understood what
15 was happening to them. So if we had relied on the agenda coming – as the only way of the agenda coming up from people with disabilities she would never have done that piece of research. So I think it's about having multiple insights rather than just one way.

COMMISSIONER McEWIN: Thank you.

20 MS EASTMAN SC: That completes Professor Bigby's evidence.

COMMISSIONER SACKVILLE: Thank you very much, Professor Bigby.

Political correctness is an interesting concept that transcends, I think, this area of discourse. Thank you.

MS EASTMAN SC: So that completes Professor Bigby's evidence. Thank you for
25 joining us at the Royal Commission. We just need to reconstitute very briefly for our panel.

COMMISSIONER SACKVILLE: Shall we have a short adjournment for that purpose?

MS EASTMAN SC: Probably five minutes.

30 COMMISSIONER SACKVILLE: Thank you very much. Thank you, Professor Bigby.

<THE WITNESS WITHDREW

ADJOURNED

[12.28 pm]

RESUMED

[12.37 pm]

MS EASTMAN SC: Thank you. Can I give the Commissioners an update just on the arrangements for the balance of the day. So we have a panel which Mr Fraser will be taking. And we're working on the panel members speaking for about half an hour or maybe just over half an hour. We had hoped that we might - - -

5

COMMISSIONER SACKVILLE: Not each, I take it?

MS EASTMAN SC: No. We had been hoping that we might be able to complete the hearing around 1 or 1.15 but that's not going to be possible. So if we have a short luncheon adjournment after this panel, we then have one final witness but we also have some administrative matters that we need to deal with for the assistance of the parties who are here and those watching who wish to make submissions.

10

COMMISSIONER SACKVILLE: Right. Well, perhaps if we have half an hour break for lunch. Will that be enough?

MS EASTMAN SC: If that's convenient to the Commissioners and to the Commission staff, then if we aim to do that perhaps just after 1 pm and then resume. So it will only be a short session after lunch and I'm sorry that we haven't been able to organise things to complete everything by 1 pm. If the Commission pleases.

15

COMMISSIONER SACKVILLE: If you wouldn't mind taking the oath or the affirmation as the case may be and follow the instructions that are about to be given, thank you.

20

<**BELINDA RUTH EPSTEIN-FRISCH, AFFIRMED**

[12.38 pm]

COMMISSIONER SACKVILLE: Thank you.

<**LEANNE PEARMAN, AFFIRMED**

[12.39 pm]

COMMISSIONER SACKVILLE: Thank you.

25

<**LISA HAMILTON, AFFIRMED**

[12.39 pm]

COMMISSIONER SACKVILLE: Thank you. Please sit down. And now Mr Fraser will ask you some questions. I think.

MR FRASER: Yes. Thank you, Chair. Commissioners, each member of the panel has helpfully provided a statement to the Commission. Dr Hamilton's statement is at tab 33 of the bundle. Ms Pearman's statement is at tab 36, and the statement of Ms Epstein-Frisch appears at tab 65. By way of background, Dr Lisa Hamilton is from the University of Queensland. Ms Leanne Pearman is the co-chief executive of the Western Australian Individualised Services, an organisation operating out of Western Australia. And Ms Epstein-Frisch, who has historically worked as a disability advocate and consultant, is currently a consultant to the Independent Advisory Council of the National Disability Insurance Scheme, though while that is her present position she is not here giving evidence in that capacity; she is giving evidence based on her own experience and expertise.

COMMISSIONER SACKVILLE: Thank you.

MR FRASER: I will take each through some formal matters and then ask them to address some of the themes that have emerged throughout the course of the hearing. Now, Dr Hamilton, you were a research fellow at the School of Social Sciences at the University of Queensland.

DR HAMILTON: Yes.

MR FRASER: And you were previously a research fellow with the Centre for Disability Studies at the University of Sydney from November 2012 to February 2014.

DR HAMILTON: Correct.

MR FRASER: In addition to the work you carried out on your thesis, which I will return to, you have had some previous experience with group home providers. Can you tell the Commission about that.

DR HAMILTON: Yes. I've been working with group homes for many years as a direct support worker myself, as a house supervisor, as the term was in those days. I've also worked with Professor Bigby at the Living With Disability Research Centre, training organisations in – and staff in person-centred active support.

MR FRASER: Thank you. Now, Ms Pearman, as I mentioned, you have been the co-CEO of Western Australian Individualised Services since 2012. Is that correct?

MS PEARMAN: Yes, that's correct.

MR FRASER: Can you tell the Commission about the work that organisation performs?

MS PEARMAN: WaiS is a member-based organisation which supports the advancement and promotion of individualised self-directed supports and services particularly around individualised living, self-management, person-centred planning

and supported decision-making. We support people themselves, family members, service providers and also local government or – at both a state and national level.

MR FRASER: Thank you. And Ms Epstein-Frisch, you have a background in social work, you have a bachelor's and master's degree in social work. Is that correct?

MS EPSTEIN-FRISCH: Correct, yes.

MR FRASER: And you have over 40 years of experience in community development, social policy, program management and advocacy in relation to people with disability.

MS EPSTEIN-FRISCH: Correct.

MR FRASER: And can you – while you're not here in your representative capacity, can you tell the Commission a little bit about the role that you are currently undertaking.

MS EPSTEIN-FRISCH: Yes. I'm currently the consultant working with the Independent Advisory Council of the NDIS. The Independent Advisory Council is set up under the NDIS legislation, and I think of it as the people's voice at the governance level. So I work with the council members to facilitate the development of advice for the NDIA board that then needs to go to the Disability Reform Council.

MR FRASER: Thank you. And for the Commissioners' reference, Ms Epstein-Frisch has annexed to her statement a report that has been prepared of which she is the author, which is entitled Pathway to Contemporary Options of Housing and Support to which I will return later. Now, if I can start with you, Dr Hamilton. You authored a thesis entitled, in shorthand, Within These Walls which had the objective of exploring and understanding how people with intellectual disability experience life in a group home setting. Now, as part of that research, it's correct, isn't it, that over an 18-month period you immersed yourself in everyday life at a particular group home. What sort of activities or tasks did you attend to there?

DR HAMILTON: Yes, that's correct. While I was in the group home which we have referred to as Lake House which is a pseudonym that the housemates and I chose, I wanted to really participate in all aspects of group home living. So when the housemates were doing the dishes, I was there with the tea towel drying the dishes. When the housemates went for a walk to the lake, I was there with them. When we had activities at the group home that were organised by the staff, I was a participant alongside the housemates at Lake House.

MR FRASER: And what was the purpose of doing research in that way?

DR HAMILTON: I was really dissatisfied with the paucity of research that was available around group homes which was very much service perspective and service

dominated and focusing around staff practices, and I had heard very little around the voices of people with intellectual disability who were living in group homes, and I had read very little, I had seen very little, but I knew from my experiences that people living in group homes had a lot to say. So the housemates at Lake House,
5 some of them had excellent language, but not all of them did, and so, typically, if they were interviewed in an interview style, that would not be conducive for them, but, also, I was really interested in exploring the home.

And home is a really abstract notion for all of us. It's a shared aspect of our humanity, and I wanted to understand what that was like from the perspectives of
10 people who live in a group home by immersing myself in everyday life. So what is life like in a group home every day? I wasn't interested in third party reports. I was interested in the experiences of the housemates and I used a range of arts-based inclusive methods to support people – to support the housemates at Lake House to share with me their experiences as I sat beside them.

15 MR FRASER: And can you tell the Commission what your study revealed about the concept of home for persons with intellectual disability in that setting. What did they themselves identify to you as being essential to a home.

DR HAMILTON: So the housemates at Lake House never once spoke to me about being a customer. Those sorts of language is just nonsensical. They never spoke to
20 me about - - -

COMMISSIONER SACKVILLE: Nonsensical to them or nonsensical objectively?

DR HAMILTON: Nonsensical to them. They didn't consider themselves as consuming a service. They considered themselves as living in a house that was their home. The housemates didn't consider themselves – didn't talk to me about staff
25 ratios. They talked about wanting somewhere to belong. They talked about being loved. They didn't talk about being cared for, but they talked about being cared about. The housemates talked about all of the things that are important to all of us about home, about having a place where you can go home to after a busy day and you can just be yourself, about being accepted for who you are, and about having a
30 life of one's own choosing.

MR FRASER: Thank you. I would now like to address the issue of support being tailored to the individual. We've heard consistent theme about the importance of that for persons with disability, as compared to what we might refer to as block treatment or standardised care. So, for example, you may have heard the evidence of Dr Peter
35 Gibilisco who spoke about a requirement that was sought to be imposed upon him in a particular group home that his morning routine be completed in 45 minutes, where for him, personally, that can take up to two and a half hours. Ms Pearman, given your statement deals with a program in Western Australia called Shared Lives, which is really about individualised support, can I ask you to address this issue and the
40 importance of that type of support being tailored to the person.

MS PEARMAN: Individualised living comes in a whole range of ways and approaches and designs and it's – the uniqueness is based around each unique individual. So there's no formulaic method, I guess, around individualised living supports, but what we know is that when individualised living approaches are based
5 in human rights and with citizenship as the foundations, then people are more in our – in our experience, certainly, mine, over more than 30 years in direct support and in the design of individualised services, that encourages and facilitates relationships, genuine relationships, belonging, people's contribution to both their home and to the community, to being seen and heard and valued, and also having choices with
10 autonomy over those choices that are not necessarily impacted on by other people that they may share their home with.

Because in relation to the term Shared Lives, in WA and across the nation, there's a range of approaches which fits under that. Sometimes known as co-residency, host arrangements, flatmates, free-renters, good neighbour. So a whole range of models
15 that can fit under the term Shared Lives, but the intention of the arrangements are that people get the support, even people that may have extremely high and complex supports and/or complex communication needs can be supported in a way that makes sense for them, and that is individually tailored around both the person, their family and with the supporter.

20 COMMISSIONER SACKVILLE: Can that be done in the context of a group home?

MS PEARMAN: My personal and professional experience is when someone is living in their own place with individually tailored supports, particularly if they have complex communication needs, then their communication partner has much more
25 availability, opportunity and impact around hearing the voices of people as opposed to living with three, four, five or however many other people.

MS EPSTEIN-FRISCH: I might, if I may add, some material from the UK where there's been programs and approaches such as shared lives for many years, and in the UK, services and supports are regulated by the Care Quality Commission. And if I can draw from a report of theirs reporting on 2014 to 2017 where they rated 98
30 shared – shared living – shared lives services covering 12,000 users, and, there, they found that they performed very well, with 90 per cent rated as good or outstanding at the time of the report. No locations were rated as inadequate. And in terms of questions related to caring and responsiveness, the shared lives services rated particularly well, and a final point, that 96 per cent of the participants using those
35 services rated their service very highly compared to a much lower rating: 66 per cent for participants in community services and 63 per cent in residential care.

If I can just go on just a little more in terms of the data that they drew from people who were living in shared lives situations where 97 per cent reported that they were part of the family most of the time. So, in these situations of shared living, the
40 people with disability were living in the homes of people who were specifically recruited, support – trained, supported and monitored to provide a home for the individual with disability. So 97 per cent felt that they were actively a part of that

family most of the time. 89 per cent felt that their shared lives carers support improved their social life.

85 per cent felt that the cared lives shared support made it easier for them to have more friends. 89 per cent felt more involved in the community. 86 per cent believed that it gave them more choice and control, and 83 per cent and 88 per cent respectively felt that their physical and emotional health had improved significantly living as part of that. So it just provides us, what Leanne is talking about, particular services in WA that are, to some extent, in most states and territories, but at – less available than they are in Western Australia, but in the UK, we can draw on more experience over a longer period of time.

MS PEARMAN: If I could just say that if – I think it's really important to note that if any of us, regardless of disability, are living in ways or in environments where we – where power is not shared or where others have full or lots of control over us and where we don't get to choose who we live with, how we live, what we do, how we do it because it's structured around a system or a service system, and, certainly, more importantly, for us to be heard and listened and actioned, then there is – there's always going to be more chance of risk in abuse, whether that's group or individual support. So where those elements of being able to form relationships and the things that we can do, as Christine alluded to, around the – the quality of the support that gets provided, but the design of the support, I think, is also as critical.

MR FRASER: On that – on that issue, we've heard some evidence throughout the Commission about conflict of interest between – that arises when a service provider controls all aspects of a – of a person's funding. For example, you might have seen the evidence of Dr George Taleporos yesterday. He referred to people being captive to their service providers, and I will quote him:

Even though we have the NDIS, we have providers who effectively provide everything to that person. They don't tell them about their options, and that's not okay.

Ms Pearman, is this an issue that you've seen emerging in your work in Western Australia?

MS PEARMAN: I wouldn't say it's emerging. I think it's been there for a long time. As people are supported and, historically, have been supported by providers that have provided the total care and support for them over many decades, that, sometimes, there is a sense of ownership at times. Providers have been, certainly in WA, working towards how they can separate the housing if they do also provide housing and support as a way of safeguarding people, and for people to be able to exercise their rights to choose which provider they want as opposed to having to move out of their home or potentially being homeless if they choose to have a different provider, but can't move out of the home for whatever reason, whether it's been built – purposely built around their needs.

MR FRASER: And, Dr Hamilton, I suppose, on a slightly different note from that same theme, I think, in your thesis, you talk about the conflict, if you like, between the group home being a person's home where they live and spend their leisure time – in fact, for some of these people, most of their time – as compared to it being a
5 workplace for the – for the service provider or for the support staff. Are you able to tell the Commission about your experiences there?

DR HAMILTON: Yes. And I think, this week in the evidence, we've heard lots of language used around "home". We've heard "service sites"; we've heard – service sites or service provision. At Lake House, the housemates called it home, but it was
10 a different home than what my home might be. So, for example, there was a roster of staff that would provide support to the housemates in the morning and then again in the evenings, but there was a period of time during the day when there was no staffing. So the housemates were able to really be themselves in a different way. So one example of that is that there's a beautiful park next door to Lake House and
15 there's a big fence and there's a gate that people can use, but the housemates were not permitted to use the gate or to use the park because it was too risky for them. There were strangers in the park. It was considered to be unsafe for them to visit the park next door.

So the staff would leave Lake House; they'd go home. There would be a period of
20 time when the housemates were not supervised. So Josh – which is a pseudonym. Josh said to me one day, "Come on, Lisa. Let's go next door to the park," and I felt a real tension. Like, if we go to the park next door, we're going to get into trouble because there was this notion within Lake House where we were all afraid of getting into trouble. So we went next door, and we visited the park, we came back.

25 Everyone was safe. The staff member came back on and nobody mentioned going. I thought this is really odd, but this is the culture that had developed. And then the staff member said, "Well, we have community access once a week." And our community access is, as a group of six or eight, we walk to the beach, and that's our community access because it's supervised by the staff member. Yet, those periods
30 during the day, the housemates could do that freely. So where is this – the housemates were at home making when the staff weren't there.

COMMISSIONER SACKVILLE: What do the housemates do when unsupervised? Were they free to wander as they saw fit or were they confined? What happened?

DR HAMILTON: I guess it's an interesting notion about being free because, of
35 course, they were free. There were no conditions on their movements, you know, as for any of us. But they were told very clearly by the staff they were not permitted to go next door because it was dangerous. Now, if you break a staff rule at Lake House there are consequences, and one of those consequences is getting a file note. Now, if you get enough file notes you can be evicted. And the housemates were fearful of
40 file notes because they had seen friends of theirs being evicted. So they were breaking rules that they were able to break. There was a reason why there was no supervision for them during periods of the day because they were absolutely able to

go next door but there were these service provider rules that said you are not permitted.

5 MS PEARMAN: I think that's a really important point around any support to people but particularly when – sometimes people's individuality and who they are can be hidden or invisible when in groups because you're just seen as a group and not you as an individual. And I think that the way in which people are seen impacts on what support they may or may not get. An example may be that someone that may have really complex supports and/or communication needs can sometimes be seen as not being able to live in their own home with support in the community. And
10 we – and the way in which they may be described is usually around deficiencies and what – how they need to be fixed, as opposed to their capacities and what can be supported.

So often options aren't explored with people, or even talked about with people because either the service system or people in their life may not see what's possible.
15 And I think that's a really important point around what options people may have when making informed choices, is that we know that there's direct violence, we know that there is systemic violence, but there is also attentional violence which is what are we paying attention to with people and what are we ignoring just because that's what we think or that's what we've known. And I think it's really important
20 that it gets challenged.

COMMISSIONER ATKINSON: One of the themes that has come through to me this week is people seem to concentrate on the disability, but you're talking about a person who's a man or a woman. They have their own cultural identity, their family, their religious beliefs or lack of them, their sexuality. There's – people are
25 multidimensional. And if you only think about their disability, you're not thinking about the whole person. Is that part of the problem?

MS PEARMAN: I would say in my experience, yes. Just to add, my history started in institutions as a – when it was matrons and nurses. So a long time ago. To where it then went to sort of large hostels, then to group homes, and probably in the last 15
30 or 17 years or so my work has been around the design of individualised supports which is focusing on people's capacities and who they are within the context of their family, themselves, their community. And when something is designed around that, it can look very different to something that's not designed around that.

COMMISSIONER ATKINSON: And I think it was said that Western Australia has
35 much more of this than the other states. What was – what was the source of that? What are the learnings that the other states can have from what's been done in Western Australia?

MS PEARMAN: Firstly, we've made a lot of mistakes. That's certainly been a lot of the learning. And also in partnership with people and their families and service
40 providers willing to go on the journey. But there's some critical investments, I think, that our state made over the last – well, since probably 1998 with the introduction of

the local area coordination model. But there was also an investment and agreement between our state disability services and our state housing – our government housing area, which had a program – it’s called the Community Disability Housing Program – which invested capital for people who wanted to live into their own home. They were able to do that as part of community housing which allowed people to be able to – to move into their own place.

There’s also – we’ve got in WA some industrial relation elements which can make living arrangements and the design of living arrangements quite – a bit more flexible because it’s under – it’s just an exception under our Industrial Relations Act. There’s also been investment from the state around capacity development of people, families, local area coordinators and service providers around understanding and knowing about individualised services to where in 2005 when our state disaggregated block funding to people to have individualised funding, by 2010 more than 50 per cent that were going through a funding process – this is obviously prior to NDIS – chose – wanted to choose individualised arrangements because what was on offer to them didn’t meet either their loved ones or their needs, or it was what was available quickly, or it was around a sense of security.

So for our organisation, what we would hope is that it’s around choice and people being able to have informed choice and good choice, decision-making, and that is about connecting with what do these options look like, who can I talk to, are there any other families that I could meet and come and see and feel, and it’s quite a process around informed choice. And I think our state had invested a lot in supporting people and families and providers to do that to then - - -

COMMISSIONER ATKINSON: And Western Australia is a state with a large indigenous population. So how has this been rolled out for First Nations people.

MS PEARMAN: It actually – lots of the individualised living arrangements in country areas inclusive of Aboriginal cultures, that’s where it started because there wasn’t an awful lot of funding or group homes that were developed. So innovation had to come to the forefront for people to see, well, what would work in this environment for this person with what they want and need, with the limited resources or no actual access to resources. So it’s not – don’t get me wrong, it – nothing’s fantastic or a magic bullet, but it – they are options for people to consider within the context of who they are and what they’re seeking within their culture.

COMMISSIONER ATKINSON: Thanks.

MR FRASER: Thank you. Ms Epstein-Frisch, we’ve heard talk about choice and options. Obviously to be able to make a choice you need options to choose from. In the report that I referred to earlier which forms part of your statement you have a section, number 4, Barriers to the Adoption of Contemporary Options of Housing and Support. And you talk there about barriers within the NDIS. Can I ask you to expand or really explain to the Commission what – what you see these barriers as being?

MS EPSTEIN-FRISCH: Yes, I'm happy to do that. I'm not speaking on behalf of the Independent Advisory Council as was said in the opening. And some of these barriers are things that the NDIA is definitely seeking to address but as everybody has said, the world has got a long way to go. Key barriers were a lack of mechanism to foster innovation. In a market approach to services where the dominant approach is group homes, there isn't a – there hasn't been a mechanism that would actually foster the growth of services that were skilled at providing more contemporary options. In the State systems, whilst they didn't take up that option very much, there were the options of block grants and what have you to get a new initiative underway, to trial it, pilot, and what have you, and then provide mechanisms for growth. Whereas in the market approach, that has been lacking. Now, the NDIA – and I'm sure they will be meeting with you in later times – there are new avenues that have been brought to the fore, and particularly one around making sure that the individualised options of people living in Western Australia, when they transitioned into the scheme, that those options weren't lost. And so options for facilitating and funding individualised supports is – is growing but there's a long way to go. The paper also argues for a lack of policy clarity around issues around housing and support, one of which is the separation of housing and support, and I think we're going to come to that a little bit later. And another issue was in terms of the status of the group home and what was seen as desirable. Lack of information – another barrier within the NDIS was lack of information about contemporary options, and – and lack of clarity about a pathway to contemporary options. There's a whole range of areas, lack of operational clarity that also were a key barrier in the way in which the price guide, the support to explore options, plan management issues and they're all canvassed in that paper for you to look at. Other issues that were outside the control of the NDIS that are also fundamental was the lack of safe, secure and affordable housing, because as Chris Bigby said and as the IAC paper notes, there are a significant number of people currently in group homes who have profiles very similar to people who are living in more contemporary community options. And under the NDIS in principle with the individualised support you should be able to take your support and run. But what is a real barrier is that people, particularly in major cities, the lack of affordable housing, you know, on a disability support pension, the opportunity of using private rental is more or less non-existent. Often the need also in these kind of options to have a second bedroom, you know, so that that can provide barriers even in social housing where if someone can get social housing where rent is related to income, you know, the – the challenges, you can get a second bedroom but there are a lot of challenges. And, you know, so they're – they're some of the key barriers to the adoption of contemporary options within, you know, today.

MR FRASER: Just in the interests of time, I might invite each of you to inform the Commission with the benefit of your own experience and expertise about what you

see as being key matters or key objectives that you would like to see this Commission achieve. If I can start with you, Dr Hamilton.

5 DR HAMILTON: I'm really keen to really – for the Commission to really think about home and what home means for people. And – and to really think about how
10 home is a space that is co-produced, and people with more severe and profound intellectual disability need support but they can be very active in their home-making. And so really challenging that notion that group homes which are segregated models where people are congregated together on the basis of their disability, and the way that we think about group homes as a service model is really the antithesis of what
15 home is talked about in the literature for people without disability, Gaston Bachelard in the 1960s in his seminal work around the poetics of home talked about home – the primary purpose of a house is a purpose for daydreaming. Well, the housemates at Lake House weren't permitted to daydream. Staff would be really challenged in how to support someone to daydream. Rose, who was one of the
20 participants, she chose her pseudonym because her mother had a rose garden and she had lived with her mother until her mother died and then she came to Lake House. Rose wanted a rose garden but she wasn't permitted to have a rose garden. So we need to think around and challenge these constructs that we have created as a sector to say that we've got services and service provision, and that's created a really one-

20 dimensional view of home, and where is that space for daydreaming.
MR FRASER: Thank you. Ms Pearman.

MS PEARMAN: I think it's really important not just to use the words around
25 human rights and citizenship because it's very easy to talk about models. It's easy to talk about service supports, everything that's within service land, different models, the way in which people are engaged and supported. So I think getting back to what does life look like for any of us, and what are our – how are we supported if we need support to exercise our rights as citizens in our community, and what does that look like and how do we measure against that, because I think that in relation to home it's
30 very for it to just – as Lisa was saying, to become just something that's within the service that you are creating and still not in community and not a part of what we all have.

So in the design of how people might want to live, that being seen in the context of genuine human rights and citizenship in co-design with people and families.

MR FRASER: And finally, Ms Epstein-Frisch.

35 MS EPSTEIN-FRISCH: There's two issues that I would like to see the Commission take forward. One is we talk a lot about informal support, and Chris Bigby, you know, brought it up in terms of the relationships and what brings quality of life to all our lives. It's being in relationship with people who care about us, not who care for us. But many, many people with disability, for them friends and connection with
40 other people doesn't come easily. And what we need is very intentional strategies

that help bring others into the lives of people with disability. The NDIS absolutely requires it if the NDIS is going to be sustainable. It means that they're really relying on – on people being supported by a combination of paid support complementing the informal support, because we have to be very careful that paid support does not drive out freely given relationships but, rather, complements that which family, friends and connection with community can provide.

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I briefly draw your attention to a study by Roger Stancliffe, I think it was 2014, with a service called Afford in New South Wales. And there was a group of people who had spent their lives in group homes and day programs, and they were facing retirement from their day programs. And they were people, because of their life circumstances, had quite depleted lives. And what the work was – was how to help them to retire into inclusive community organisations. And a great deal of time and effort was spent with each individual, understanding their interests, mapping that to opportunities in their community, identifying people within that knitting circle, within that bingo club or, you know, senior citizens opportunities, to find people who had a natural kind of – who looked out, who took an initial connection, fostering that relationship, supporting that informal supporter, and then, you know, actively getting that relationship underway, and gently moving back, but always having a presence available, not on site but available for that informal supporter to be able to call and say, “Hey, I don’t – I’m a bit worried about X and Y.”

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And that was – you know, so these were people whose lives had been diminished but who did get opportunities through the development of informal support. And I think that we talk about it as if it’s easy. It’s not. There are intentional strategies that make it effective. And I would also draw your attention to a service in South Australia called the Community Living Project where they developed circles of support around people coming out of a large institution, right, and through bringing in community members in intentional strategies to develop long-term relationships it improved the quality of life. So – and none of those are perfect but they’re a sample for you and I think that if the Commission was able to draw attention to some of these mechanisms that help prevent or reduce violence, abuse, etcetera, that would be useful.

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The second issue I would like to draw to your attention is that in – in the space of housing and that is about the separation of housing and support. We’ve had some discussion about conflict of interest. But let me draw your attention to key research by the social policy research centre in about 2011, and my paper would make reference to it, where they were commissioned by the Disability Reform Council to look at evaluation of supported living so more community living options with supported accommodation, group home and larger options. And their research identified three factors that were pivotal in – were always present in the more effective options.

And those – those features were (1) the separation of housing and support, because all the alternatives that are discussed in the IAC paper are only possible if housing and support are not tied together; if they’re tied together none of these options are

facilitated. The second notion that they identified was each individual having a budget, a personal, nominal personal budget over which there is flexibility in the NDIS in principle, that exists. And the third was that support was provided by a combination of paid and informal support and there were intentional strategies in place to develop and support that informal support. So I think housing – the separation of housing and support is really pivotal to enabling better opportunities.

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COMMISSIONER SACKVILLE: Thank you.

MS PEARMAN: Could I just make one – just following on one other comment just around informal supports. I think it's a really important thing to note that

10 relationships can't be manufactured. We can't just make people connect with other people but we can create environments that will facilitate more than that. And one of the things that we've seen is – because relationships keep us all safe. If we've got people looking out for us, loving us, caring about us, knowing where we are, knowing what we're doing, checking in, it doesn't matter whether we have a disability or not, it's what all – all of those relationships help keep us safe.

15 And if – if people have a view which certainly has come up in our experience that somebody is too difficult to make relationships with, then it's going to be – or are seen in a deficiency view which has been – you know, certainly is a theme around how people are supported, then it's going to be less likely that they will connect with other people because they need that fully facilitated. And I think that certainly is an impactor but a critical focus around the Royal Commission.

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COMMISSIONER SACKVILLE: Thank you.

MR FRASER: I have no further questions, Commissioners.

COMMISSIONER SACKVILLE: Thank you very much, Dr Hamilton, Ms
25 Pearman. I take it you came all the way from Perth, did you?

MS PEARMAN: I did.

COMMISSIONER SACKVILLE: Thank you very much for travelling to Melbourne. And Ms Epstein-Frisch, thank you very much as well. We will now take 30 minutes, shall we?

30 MS EASTMAN SC: If that's – sorry, I apologise. My estimates of time today have not been entirely accurate. It's - - -

COMMISSIONER SACKVILLE: This is very unusual for counsel.

MS EASTMAN SC: It's Friday of the final day.

COMMISSIONER ATKINSON: I think you will find it's our fault, not your fault.

MS EASTMAN SC: So it's 22 past. I wonder if we perhaps adjourn till 2 pm.

COMMISSIONER SACKVILLE: Okay.

MS EASTMAN SC: If that's convenient.

5 COMMISSIONER SACKVILLE: How long do you think we will need this
afternoon?

MS EASTMAN SC: I'm not sure. So I'm not going to give an estimate. I will
make some inquiries and I will be able to let you know as soon as we resume at 2.

COMMISSIONER SACKVILLE: We will resume at 2 o'clock. Thank you very
much. And thank you again for your attendance.

10 MS PEARMAN: Thank you.

<THE WITNESSES WITHDREW

ADJOURNED

[1.22 pm]

RESUMED

[2.00 pm]

COMMISSIONER SACKVILLE: Yes, Ms Eastman.

15 MS EASTMAN SC: Mr Harding.

MR HARDING SC: Commissioners, it's Mr Harding.

COMMISSIONER SACKVILLE: I'm sorry, Mr Harding.

20 MR HARDING SC: Commissioners, the next witness will be Sam Petersen. She
has prepared a statement which is tab 38 of the tender bundle. And now she's going
to administer the affirmation.

COMMISSIONER SACKVILLE: Yes. If you wouldn't mind taking the oath or the
affirmation and follow the instructions. Thank you.

<SAM PETERSEN, AFFIRMED

[2.00 pm]

<EXAMINATION BY MR HARDING SC

COMMISSIONER SACKVILLE: Thank you very much. Thank you. Mr Harding.

MR HARDING SC: Sorry, Commissioner. Ms Petersen, is your name Sam Petersen.

MS PETERSEN: Yes.

5 MR HARDING SC: And have you made a statement for this Commission and would like to read it?

MS PETERSEN: Yes.

MR HARDING SC: Would you like to read your statement, then?

MS PETERSEN: Yes.

10 COMMISSIONER SACKVILLE: Please go ahead.

MS PETERSEN:

15 *This statement made by me accurately sets out the evidence that I am prepared to give to the Royal Commission into violence, abuse, neglect and exploitation of people with disability. This statement is true and correct to the best of my knowledge and belief. I am 35 years old. I am disabled. I own it. I have dystonia, a condition which causes my muscles to contract involuntarily. I also had a stroke five years ago which affects my ability to move the right side of my body. I also have dyslexia and the stroke has made it worse.*

20 *As a result, I require support with getting in and out of bed, getting dressed, showering, being put over the toilet, cooking, and some assistance getting out into the community and with communication. I also use an electronic speech device and an iPad to assist with communication. I lived in shared supported accommodation, also referred to as a group home, for three and a half years. Before then I was in a nursing home/rehabilitation for 18 months and before that hospital/rehabilitation for six months. This drastic life change was a result of me not being able to get support any other way after my stroke. I currently live in specialised disability accommodation, SDA. I explain this in more detail later in this statement.*

30 *I do not wish to name the organisation that ran the shared supported accommodation I was in, or demonise anyone because in my experience this kind of behaviour is society-wide. None of the support workers who assisted me there were bad people but I experienced a number of problems which I explain below. I will say support instead of care and could you please say support instead of care when you are referring to me.*

5 *My experience in shared supported accommodation. I will explain why I see the whole system of shared supported accommodation as wrong. First of all, there is, in my experience, an imbalance of power when you have a disability. I have felt this power imbalance used over me in many ways and in many of these incidences I was in a group support environment. The most common way is patronising behaviour, being talked down to or not being taken seriously as the expert in your own support. They would say, "You should do this, you should do that" and would keep saying it over and over again.*

10 *As a resident I wasn't able to choose the people supporting me. This takes away an important part of the relationship when I wasn't able to simply say I didn't want someone supporting me. This felt like it set off a sequence of entitlement in the support workers' mind so that they're not as conscious about making you content in the relationship or putting you first. And it is a pretty important relationship to get right because in most cases they are doing really intimate support. I have grown pretty tolerant to inadequate support out of necessity but I wish I did not have to.*

15 *The support workers were easily distracted. For example, a few times when I was being supported to transfer to bed a support worker would lower me into the wrong position. I would make facial expressions indicating something was wrong but was not able to say what as I do not have access to my communication devices during transfers and they were talking to another support worker and so didn't notice. I feel that group environments reinforce abusive behaviour toward people with disability. There is often little time to build a working relationship with a support worker. There is little time for correction and often when I gave feedback it was met with resistance.*

20 *Often there was more than one support worker involved so then there were a number of people resisting me and it felt like they would form a group against my feedback. For example, when multiple support workers were getting me dressed and I would try to give direction they would just keep going with what they were doing and talk to each other. In the shared supported accommodation there was a buzzer system which I would press to let support workers know I needed assistance. For example, to let them know I was ready to get off the toilet or out of the shower. The buzzer system meant that I was often waiting. I could be waiting regularly for up to an hour or an hour and a half. My bottom would get sore from sitting on the commode chair.*

25 *Sometimes the buzzer did not work and yet other times I would buzz and the support workers would go to someone else because they did not look properly at the number on their pager to identify that it was me that had buzzed. The pagers were confusing to look at. I complained internally with little result.*

30 *They really needed a better buzzer system. A couple of the support workers said I buzzed too much but I'm hyperaware of not crying wolf and only buzzed after 15 minutes if someone had not attended to me, so it was very insulting. I wish that all the support workers could have given me the benefit of the doubt*

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when interacting with me. Most of them were good but sometimes I have been misinterpreted as being hostile when giving feedback with my techno voice or dystonic body language. It hasn't been nice and I'm actually really shy of anger.

5 *At times I was left quite shaken because support workers would raise their voices in response to me giving them feedback. For example, a support worker didn't put my CamelBak lid on right and when I tried to tell them to fix it they said they have a CamelBak so know how to do it, but it still leaked. And then when I told them they said angrily that I was making this out to be bigger than*
10 *it needs to be. I have been called rude, impatient and fussy. And a lot of the time I just shut down. If I showed anger I would be labelled as "the angry one" which would impact the support I received.*

There are only so many words that I can type in one day. I would try to explain and give feedback via email as my communication in the moment can be quite
15 *slow but it would sometimes be taken out of context or often there was no response. The added avalanche of verbal words from support workers when they were supporting me was impossible to keep up with. They told me stuff when I was getting dressed and couldn't respond as I didn't have my communication devices. I told them to stop it but they would forget. Some*
20 *support workers didn't seek my input about what I needed and what I'm okay with. If I really wanted my speech device I could always get it but sometimes I risked them going away to work with someone else while I wrote. They could be gone for ages.*

The result was that I was reluctant to assert my right to communicate. I had to
25 *choose between communicating and getting dressed. When the support workers would dress me often they would have three people doing it at once. They would all ask me things at once and I couldn't respond to all three of them without my speech device. They saw it as being efficient but I saw it as taking my say away. In the shared supported accommodation, one support*
30 *worker was putting my catheter bag on and then another support worker was putting my bra on and I was indicating "wait, the bra straps have come loose" and the one putting my catheter bag on would be saying in an angry voice, "You need to concentrate on me."*

I had told them in the shared supported accommodation that I don't like having
35 *three people dressing me and preparing my breakfast at the same time but they said they often didn't have time for one person to complete the tasks. They did eventually make a rule that they would only dress my bottom half and then my top half to not have people doing different tasks, but they didn't all get the memo and it was still not what I wanted. Now, where I live I have one support*
40 *worker at a time and it is so much better. It takes twice as long but it is still so much better.*

5 Constant micro-aggressions day after day do add up. It's a tone of voice and a
tone of voice is so hard to explain but behind that tone is a misunderstanding of
you, a misjudgement of you. And the misjudgement gets repeated day after day
and can get repeated by others. And this misjudgement can become someone's
10 conclusion about you which affects their behaviour toward you and they end up
not treating you equally. I did complain to the management lots of times. They
were always saying, "It is great to complain" but when I did it took a whole lot
of explaining why I was complaining because what I was complaining about
was not visible to many people.

15 I felt that staff weren't taking my complaints seriously. Any mention by me of
needing more support workers for the shared supported accommodation so that
the support workers weren't so rushed was met with a no. One person in
management at this service provider convinced me that they would fix it by
talking to all of the support workers, but then they disappeared without doing
20 anything. This empty promise was one of many. Management seemed to put
their heads in the sand.

 At the hospital/rehabilitation, nursing home/rehabilitation and shared
supported accommodation, they would all talk about the other residents in front
of me and to me and, often, it was negative stuff and private stuff. I eventually
25 said, "Please don't talk about others in my presence anymore." This was
because I realised it was impacting my relationships with the other residents,
and I had concerns about privacy. Most of the support workers did listen to
me. It was also a symptom of the support structure. They were flying in and
out of different residents' rooms and had to talk to each other about what was
30 going on. They needed time and space for debriefing and handover away from
the residents.

 So, often, in all the shared living arrangements I have lived in, including the
shared supported accommodation, the support workers would often leave me in
the middle of doing my support routine. They could be called away at any time.
35 It was out of sheer necessity of the moment when there was someone in need of
more support. If it was just a couple of times, I wouldn't mind, but it was
continuous. The support workers would often use my room as a throughway to
get to the other residents.

 I often had my door open for air and it was a few feet closer than the other
40 residents. At first, I liked it because it was a way of checking in with me, but as
I grew more confident I really needed my private space. I could not physically
lock my door. I was often not told when tradies would be coming. So, often, I
would come back in the middle of the day and, there, they would be working in
my room. The support workers would say they forgot or they didn't know
either. A few times, I have had tradies just walk past me in my room without
asking.

Now, I save the best till last and so did the shared supported accommodation. At the end of last year, I finally received confirmation of a new SDA flat, a place all of my own. Yay! Only, it wasn't ready yet. On New Year's Day weekend, the deputy manager asked me when I was moving to my new place because they were moving us out of the shared supported accommodation in February to start construction work to bring it up to the highest level of NDIS funding. At that time, I didn't have a moving date for my SDA flat. Then the deputy manager said they were starting at the other end of the units, so I didn't have to worry because they wouldn't get to mine till June, and I would be long gone before then.

They were talking about the works for about a year, but in all that time, they had no proper plans of where to house us while the work was going on. Then, on the 17th of January, the grade 5 told me that they had changed their plans, and I and the person who shared the flat with me would be going to a local motel on the 4th of February. Their excuse was that the builders hadn't given them any notice, but we, the consumers of their support, should have been their number one priority and, therefore, they should have told the builders to wait. I had a meeting with the manager on the 23rd of January and I felt a bit better about it. I would be in a unit of my own and I finally got something in writing. On the 25th of January, the manager and another manager came into my room without invitation, and said they were not sending me to the unit any more. I would still be going on the 4th of February and would be sent to a home, but they didn't know where yet, just that it was in the east. I sent a complaint by email to the service provider about the managers just coming into my room like that, and one of the managers came into my room, uninvited again, to say she was sorry. I could not be bothered saying it again. I was going through so much stress already.

With only three days' notice and three days before the 4th of February, they sent me to their respite facility. This was a place even more in need of a renovation. For example, the light often didn't work in my room. People were screaming at any time of the day and there was so much other noise at any time. I didn't get much sleep and I got sick. I had to hear everyone's business and there was even less privacy. The bathroom was shared and I was disturbed on the toilet by other residents, and though the managers had said there would be, there wasn't a buzzer system. People told me, "Don't worry, you will be fine," but they were doing the very thing I am afraid of: not acknowledging that my feelings are valid. And, really, they were just trying to make themselves feel better. I should have the same power to shape my life as anybody else, but, for years, I had very little.

My new home. I now live on my own in a flat. This is much better than the other places that I have lived. It is a SDA unit. I pay for rent out of my disability pension and then my NDIS package pays for my support workers. A service provider manages the staff at my SDA unit and provides support

workers who support me in the morning and night-time. I get some say in the support workers that support me, and I get to select the shift times for when people come and support me get into and out of bed. My daytime support workers are chosen by me. I currently have three support workers who support me during the day.

5

While my new place isn't perfect, it is so, so much better. For the most part, I'm respected, and that is all I was asking for. The support actually is set up for me and it's a place of my own. I think the most important thing you can do is to truly listen and support people with disability to drive the process of our lives. You can do this by really seeing consciously and, therefore, subconsciously, that there is no hierarchy. It's much better to see people with disability as equals for that is what we are. Again, I do not wish to prosecute anyone here because no one person is to blame; it's a social issue. I just want to help bring change by putting my story out there. What is happening to people is not okay and the stories need to be told.

10

15

COMMISSIONER SACKVILLE: Thank you, Ms Petersen. Mr Harding, do you have any questions?

MR HARDING SC: I have some additional questions, Chair. Thank you very much for your evidence, Ms Petersen. Now, in paragraph 4 of your statement, you talk about living in a nursing home. Was it your decision to live in a nursing home?

20

MS PETERSEN: I was given a choice: nursing home/rehabilitation or stay in hospital/rehabilitation and the nursing home/rehabilitation was closer to my network.

MR HARDING SC: And what about shared support accommodation? Was that your choice?

25

MS PETERSEN: Again, there wasn't much choice. I was only given one choice of shared supported accommodation. The nursing home was closing down. The management said they weren't, but the writing was on the wall. Also, in a shared supported accommodation, I would have an en suite. Something I feel is essential when you have a disability, but I heard they were not common in shared support accommodation. They were also offering more independence, so I said yes.

30

MR HARDING SC: In the shared support accommodation, did you decide what your daily routine would be?

MS PETERSEN: I decided that it was always the bare minimum because I was always made to feel I was too much for the support workers and, in many ways, I was too much because there wasn't enough support to go round. People just don't realise how long I take to do anything properly. I wasn't able to choose how I got those supports like who was supporting me or how many people were supporting me.

35

MR HARDING SC: Well, now you can choose your daytime support workers. What's that like?

MS PETERSEN: It puts the power into my hands where it should be.

MR HARDING SC: Very succinct. Have you got a message for the Royal
5 Commission about what you would like to see it do?

MS PETERSEN: Yes. I hope that hospital stays are shortened for people with a disability. I hope that all people with a disability will have the support to explore and have the opportunity to live in a place of their choosing. I hope that providers are more accountable. I hope for better education and conditions for support workers
10 because you cannot have one without the other, but, most of all, I hope that people's attitudes will change. I know I have privilege. I got out.

MR HARDING SC: Thank you very much, Ms Petersen.

COMMISSIONER SACKVILLE: Ms Petersen, thank you very much for coming to the Commission and sharing with us your thoughts and experiences. We do
15 appreciate it very much. Thank you so much.

<THE WITNESS WITHDREW

[2.31 pm]

COMMISSIONER SACKVILLE: Does that conclude our evidence?

MS EASTMAN SC: Yes, Commissioner. That concludes the evidence that has been presented that we wish to present during the course of this hearing.

COMMISSIONER SACKVILLE: Should Ms Petersen – would you like to
20 move - - -

MS EASTMAN SC: Ms Petersen is very welcome to stay if she wishes - - -

COMMISSIONER SACKVILLE: Stay or go as you wish.

MS EASTMAN SC: - - - while we conclude the hearing, but, equally, if you wish to
25 go, that's fine as well. Just take your time. You decide what you'd like to do. I want to just say a few things by way of administrative matters in closing. As I said at the beginning of this hearing, it is just the beginning, and the work of the Royal Commission looking at the important issues of home, belonging and accommodation will form part of the ongoing work of the Royal Commission over the coming years.
30 So this isn't the end. We've heard from many people this week, but we know that there are many other people who wish to contribute to the Commission's work in this area.

So can I deal with some administrative matters. On Monday, we provided the Commissioners with the documents for this hearing, and I described that as the tender bundle. Over the course of the week, the contents of the tender bundle have changed slightly. Some of the documents that we initially provided will no longer be
5 relied on. There are a small number of documents that have been added and provided by other parties over the course of the week. Some of the documents in the tender bundle are now the subject of specific non-publication orders in an un-redacted form, and the copies now in the tender bundle have the redactions that have been applied.

10 The parties with leave to appear at this hearing will be provided with an updated index to the tender bundle as soon as possible. I can assure you the index exists and it will be on its way shortly. You, Commissioners, have also been provided with an updated index to the tender bundle. The updated index includes new headings which provide separate exhibit numbers for each witness statement, including the
15 annexures, the remaining documents in the tender bundle are included as additional separate exhibits, and I would ask that the updated tender bundle be admitted into evidence which we describe as exhibits 1 to 27.

COMMISSIONER SACKVILLE: Yes. Well, that – we will do that. The document that I have actually starts with exhibit 2.1. I assume there is – is exhibit 1 the
20 previous version or is exhibit 1 something else?

MS EASTMAN SC: Exhibit 1 is the start. So you will see it's exhibit 1, reports and publications.

COMMISSIONER SACKVILLE: Yes. I have that.

MS EASTMAN SC: And because of the changes, we've tried to manage this so that
25 it's easy to follow. So tabs 1 and 2 are intentionally blank, and you will start with tab 3 which is a copy of the UN Convention. So if you see through - - -

COMMISSIONER SACKVILLE: And tab 3 forms part of exhibit 2.1?

MS EASTMAN SC: No, it's part of exhibit 1.

COMMISSIONER SACKVILLE: I believe what you say.

30 MS EASTMAN SC: All right. Standing next to me is the Solicitor Assisting the Royal Commission. He tells me that you and I have slightly different documents which might causing - - -

COMMISSIONER SACKVILLE: Of course we do.

COMMISSIONER ATKINSON: I expect he told you what the problem was.

35 MS EASTMAN SC: This might be the one time I blush in the Royal Commission.

COMMISSIONER SACKVILLE: Why don't we sort it out in due course and advise the - - -

MS EASTMAN SC: I was - - -

COMMISSIONER SACKVILLE: - - - parties who have leave to appear.

5 MS EASTMAN SC: All right. I was trying to do this with some elegance, but it is Friday afternoon. So excuse me blushing, and we'll sort the tender bundle out.

COMMISSIONER SACKVILLE: Let us sort the tender bundle out, one way or another.

10 MS EASTMAN SC: So, equally, Chair, there are also the issues in terms of the non-publication directions.

COMMISSIONER SACKVILLE: Yes.

15 MS EASTMAN SC: So you made a non-publication direction on the 27th of November prior to the hearing, and in relation to that particular order, you have now made a new direction that revokes the 27 November order, and the new order will now be operative in relation to the non-publication order. So that's also been contained, I think, in a relevant document. You have also made an additional direction in relation to three documents that we propose to include in the tender bundle, and these are documents over which Yooralla has claimed confidentiality. There has been ongoing discussions, and I hope those discussions will conclude

20 shortly between the solicitor assisting the Royal Commission, who you've just seen a moment ago, and those acting for Yooralla.

The next issue is a timetable for submissions. As we have said during the course of the week, that the – we have been very grateful for all those appearing before the Royal Commission with providing us with statements and documents on very short

25 notice, and the intention was to ensure that if there was any additional material or submissions, that any party would have the opportunity to provide that additional material. So the – any submissions or material that any of the parties who have been given leave to appear in this hearing wish to provide should do so by the 28th of February 2020, and we will ensure that that's also recorded on the Commission's

30 website.

The Commission will also recall that, in addition to the work done for this particular public hearing, the Royal Commission has an issues paper dealing with the question of group homes, and any person can make submissions in relation to the issues paper. So you don't have to be a party to this hearing. You don't have to have appeared at

35 this hearing, but if you have followed the work of this hearing and you wish to make submissions, the Commission encourages you to make a submission and, again, details are on the website. And, finally, in relation to the position of the Commonwealth. Throughout this hearing there has been evidence relating to

Commonwealth departments, Commonwealth agencies, and the National Disability Insurance Agency.

We've also heard some evidence about the Commonwealth legal framework, and as foreshadowed in my opening, these issues will be dealt with at future hearings. The Commonwealth will seek to provide submissions on matters relating to it and its agencies, including matters raised in this hearing when the Commission deals specifically with issues concerning the NDIA and the other Commonwealth matters. Unless there are any other matters – Mr Markus might tell me – that concludes the business that I need to attend to.

10 And may I say on behalf of all working in the Royal Commission, we have been very grateful for the participation of everybody who has given their time, not only in preparing statements and coming to the Royal Commission, but also thinking very carefully about the issues that they wish the Royal Commission to explore over the next few years. We're also grateful for the assistance of the legal representatives of the various parties in the assistance that they have provided the witnesses to be able to attend and participate. And I also, on behalf of the counsel team, thank all of the staff of the Royal Commission in assisting us to have this hearing on a fairly short notice. If the Commission pleases.

20 COMMISSIONER SACKVILLE: Thank you very much, Ms Eastman. I would like to make some – just some brief remarks. This has been a challenging and, at times, confronting, but very important week of hearings held by the Royal Commission. We have heard much evidence of the routine abuse and dehumanisation of people with disability in institutions and in some group homes. As we heard in the evidence from Yooralla, the interchanges that took place, the abuse and dehumanisation we have been told about cannot be given the comforting designation of “historic”. The accounts we have heard reflect what has happened in Australia in the 21st century and, indeed, despite many official reports and many legislative reforms, as Kevin Stone of VALID and the panel of advocates yesterday so forcefully told us, the abuse and dehumanisation continue even today.

30 Professor Patsie Frawley explained in her evidence that in order to bring about transformational change it is necessary to have a close understanding of the pervasiveness of violence and abuse in the lives of people with disability, particularly in group homes, but not exclusively. The abuse, as Professor Frawley noted, is sometimes violent, sometimes shocking, but it often takes the form of seemingly small, relatively minor indignities, or poor practices, yet which have a profound impact on the daily lives of people with disability. And we've just heard from Sam Petersen about – we've heard from her about the impact that poor practices and what she described as micro-aggressions can have on the daily lives of people with disability in group homes.

40 Part of the task of this Royal Commission is to expose the violence, abuse, neglect and exploitation experienced by people with disability. The most effective way of

doing this is through the evidence of people with lived experience of disability, people like Dr Gibilisco, Dr Taleporos, Jane Rosengrave, Alan Robertson, and Sam Petersen from whom we have just heard. We've had the privilege of hearing from these people during the week. But other people also have an important part to play in this process. They include the families of people with disability and people with complex needs, such as the parents from whom we heard on Monday. It does seem a long time ago but it's only four days ago. And their names, of course, are subject to suppression orders.

The advocates who gave evidence drew on their vast experience of supporting and advocating on behalf of people with disability, especially people with intellectual disability and complex needs. Their experience allowed them to describe the violence, abuse, neglect and exploitation of people with disability. We listened to and heard Colin Hiscoe's passionate plea for people with disability to be treated just the same as everybody else in the community. The evidence of the advocates was complemented by the experience of people who work at the coalface in institutions, including group homes. And that includes the evidence that we heard from community visitors, David Roche and Cindy Masterson.

Academics have a particularly significant part to play in this process through systematic and rigorous studies that shed light on practices and policies that otherwise might remain hidden. Their work provides an intellectual framework for understanding the causes of these practices and policies and for identifying approaches that can be taken in order to move us towards the goal of social inclusion for people with disability. And we have gained over the course of this week, we've benefitted from the insights from the research conducted by Dr Claire Spivakovsky, Professor Patsie Frawley, Professor Sally Robinson, Professor Christine Bigby, and Dr Ilan Wiesel.

Today, Ms Rosemary Kayess explained the operation of the United Nations Convention on the Rights of Persons with Disabilities, in particular Article 19 which recognises the right of people with disability to choose their place of residence and where and with whom they live on an equal basis with others. Professor Bigby's evidence today canvassed the complexities and nuances of the concept of choice for people with profound intellectual disabilities. We have also had during the week valuable contributions from the regulators and administrators who participate in the system. Their roles in administering programs and supervising the conduct of accommodation for people with disability are critical in enforcing standards and ensuring that the entitlements of people with disability are received.

We heard evidence from Dr Colleen Pearce, the Victorian Public Advocate, Mr Arthur Rogers, the Victorian Disability Services Commissioner, as well as Ms Janine Toomey, executive director, disability and NDIS in the Victorian Department of Health and Human Services. We've heard from people who have devoted considerable thought and in some cases considerable resources to developing alternatives to current models of accommodation. This evidence included that given

by representatives of the Summer Foundation, Dr Di Winkler and Dr George Taleporos, and also from the members of the panel we heard from this morning. As I said in my opening, the hearings of this Commission are intended not only to expose abuse, violence, neglect and exploitation, but to chart a course or courses that

5 are designed insofar as possible to make these shameful practices genuinely historic. To chart these courses we have to understand and respect the themes that have been so clearly articulated by virtually all the witnesses this week. These themes include the need for people with disability to have the freedom to make their own choices about the way they wish to live to the extent necessary to be supported in their own

10 decision-making; the need for people with disability to be accorded the respect and dignity which is the entitlement of every Australian; the need for the human rights of people with disability to be understood, respected and enforced; the need to support the critical role played by advocates in achieving these goals, and the need to separate housing from sources of support, a matter upon which we heard evidence

15 from a number of the witnesses. And there is something else. As the evidence concerning Yooralla demonstrated, people with disability, like everybody else, when they experience violence, abuse, exploitation or neglect, they are entitled to justice. Can I give some thanks to some people, some of whom have already been mentioned by Ms Eastman. First and

20 foremost on behalf of the Commission may I thank the people – all the people who have made a statement or given evidence to the Commission this week. In particular, we are profoundly grateful to people with disability and their advocates who have come and told their stories so that everybody can hear and understand their experiences.

25 To the staff who have worked so hard to enable this hearing to proceed smoothly, our thanks as well. There is an enormous amount of work required to enable a hearing like this to take place, to ensure that the room, for example, is fully accessible and to ensure that support is provided, is on hand for anybody who may need assistance during the hearing. The staff have done a magnificent job. To the interpreters and

30 transcript recorders, both our thanks and our wonder at their skills in translating or recording evidence that has often been spoken at just under the speed of light. Fourthly, the legal team within the Royal Commission has done an extraordinary job. The entirety of the legal team. They have worked, as Ms Eastman has said, under extreme pressures of limited time and finite resources. It's no easy task to gather

35 together such a diverse range of witnesses and to ensure that their evidence is presented in a systematic and comprehensible way. The legal team has done an outstanding job, as have all the other members of staff who have contributed to the process. Our thanks go to Counsel Assisting the Commission, Senior Counsel and junior counsel, for their professionalism, diligence and their skills. And I also, like

40 Ms Eastman, express appreciation to the legal representatives of the parties who have been given leave to appear for their cooperation in facilitating the giving of evidence at this hearing and the conduct of the hearing itself.

We hope to issue a schedule for hearings at least for the first half of 2020 before the end of this year. Not a lot of time to go to the end of this year but we will do that. I can say that the next hearing is likely to take place in February 2020 in Western Sydney. That hearing will deal with the issue of access for people with cognitive
5 disability to health services and the outcomes for those people from their access to health services, but there will be other hearings, of course, in the first half of 2020 and we hope to make that schedule available very shortly.

As Ms Eastman has said, I encourage everybody who has an interest in the area that we have covered in the hearings this week to make their contributions based on the
10 Issues Paper that has been published or, if they don't wish to follow the form of the Issues Paper, in any form that they consider appropriate. And we encourage people, I hope who have viewed or heard the proceedings this week, to make their own contributions, people with disability who are prepared to come to the Commission and tell us their stories or the stories of family members who are people with
15 disability.

Thank you very much. We will now adjourn.

MATTER ADJOURNED at 2.50 pm ACCORDINGLY

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