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O/N H-1063565

THE HONOURABLE R.R.S. TRACEY AM RFD QC, Commissioner
MS L.J. BRIGGS AO, Commissioner

IN THE MATTER OF THE ROYAL COMMISSION
INTO AGED CARE QUALITY AND SAFETY

MELBOURNE

9.15 AM,WEDNESDAY, 11 SEPTEMBER 2019

Continued from 10.9.19

DAY 49

MR R. KNOWLES, counsel assisting, appears with MS E. HILL
MR S. FREE SC appears with MR B. DIGHTON for the Commonwealth

COMMISSIONER BRIGGS: Good morning, and good morning, Mr Knowles.

MR KNOWLES: Good morning, Commissioner. Today, the first witness I seek to call is Ms Vicki Rundle.

<VICKI DENISE RUNDLE, AFFIRMED [9.15 am]

<EXAMINATION BY MR KNOWLES

MR KNOWLES: Ms Rundle, could you tell the Royal Commission your full name for the transcript.

MS RUNDLE: My name is Vicki Denise Rundle.

MR KNOWLES: You're currently the acting chief executive officer of the National Disability Insurance Agency.

MS RUNDLE: That's correct.

MR KNOWLES: Since when have you occupied that position?

MS RUNDLE: Since 30 April this year.

MR KNOWLES: In that position you have overall responsibility for the NDIA.

MS RUNDLE: I do.

MR KNOWLES: Yes. And you have responsibility for its evidence to this Royal Commission.

MS RUNDLE: I do.

MR KNOWLES: Can I first take to you the document at tab 146 of the general tender bundle, and it should come up on the screen beside you there. Do you see there, there's the NDIAs response to a notice issued by the Royal Commission dated 21 August 2019 it's document CTH.0001.8000.0001.

MS RUNDLE: I can.

MR KNOWLES: Now, can I take you in that document to paragraph 17. That appears at page 0009. Now, in sub-paragraph (b) of that paragraph you'll see, Ms Rundle, a reference to 15,7000 people; is that an error?

MS RUNDLE: No. To my knowledge, this is the – the estimation that the Productivity Commission estimated in 2011.

MR KNOWLES: Yes. Should it be 15,700 people though?

MS RUNDLE: Thank you, yes, it should definitely be 700, yes.

MR KNOWLES: Yes. Thank you. So save for that matter, have you read the response to the notice yourself?

MS RUNDLE: I have.

MR KNOWLES: Yes, and you've otherwise, save for that matter, satisfied yourself that its contents are true and correct to the best of your knowledge and belief?

MS RUNDLE: I believe so.

MR KNOWLES: Thank you. Now, that document, Commissioner has already been tendered in the general tender bundle, as I say, at tab 146.

COMMISSIONER BRIGGS: Thank you.

MR KNOWLES: Can I now take you to another document in the general tender bundle. It's at tab 118, and you should see there another response from the NDIA to a further notice issued by the Royal Commission. Do you have that in front of you, Ms Rundle?

MS RUNDLE: I do.

MR KNOWLES: Yes. And that is the response with document number CTH.0001.8000.0116, and have you had an opportunity to consider that document before giving evidence today?

MS RUNDLE: I have.

MR KNOWLES: Yes. And are you satisfied that the contents of that document are true and correct to the best of your knowledge and belief?

MS RUNDLE: I believe so.

MR KNOWLES: Yes. Thank you. Now, can you tell the Commissioner something about your experience and the previous positions you've held prior to becoming the acting CEO of the NDIA?

MS RUNDLE: Yes. In the NDIA from October 2015 when I started, I ran for a period of time part of the operations of the agency when it was still in trial, before it started transitioning in July 2016. I managed that until I took over the role of acting

deputy where I was looking after markets, information technology and people and culture, and I was in that position until September of 2017, I believe, and then I took over another deputy role looking after communications, media, government policy and I think that was – that was the role at that time. That's right. And then I stayed in that role until I took over the acting role of CEO in April.

MR KNOWLES: So you've had considerable experience at the NDIA since 2015 acting in various roles. And are those roles – have they been relevant to issues relating to younger people in residential aged care?

MS RUNDLE: Some of them more closely than others. In the early days when I first joined the – we were in trial and so I was – to the extent that the regions I was looking after would have had some people in residential aged care coming into the scheme in the early days in trial, I would have had some remote oversight of that because I had people running – when I say "remote" I had oversight of it but I had people running those regions who would have been much more closely involved with those participants, small in number, I would have thought, at that time. And then I probably became more closely involved again in my last role previous to this role where I was working with DSS and Health in thinking about the – you know, the rollout of the scheme more broadly and the role of the agency and residential people in aged care.

MR KNOWLES: Yes. And prior to working at the NDIA, you've also had other experience in Commonwealth and State Government agencies; is that correct?

MS RUNDLE: I have.

MR KNOWLES: That's largely been in health and human services areas.

MS RUNDLE: It's been in social services, policy and delivery in the main, that's correct, in State and Territory and Commonwealth governments.

MR KNOWLES: Yes. Now, can I ask you to look at a copy of a statement that you've prepared for the Royal Commission which is document WIT.0436.0001.0001, and that is your statement there on the screen, and I think you have a copy with you as well, Ms Rundle.

MS RUNDLE: I do.

MR KNOWLES: Dated 3 September 2019.

MS RUNDLE: That's right.

MR KNOWLES: Have you read that lately?

MS RUNDLE: Yes, I have.

MR KNOWLES: Are there any changes you wish to make to the statement?

MS RUNDLE: I don't believe there are.

MR KNOWLES: Are the contents of the statement true and correct to the best of your knowledge and belief?

MS RUNDLE: Yes.

MR KNOWLES: I seek to tender the statement of Ms Rundle dated 3 September 2019, Commissioner.

COMMISSIONER BRIGGS: The statement of Ms Vicki Rundle dated 3 September 2019 will be exhibit 9-10.

EXHIBIT #9-10 STATEMENT OF MS VICKI RUNDLE DATED 03/09/2019 (WIT.0436.0001.0001)

MR KNOWLES: Ms Rundle, have you had an opportunity to see any of the evidence that's been given this week by other witnesses?

MS RUNDLE: I haven't seen all of the evidence. From Monday – I saw very little from Monday. I saw most of yesterday's evidence.

MR KNOWLES: Yes. And so I take it that you've seen witnesses, not only from government, but people who have told of their direct experiences living in aged care or of their loved ones' experiences living in aged care.

MS RUNDLE: I have.

MR KNOWLES: And do you accept that the theme of that evidence in considerable part is that for some people they've not been able to choose their place of residence at all. They've been forced into residential aged care, they've felt.

MS RUNDLE: Yes, I do.

MR KNOWLES: And in residential aged care, do you accept that they have given evidence that they've felt isolated from people with similar interests to them?

MS RUNDLE: Yes, I do.

MR KNOWLES: Can I, before going further though, ask you some questions just broadly about the NDIS. You mentioned earlier the trials; did they start in July of 2013 in terms of the initial trials for the NDIS?

MS RUNDLE: They did.

MR KNOWLES: Yes. And am I right in saying that since 2016 the NDIS has gradually transitioned to full scheme implementation.

MS RUNDLE: That's right.

MR KNOWLES: And it's now, save for, I think, Christmas Island and Cocos Islands, fully implemented across the country.

MS RUNDLE: It's fully available across the country. I think it's fair to say that we are still implementing and bringing people into the scheme. I would think it would be more fully implemented when we have everybody into the scheme that we envisaged would come into the scheme and that that will be the case – well, what we envisage is that over the next five years we would have around 5000 people in the scheme but we certainly would expect that the people envisaged to come into the scheme would be in the scheme in the main by 2020.

COMMISSIONER BRIGGS: I take it you mean 500,000 people in the scheme.

MS RUNDLE: Did I say 500? Commissioner, I'm so sorry, 500,000.

COMMISSIONER BRIGGS: Thank you.

MR KNOWLES: Yes. And can I ask you just for the broader audience, can you just explain in summary how the NDIS works? Such as how does it – who does it provide funding for, specifically, and what does it provide funding for and how does a person access funding?

MS RUNDLE: Could I first provide a little context - - -

MR KNOWLES: Sure.

MS RUNDLE: - - - about the intent of the scheme because that might be helpful. The NDIS Act – and if you look at the objects and principles of the Act, it describes that the role of the agency and other parties is to establish a National Disability Insurance Scheme that gives people with disability and their families and carers the right to participate socially and economically in a way that they haven't ever been able to before, and it's based on the UN rights of the convention of people with disability – UN Convention of the Rights of People with Disability, I'm sorry, struck in 2006. And it's an important principle to understand to be able to then understand how the scheme works because the scheme is intended to work as an insurance scheme whereby, firstly, it should give – it's been set up so that everyone participates in funding the scheme.

All Australians pay for the scheme and it's there for everyone should they need it. So there's peace of mind for all Australians that if ever they have a permanent and

significant disability or their family member does, that they will be able to access this at no large cost to themselves, which was often the case for participants – for people with disability beforehand. In discharging the Act and the objects and principles of the Act the scheme is required – the scheme was set up to do a range of things. It was set up to make assessments about the sort of people who need to come into the scheme and who should get access to the scheme and that's one of the biggest decisions that the CEO or delegates of the scheme makes and it's also required to make decisions about funded supports and the sort of supports that people have in their packages to enable them to achieve their goals and aspirations, including social and economic participation.

What it's also intended to do is give them the sort of choice and control that they need to be able to sort of work out what they need, what sort of supports they want to buy and it gives them a whole lot more choice rather than the system that they were – had to endure before which was one where services were block funded and participants really got what they were given and they had very little choice. And I think it's important to understand all of that to then – and particularly in the context of young people in residential aged care and where the scheme is placed to be able to help those individuals. So to answer your more detailed question around how does the scheme work, what we do is we – we first become aware that a person might want to get access to the scheme and we either get that through data that we've been given by States and Territories or because a person may make a separate access request to the scheme.

We consider all of the information about that individual, their disability, whether or not they are citizens, their age, a range of other considerations and we then decide under the Act whether or not that person should gain entry to the National Disability Insurance Scheme, understanding that many people with a disability won't come into the scheme and it was never intended for everyone in Australia with a disability. And then what we do is we have a planning process, if you like, a pathway that we take people along to enable them to understand what it's like to be able to get a plan, what they – what their goals, you know, what sort of goals would they like to put into their plan, how might the supports that they're looking for achieve those goals and then we fund those supports in their package. Now, I've sort of skimmed along the top of the planning process without going into a great deal of detail.

MR KNOWLES: That's helpful, Ms Rundle. In terms of what you say about plans and goals, it emphasises the choices that are available to people who are participants in the scheme, those that are found to be eligible to be participants.

MS RUNDLE: That's correct.

MR KNOWLES: Yes. And that's, as you say, something that's enshrined in the guiding principles in the sections towards the beginning of the NDIS Act.

MS RUNDLE: That's right.

MR KNOWLES: Yes. And am I right in taking it that what you say about that is that those principles in many respects are intended to reflect what is set out in the Convention On The Rights of Persons With Disabilities?

MS RUNDLE: That's right.

MR KNOWLES: Yes. And in that regard, no doubt in terms of where people live, you would be aware of article 19 of the convention; yes?

MS RUNDLE: I am.

MR KNOWLES: And just for the transcript, article 19 of the convention states that:

> *States, parties to the present convention recognise the equal rights of all persons with disabilities to live in the community with choices equal to others and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that (a) persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement.*

Just pausing there, the people who've given evidence this week, they haven't had the ability to enjoy that right, have they?

MS RUNDLE: I think that's – that's right in the main.

MR KNOWLES: And then:

> *(b) persons with disabilities have access to a range of in-home residential and other community support services, including personal assistance necessary to support living and inclusion in the community and to prevent isolation or segregation from the community.*

And, again, insofar as that goes to prevention of isolation, would you agree that the rights of people – most of the people who've given evidence this week haven't been fostered?

MS RUNDLE: I think that's right.

MR KNOWLES: Yes. And, lastly:

> *(c) community services and facilities for the general population are available on an equal basis to person with disabilities and are responsive to their needs.*

Again, would you agree that, in terms of the evidence that we've heard this week, that right also doesn't appear to have been something that they've been able to enjoy?

MS RUNDLE: In the main I agree with that.

MR KNOWLES: Yes. Now – and do you agree that this is a human rights issue - - -

MS RUNDLE: Yes.

MR KNOWLES: - - - in terms of the younger people in residential aged care or at risk of entering residential aged care?

MS RUNDLE: Yes.

MR KNOWLES: Now, not all younger people who are in residential aged care or entering residential aged care will even fall within the boundaries of the NDIS, will they?

MS RUNDLE: It's correct that some don't. And when you look at our data, it shows that some people don't get access to the scheme who are in residential aged care settings. In the main, though, the majority of participants – the majority of people do.

MR KNOWLES: Yes. Well, in that, you've no doubt heard evidence that has already been referred to this week in the form of the recent Australian Institute of Health and Welfare report that said that 12 and a-half per cent of young people in residential aged care listed cancer as their primary condition.

MS RUNDLE: Sorry?

MR KNOWLES: Well, perhaps I will go to it. If I could go to tab 28 of the general tender bundle. This is the AIHW - - -

MS RUNDLE: Yes.

MR KNOWLES: - - - report. Yes. And so in the report – this is at page 15 of the report – do you see there the table from the report that refers to cancer being listed as a primary condition for 12 and a-half per cent of people who first enter residential aged care under the age of 65?

MS RUNDLE: I can see that.

MR KNOWLES: Yes.

MS RUNDLE: Yes.

MR KNOWLES: And it's likely, isn't it, that it might not be the majority of people, but there is a sizeable minority of people who will not be covered by the NDIS - - -

MS RUNDLE: That's correct.

MR KNOWLES: - - - who are younger people in had residential aged care or at risk of entering into residential aged care?

MS RUNDLE: That's correct.

MR KNOWLES: And if I can now take you to another document, which is in the tender bundle at tab 137. And do you see there there are some minutes from the Younger People in Residential Aged Care Action Plan Project Board. Now, I will come back to the action plan in due course, but at this juncture, if I could just take you to the third page of that document, and in particular agenda item 4. And this is an agenda item of the meeting of the Action Plan Project Board in which this AIHW report data about people with, in particular, cancer in residential aged care is referred to. And do you see in the second dot point there's a reference to the fact that that cohort presenting a challenge for health, because if entry to aged care is closed to all under 65s with the assumption that the NDIS will care for them instead, there will be a substantial unmet need.

MS RUNDLE: Yes. I can see that. Yes.

MR KNOWLES: Yes. So do you agree that while the NDIS is certainly a part, and a not insignificant part, of the solution to solving the question of younger people in residential aged care, it is not and cannot be the only part of the solution? There are other parts that have a role?

MS RUNDLE: Yes, I do agree with that.

MR KNOWLES: Insofar as it's not just the NDIS that will present solutions for people, do you agree that this multi-government, multidisciplinary issue will require advocates for people who are seeking to avoid entering into residential aged care, or getting out, if they're in residential aged care?

MS RUNDLE: I do. I think the role of advocacy is really important.

MR KNOWLES: And do you think that just highlights the importance of a need for greater dedicated funding for advocates in relation to this specific issue going to younger people in residential aged care?

MS RUNDLE: I'm not the best person to comment with any detailed knowledge on the funding for advocacy around Australia, because that is not a function of the scheme. It doesn't fund advocates. It – advocates are funded both by State and Territory Governments and also by Department of Social Services. But we do

recognise that advocates do struggle with, you know – with having the resources available sometimes to be able to support the people that they want to support.

We – one of the things which the scheme does do – I didn't talk about this earlier when I talked about the establishment of the scheme and what it does, but it also has some other functions. And one of them is to look at the development of the community linkages and community capacity. It's not – we're not the only – the NDIS is not the only party in that, but to do that we do have an annual appropriation and we do provide grants. In that grant system, we don't provide grants to advocacy organisations for systemic advocacy, because we try to be very clear that that is actually the role of other parties.

But what we do fund, and we're encouraging it, and it is by far and away the largest proportion of our ILC, we call it – our ILC grants funding – is a program that goes to teaching people themselves how to give people peer support and teaching people themselves have to be self-advocates. And in the peer support program, we are encouraging people with disability and other people who've experienced – have lived experience with disability to – to support those individuals to be – and to support themselves and to build their own capacity. Now, I know it's not quite the same as advocacy, but it's the other – it's the other side of the coin.

MR KNOWLES: Yes. But in this context where, I think as you've acknowledged, a not insignificant group of people within the overall cohort of younger people in or at risk of entering into residential aged care may not even qualify for the NDIS and need to establish where they might go, do you agree there really needs to be advocates for individual people or at least navigators for individual people to understand where they should go, how they should navigate this system, which isn't simple, and has many different parts to it at the moment, that requires some understanding that is beyond most average people who are trying to understand where they should go?

MS RUNDLE: I do agree the role of advocacy is important. And I said that earlier.

MR KNOWLES: Yes. Now, in relation to the scheme, participants are eligible to receive funding for reasonable and necessary supports; is that right?

MS RUNDLE: That's correct.

MR KNOWLES: In the broad.

MS RUNDLE: That's correct.

MR KNOWLES: Now, until 28 June this year is it right that the NDIA didn't agree to fund disability-related health supports for NDIS participants?

MS RUNDLE: It's correct to say that there – I – if I could characterise it differently - - -

MR KNOWLES: Yes.

MS RUNDLE: - - - please. I would say that when the scheme was first set up and the agreements – the bilateral agreements were reached with State and Territory Governments and the Commonwealth it was agreed that there were many things that weren't entirely clear. One of the things that needed to be clearer – there needed to be more clarity on was this issue, who funds health supports for people with disability.

And there were – there was a set – there were a set of principles developed called the APTOS principles. And what they did was they tried to describe the relative roles and responsibilities of all parties. In that document it described the roles of States and Territories in mostly continuing to provide health supports for participants. I'm abbreviating to some extent, rather than going into the absolute detail.

The – what we found, however, is that in the APTOS principles, as is the case often with legislative schemes when they're first set up and other like cases, examples, the information is not sufficient to enable people to make decisions. And so we found that planners, as they were putting supports in plans didn't really still understand when you had grey areas, who would fund those areas. And it became evident that the APTOS principles were insufficient to be able to give clarity to all parties. So the governments worked together to develop a different approach, which is the one that you're referring to that went to DRC in June.

MR KNOWLES: DRC being?

MS RUNDLE: The Disability Reform Council - - -

MR KNOWLES: Yes.

MS RUNDLE: - - - in June.

MS RUNDLE: What we did was in order to try to clarify that, we did some actuarial work, which, of course, is another strong feature of an insurance-based scheme. And we looked at the particular groups of individuals in the scheme that where we know their disabilities significantly use health supports. And we then looked at the sort of supports that they used and we decided we would develop a set of principles and approach it differently. And the reason we did this is because it had been intractable and we found that – that you could continue both parties, you know, arguing about who would fund for what, but we had to try and reach – we had to try and cut through it and reach a solution.

So the way we did that was we, with the board, developed a set of principles and we said, essentially, the main principle is that if a health support is related to the disability and the disability only and not related to any other health event, then it is reasonable for the scheme to fund that support. And that helped us. That gave us greater clarity. And we then looked at all of those groups that we had been looking

at and we looked at those supports and we tested those supports and said is there anything in there that wouldn't fit that principle. And in the main we found that – that all of those things would be funded by the scheme.

Having said that, there are a range of things sitting outside of that that we also agreed wouldn't be funded and shouldn't be funded by a lateral disability insurance scheme, because they're rightly funded by other States and Territories Governments. So, for example, a citizen who has got a disability has the same right as any other citizen to access a health service. And if they break their arm, they have the same right as everybody else to go to hospital and have that break fixed. And so there are a range of things that we felt quite strongly about that participants really needed to have that same access. But to the ex-tent that the health supports relate to the disability that they have, we agreed that the scheme would fund those things.

MR KNOWLES: Yes. But prior to that point in time, the policy position was not to fund those things?

MS RUNDLE: Correct. But, in saying that, I just need to be clear, that they were still provided by States and Territories Governments.

MR KNOWLES: I understand that. But there was a position taken by the NDIA prior to that not to fund disability health-related - - -

MS RUNDLE: No, I wouldn't say that. The position - - -

MR KNOWLES: Disability-related health supports.

MS RUNDLE: No. No, counsel. With respect, I think the disability insurance scheme, the agency, didn't take that position alone. That was a position reached through the APTOS principles by all governments, not just the NDIA.

MR KNOWLES: Well, in relation to those disability-related health supports, what's an example of that? Is it nursing services that might be provided to somebody that they need by reason of their disability?

MS RUNDLE: It could be. It's probably not the best example to use, because in some cases where nurses are currently used, some participants would tell you – and I could give you – I could tell you the names of many participants, but I won't – who have said to us, "We would rather not pay for a nurse for this particular support, even though it has traditionally been delivered by a nurse, because we can get this through a well-qualified support worker. And that means that we've got more money available in our plan to buy other things." But there are definitely cases where a registered nurse is most appropriate for some supports. That's correct.

MR KNOWLES: Yes. And those – that sort of funding for that service will assist some people to live in the community in, whether it's specialist disability accommodation or their home, somewhere other than residential aged care, won't it?

MS RUNDLE: That's right, yes.

MR KNOWLES: Because that might be the thing that they otherwise need – receive - - -

MS RUNDLE: That's right.

MR KNOWLES: - - - when they are in residential aged care.

MS RUNDLE: Yes. That's correct.

MR KNOWLES: So would you agree that the unavailability of funding for that from the NDIS may have had a bearing on the ability for people to leave residential aged care in the past?

MS RUNDLE: It's hard to answer that conclusively in any – in either direction. And I say that because I'm aware that there will be participants and are who have been able to move out, who have been able to get the sort of supports that they need prior to that decision from health services. And so I recently, toward - - -

MR KNOWLES: Do you think there would be any that couldn't have, though, prior to that decision, who may have – any that might have been unable to leave residential aged care by reason of that policy setting being in place?

MS RUNDLE: Because I can't answer – I actually can't confirm that either way, but then I would have to accept that that could be the case.

MR KNOWLES: Yes. Now, isn't the question one that comes back to whether or not those relevant supports were reasonable and necessary, ultimately, in terms of whether or not they fall within matters that ought to be funded under the NDIS Act? In terms of a legal position – and I'm not asking you to - - -

MS RUNDLE: Yes.

MR KNOWLES: - - - present a legal opinion here, but that really is the defining issue, isn't it?

MS RUNDLE: I'm not sure I really understand your question. And if I – if I might – if I – if I perhaps explain what I understood to happen previously, then – then that might help me understand.

MR KNOWLES: Yes.

MS RUNDLE: You may be able to rephrase it for me. The – if a – previously it was agreed that health supports – in the main it was agreed and acknowledged that health supports were funded by States and Territories Governments and - - -

MR KNOWLES: Is that via are the – sorry to interrupt – the APTOS principles?

MS RUNDLE: Yes. Yes.

MR KNOWLES: Can you just tell the Commission for the transcript - - -

MS RUNDLE: What it stands for.

MR KNOWLES: - - - what the APTOS principles are and - - -

MS RUNDLE: I knew you would ask me that, Counsel.

MR KNOWLES: - - - what that stands for.

MS RUNDLE: The Applied Principles – APTOS – look, I'm sorry, I will have to check it and come back to you.

MR KNOWLES: That's all right.

MS RUNDLE: I know it, but it has just escaped me.

MR KNOWLES: That's okay.

MS RUNDLE: It's the principles that describe the health – you know, what is funded through not just health supports, but also child protection. It goes to a range of other things, as well.

MR KNOWLES: Yes. Okay. But, sorry, I interrupted you.

MS RUNDLE: No. That's okay.

MR KNOWLES: So that's the arrangement, though, that you say existed previously in terms of the policy settings - - -

MS RUNDLE: Yes.

MR KNOWLES: - - - for designation of respective responsibility for funding.

MS RUNDLE: Yes. I should add that – and the Act does refer to this – that what the Act says is that where – in deciding which are reasonable and necessary supports to fund, we have to take into consideration supports that are funded by – are more rightly funded and more correctly funded by other parties. And so your question about whether it was reasonable and necessary to fund them previously, it was hard to answer, because they were already – it was already answered because of the fact that they were being provided for by another party, by States and Territories, if you understand me.

MR KNOWLES: Well, were they, in the sense that were they being provided for previously or was there a gap in the system by reason of a disagreement that might have existed between the Commonwealth and the States in the past?

MS RUNDLE: Well, I – I think in the main I would say that they were. And the reason I feel more confident about saying that is because when a plan is developed with a participant, a range of things are taken into consideration, their goals, aspirations, but also a range of things in relation to their current living circumstances and their other supports.

And so when you're sitting down with a participant and you say, "What else – tell me what else – what other supports you get", when a participant says, "I have a nurse visiting me every day to do X" or, "I go and have this particular specialised treatment every week", those things are taken account – those things noted. Formal and informal supports are noted in participants' plans. And to that extent they become part of the plan; it's just that they are not funded by the National Disability Insurance Scheme, because it's recognise that they are funded by someone else.

I'm sure if ever there were the event that when you sit down and do a plan with a participant and they say "I had health supports, but they've stopped and I need them", that would be a point at which that would escalate through and – to the agency or to another party, which is how we became aware of the issue in the beginning.

COMMISSIONER BRIGGS: Might I ask the question - - -

MR KNOWLES: Yes.

COMMISSIONER BRIGGS: I appreciate what you're saying, but if that were the case, then why was the need for the policy change? There must have surely been a problem that had been identified. And that suggests that maybe some of these health supports weren't as forthcoming as they should have been, Ms Rundle.

MS RUNDLE: It's a good question, Commissioner. And I think the – definitely the reason that we decided to develop something that worked better is because there were issues being escalated to us, so we were aware – we were aware of issues where people weren't getting the supports that they needed or we didn't have the clarity we needed around who would fund them. And we, in fact, developed an escalation process, not just for health supports, but for a range of areas where there were grey – it was grey and people needed assistance to cut through to work out what – how we could get the person the support they needed.

COMMISSIONER BRIGGS: So it was a bit hit and miss, basically. Mr Knowles.

MR KNOWLES: Thank you, Commissioner. If you are a younger people in residential aged care, is there a difference to what you might be eligible for under the

NDIS for nursing supports than what you would be eligible for in the broader community if you were living out of residential aged care?

MS RUNDLE: I don't – I can't see – I'm not exactly sure where – what your question is sort of asking me, but I – I – can I just clarify. Are you asking me, "If a person in a residential care setting needed health supports, would they – would they have the same ability to receive them as if they were in the community?"

MR KNOWLES: Yes.

MS RUNDLE: Yes.

MR KNOWLES: That's what I'm asking.

MS RUNDLE: I would imagine the answer to that is yes.

MR KNOWLES: Under the NDIS.

MS RUNDLE: Under the NDIS. So would the NDIS fund those health supports - - -

MR KNOWLES: Yes - - -

MS RUNDLE: - - - in the - - -

MR KNOWLES: So if they were not receiving the same health supports as they might be able to get in the community because they were in a residential aged care facility where there was only one nurse who was unable to provide them with the extent of care and treatment that they might otherwise get if they were living outside of residential aged care, is that where the NDIS would provide funding for additional nursing services for the person?

MS RUNDLE: This is – this is a little more complicated, because of the agreement with health and aged care about what aged care will reasonably provide for a person in residential aged care who has a disability. And so it is hard to answer your question, because none of those issues have been brought to my attention. None of those – I'm not aware of that having been raised. I'm not saying it hasn't been.

It's unlikely that I would know every detail of every participant, so I can't confidently say that hasn't happened, but what I think – when we do a participant's plan in a residential aged care setting, if we become aware of anything that they would require and need, we would either satisfy ourselves that they are receiving that through the arrangements with the aged care provider or, if we weren't satisfied, we would then look to see whether we should be funding and providing that separately.

MR KNOWLES: Okay. Now, you've said in your statement – sorry – pardon me – in the first response to a notice from the Commission – and this is document at tab 146 of the general tender bundle, at paragraph 113 – that:

> *The annual costs of funding disability health-related supports is presently unknown.*

But there's an estimate, as I understand it, from the scheme actuary of approximately $90 million a year.

MS RUNDLE: That's correct.

MR KNOWLES: Now, when was that estimate arrived at?

MS RUNDLE: That was arrived at last year. I couldn't tell you exactly the date, but toward the end of last year – early this year - - -

MR KNOWLES: Yes.

MS RUNDLE: - - - when we were preparing for the work we were doing for Disability Reform Council.

MR KNOWLES: And you've said that that would be funding for approximately 60,000 participants who would be eligible for this type of funding and support?

MS RUNDLE: Yes. And the – would you like me to describe how we came to that figure?

MR KNOWLES: Yes, if you could.

MS RUNDLE: The – as I described before, we had – we looked at particular groups of individuals. And in the majority these are people with acquired brain injury, spinal injury, deteriorating neurological injuries, cerebral palsy, for example. They're the largest groups. And we looked at the supports that they needed. And we, therefore, estimated with a number of people in the scheme with those particular disabilities and then the – the average cost of those supports. And we looked at a range of resources to look at the average cost of those supports. So average cost of nurses, average cost of highly paid – highly skilled support worker to do a particular functions.

So we looked at all of those things and we came up with – with a figure. I mean, it was much more act actuarially sound than what I'm describing, but we, essentially, did that for that group. Now, in saying that, that is not to say that if a person with a disability needs a health support that is related to their disability, then they would receive that. So this is not a cap.

MR KNOWLES: Yes. I understand.

MS RUNDLE: It was an estimate to try to answer the question.

MR KNOWLES: But is it fair to say that in arriving at that figure there were amounts that were not taken into account because they're otherwise funded through – by health through residential aged care?

MS RUNDLE: To my knowledge, that wasn't the case, because we looked at it differently. We didn't look at their setting. We looked at the disability cohort or group no matter where they resided. So those participants in doing – in had undertaking that costing, those participants that I've just described with those characteristics earlier, are – would have been included even had they been residing in a residential aged care setting.

MR KNOWLES: And was – in arriving at the figure of $90 million, was any amount deducted for funding that they were already receiving via aged care funding instrument funding, ACFI funding?

MS RUNDLE: Now, look, I would need to check that; in fact, I would even need to check my earlier reference, but I'm pretty sure that in both cases I am correct in saying that we didn't – we – we were looking at the provision of supports for people no matter where they resided, rather than their place, their setting. And irrespective of whether or not they were in an aged care setting and it was provided through the aged care provider, but I will – I will need to come back and confirm.

MR KNOWLES: Yes, if you could, because if that amount was taken into account that's already paid for through the ACFI funding, it's difficult to see how – I think on average it works out to $1500 per week in disability related health supports.

MS RUNDLE: It's hard to average it out because the groups are different.

MR KNOWLES: Yes.

MS RUNDLE: And they have – so the distributions – the distribution is quite significant.

MR KNOWLES: Now, can I turn to the question of eligibility for home modifications or supported – sorry, specialist disability accommodation, and supported independent living. What are the determinants for eligibility in respect of each of those particular matters?

MS RUNDLE: And again, counsel, I'm unlikely to give you a – a perfectly textbook defined definition because I'm, you know, I'm not intimately close to, you know, planning with the participants but the – in my role, but the – firstly, home modifications are available to any participant for whom – for whom – where their disability requires some adaptation to their home and their living – everyday living circumstances. And so I mean, obviously, they need to be a participant in the scheme and once, you know, once you've determined that – that they've got a

particular functional impairment, so disability – access to the disability scheme is based on functional impairment and a number of other things.

And access to getting home modifications is also based on the level of function, and the sort of things that they might need to be able to help them function more fully. Equally with SDA, with specialist disability accommodation, specialist disability accommodation is available to a smaller number of people and the Productivity Commission envisaged that there would be around six per cent or 28,000 people at full scheme who required specialist disability accommodation, and that – that is available for people who have significant disability such that – and where an SDA property, where an SDA solution will meet that need or part of that need.

MR KNOWLES: Yes. Is it right to say that the relevant NDIS SDA rules require that a person has extreme functional impairment or very high support needs?

MS RUNDLE: That's correct.

MR KNOWLES: So if you don't fit into one of those categories, you're not eligible for SDA.

MS RUNDLE: That's right. Because there are other – there are many other innovative solutions other than SDA.

MR KNOWLES: Well, if you're a younger person in residential aged care that doesn't have extreme functional impairment or very high support needs then you wouldn't be eligible?

MS RUNDLE: Yes, that's correct in the application of the SDA rules as you've just read them out. The – I would – I would add, though, that for most people in residential aged care with a disability who have access to the scheme, many of those people, in fact the majority, would have access to SDA.

MR KNOWLES: Even accepting that, why isn't it the position that all – given the desirability of younger people not being in residential aged care, why isn't it the case that all younger people in residential aged care automatically qualify for SDA?

MS RUNDLE: Well, currently, setting aside the – setting aside our wish and our intent to make sure that people have SDA in their plans when they need them, setting that aside, the rules – the SDA rules require us to apply the rules - - -

MR KNOWLES: Yes.

MS RUNDLE: - - - and therefore apply a test of functional impairment.

MR KNOWLES: I understand that. What I'm saying though, Ms Rundle, is in terms of the policy setting that those rules reflect, do you think that it's appropriate in

that – wouldn't it be more appropriate that all younger people in residential aged care automatically qualify for SDA?

MS RUNDLE: What I would – I would – as I said before, counsel, I think that that is from the main the case. And I understand what you're – you are saying, but the Act requires us to make – to make some assessment of someone's functional impairment. And as I explained, most people meet that impairment test because - - -

MR KNOWLES: Yes, I accept that. I guess I'm asking you for a question about whether or not you think that the rules, as presently cast, reflect an appropriate policy setting in connection with the desirability of younger people in residential aged care having, as little impediment as possible to leave that place if they so desire? To achieve that end, wouldn't the policy setting be better served by automatically qualifying younger people in residential aged care for SDA?

MS RUNDLE: It's a really good policy question. I'm sorry, I didn't realise that's what you were asking.

MR KNOWLES: Pardon me.

MS RUNDLE: And that's a really good question and it is one for us to consider alongside of governance because the policy setting for SDA was developed by a range of parties including the Disability Reform Council, DSS, State and Territory governments.

MR KNOWLES: That approach would be consistent with residential aged care being a last resort for younger people, wouldn't it?

MS RUNDLE: Yes, it would. Providing accommodation is available, of course.

MR KNOWLES: I mean, do you personally see that as a – an improvement on the present arrangements in terms of a small, perhaps, minority of younger people in residential aged care who might not presently meet those requirements for SDA?

MS RUNDLE: I guess I hadn't thought about it like that before, and if you're asking me for my opinion I would say that that would – you know – you know, it would be a policy setting that would improve, possibly for that small group, but I – I am also not aware of any resident with disability in an aged care setting so far that hasn't qualified for SDA. That isn't to say they haven't, but I'm not aware and I'd be – you know, I think that in the main it is almost by default the fact in practice. It's just that I realise you're not asking that; you're asking about the rules themselves.

MR KNOWLES: Yes. In terms of the various accommodation options, is the preferred position of the NDIA, as a matter of general policy, that wherever possible, if a person has their own home, one seeks to have home modifications such that they can move there?

MS RUNDLE: Yes.

MR KNOWLES: Yes.

MS RUNDLE: If they wish, if that's their choice.

MR KNOWLES: Yes, and what options are there, if a person is still awaiting completion of modifications for accommodation?

MS RUNDLE: When you say "arrangements", are you asking about people currently residing in residential aged care?

MR KNOWLES: I'm more asking about people who may be at risk of entering into residential aged care. What options are available to them to avoid that outcome, even on a respite basis, if they are awaiting home modifications?

MS RUNDLE: Yes. We do – we do have the availability of short-term accommodation for people who might be – might be needing to go into short-term accommodation while they're awaiting home modifications. I would add, though, that one of the difficulties we've got is that the reason – home – if the home modifications and particularly if someone is waiting for an SDA property, if they're significant, it's also very difficult to find a short-term accommodation placement that offers that same amenity, if you understand what I mean.

So this is why we have the – this is why we currently have so many people, unfortunately, residing in residential aged care settings, but also in hospitals, sometimes awaiting discharge, because we are aware it's not possible to accommodate them in short-term accommodation or find them a temporary solution in a house that meets their needs. If it's something that requires significant modification, we still have the same issue of supply.

MR KNOWLES: It really depends on the nature of the disability the person has, doesn't it?

MS RUNDLE: Yes, it does.

MR KNOWLES: Now, in terms of SDA, can you tell the Royal Commission how many people who are young people in residential aged care who have SDA in their plan currently?

MS RUNDLE: There are a small number of people who have SDA currently in their plans, but we're not entirely confident of the reporting on this yet. So at the moment the most recent data we have is that there are 66 people with SDA in their plan.

MR KNOWLES: Out of how many younger people in residential aged care?

MS RUNDLE: Out of – there are 4700 and I think it's 21 people at the moment with an approved plan and the – the reason for this is because until the rules were changed earlier this year in February/March, the SDA rule, it wasn't possible to put SDA into a person's plan if they hadn't already identified a dwelling. Once the rules were changed earlier this year, it's now possible to put SDA into a person's plan before they've identified an appropriate dwelling and they don't have to exhaust all other options, if they've chosen a dwelling and they know it to be available, and even if they haven't we can assess them for SDA and put that into their plan. The – so the reporting on that is very immature, if I might say that.

MR KNOWLES: But that 66 out of 4721 people who have SDA in their plan, you've said in – pardon me – but in the response that's been provided by the NDIA it's identified that SDA is really a major part of the solution to the problem of younger people in residential aged care?

MS RUNDLE: It is. It is.

MR KNOWLES: So why are there so few people who are in residential aged care who have SDA as part of their plan?

MS RUNDLE: So I think if I could just describe something for you, a little more context if that's possible, counsel. The – the – before the rules were changed in February/March, the – it was possible to put different things into a participant's plan to help them look for accommodation. So it wasn't that we weren't looking for SDA properties before then because we were. We had a previous SDA rule. It just didn't allow us to put the SDA support in the person's plan until it identified a property. That was what changed in February. Prior to that, however, we used to add into people's plans, both in residential aged care settings and elsewhere. We had different names for this, but a common name was a housing options package where we would pay for assessments for that person's functional capability, so we understood what supports they might need in an accommodation setting and also we'd pay for support coordination and other supports to try and match them up to accommodation.

So those things aren't captured in the data. All of that earlier effort and the fact that we were helping people weren't captured in the data. The – what we have done now is we've changed the rule so that it's a lot easier to capture in the data since, you know, February/March and it was, you know, after that time that we started doing the plans to be able to put those in. And I think we've said in our plan, in our agency action plan that we will have SDA in people's plans by July 2020, and what we'll do is for any new people coming in and hopefully we – you know, we can reduce the number of people coming into residential aged care settings, that's one of our goals, they would have an SDA assessment in their plan. At all plan reviews, they would also have an assessment of SDA.

Anyone who wishes to have an earlier plan review or if there's a change of circumstance for that person, they can also have their plan re-assessed for SDA,

simply because we would very much like to be able to do this much faster but this has to be seen – it's – it's incredibly important but the rollout of the scheme and all of the other functions of the agency also have to be met.

MR KNOWLES: Can I just ask you, in relation to this particular question of SDA though, I think you referred earlier to the Productivity Commission highlighting a need at full scheme for 28,000 places for accommodation for SDA?

MS RUNDLE: Yes.

MR KNOWLES: Yes.

MS RUNDLE: I did.

MR KNOWLES: And that report was from 2011.

MS RUNDLE: 2011, yes.

MR KNOWLES: So for eight years there has been an awareness on the part of the Australian Government that there was going to be a need for 28,000 places by full scheme, that is, now and that at full scheme the Productivity Commission estimated that even then there would be a shortfall of some 13,000-odd places. Do you agree with that, roughly?

MS RUNDLE: Yes.

MR KNOWLES: Yes. So why hasn't there been a better preparedness now for that shortfall that was predicted back in 2011?

MS RUNDLE: Well, firstly, I think you're asking me to comment on matters unrelated to the scheme. And I'm happy to – very happy to - - -

MR KNOWLES: I am.

MS RUNDLE: - - - to give you my - - -

MR KNOWLES: I'm keen to hear from you in that regard.

MS RUNDLE: And I heard yesterday the evidence given by others that – that – you know, the previous attempts, whilst there were some small gains, they – they were unsuccessful in meeting the aspiration of all of those initiatives. They didn't work to get people out of residential aged care in the way that they were intended to. The difference, if I might say so now, is – is not just the presence of the NDIS. And the timing of that, of course, was much later than the date that you're referring to. The – and the timing of the SDA rules is also much later. They didn't come into play until 2017 in the National Disability Insurance Scheme. But the thing - - -

MR KNOWLES: That's part of what I'm asking, Ms Rundle, is, given that fact that in 2011 this issue was identified for the scheme that there would be a shortfall – I think it's 12,300 participants in the scheme at full scheme would be caught short in relation to this type of accommodation. That has been known since 2011. Why wasn't there more done earlier to prevent that shortfall being realised?

MS RUNDLE: I can't comment on – I simply cannot comment on areas that I had no involvement in or responsibility before, except to the except that I heard evidence yesterday.

MR KNOWLES: Yes.

MS RUNDLE: And I would agree that – that they didn't – they were not successful. They failed. So to – so if I might just say that the scheme commenced in 2013 – July of 2013 in trial for a very small number.

MR KNOWLES: Yes.

MS RUNDLE: And it commenced properly in transition in July of 2016. So the – the – if you're ask – are you asking me why – I don't understand if you're asking me what the scheme – what the NDIS should have done earlier that it didn't do.

MR KNOWLES: Why weren't SDA rules not in existence from the outset? Why were they cast in terms that you've referred to earlier that, firstly, made it more difficult for people to include SDA in their plans, and, secondly, prevented the agency from obtaining clear data about who actually needed SDA? They're the sorts of questions I'm asking you.

MS RUNDLE: Yes. I understand. And it's a good observation, a really good observation.

MR KNOWLES: Would you agree that that is – that the SDA rules were introduced just too late, given the knowledge that had been provided by the Productivity Commission?

MS RUNDLE: Yes. I agree that it would have been much better for the rules to have been agreed earlier. I do.

MR KNOWLES: And do you agree that the rules should have included what they now do as a matter of common sense, that you don't need to identify a particular place before you can have SDA in your plan?

MS RUNDLE: I agree in hindsight that would have been – that would have been a very obvious things to – to include in the original rules. If I might just provide a comment on – on the development of the rules. The – the rules – everything in this scheme has had to be developed collaboratively and jointly with a range of parties. DSS is actually the policy lead for all of these things, so the development of the rules

is the responsibility of the policy lead for the policy department for the Commonwealth, but in consultation and jointly with states and territories.

And the only comment I would make is that it's – it's like a range of things in building the National Disability Insurance Scheme. There were two things happening at once. One was we were rolling out the scheme to participants to bring them in. And the other thing is that we were building it as we were going. And there were a range of things, including the policy agencies and states and territories that everybody was building as they went. Now, was it early enough? No. But it is a – it is a – it is a reality and a consequence of such a large reform that nothing is going to be built from the beginning and designed perfectly from the outset. And we've learnt a lot from experience.

MR KNOWLES: Yes. But where one knows that there is a projected shortfall, which is, would you agree, sizeable?

MS RUNDLE: Yes.

MR KNOWLES: 12,300.

MS RUNDLE: Yes. I do.

MR KNOWLES: Where one know that is in advance of the scheme coming into existence, why would one then insist in the face of that projected shortfall that a person identify a particular place before SDA can be included in the plan?

MS RUNDLE: I mean, I can only but agree that having – having SDA rules set up earlier would have been far and away more preferable. I can't – unfortunately, I can't – I can't explain why that isn't the case, because I wasn't involved in – in that particular aspect and I just don't have – I can't explain and give more context. And perhaps if Mr Lye had been asked that question, he may well have been able to give you a good answer about starting much earlier. I can't even describe the trajectory of the development from the beginning, but I would agree overall that it would have been better.

MR KNOWLES: Yes. Would you agree that the ability for a person to have SDA in their plan and therefore go out to market to seek SDA, that's a matter that will stimulate the market?

MS RUNDLE: That's correct.

MR KNOWLES: And so until two thousand and – was it 17 you said in terms of - - -

MS RUNDLE: 2017 were the first rules.

MR KNOWLES: The first rules. Until then, there wasn't even a rule that you could get SDA and not until earlier this year could you stimulate the market by saying, "I want SDA."

MS RUNDLE: That's – I mean, that is correct.

MR KNOWLES: Would you agree with that characterisation?

MS RUNDLE: Yes. Yes, I do. Yes.

MR KNOWLES: It points to, in the face of an anticipated shortfall, a decided lack of inaction, doesn't it, on the part of the Australian Government?

MS RUNDLE: Well, I would say two things to that. One is there was no inaction; it just took a while. There was earlier action. So I think I've described that, in fact, the SDA was intended to be available for participants in transition from July of 2016. In the absence of the rule being developed, the then CEO issued a directive, a CEO directive, to try to enable planners to be able to put SDA into a participant's plan – or the SDA supports into a participant's plan for existing participants.

So there was an earlier directive to try to start the initiative when it was first due to commence in July of 2016. However, it was constrained in a number of ways, because it wasn't supported by a rule. The rule was introduced and finally passed. It took a while to get the rules agreed, because all states and territories, I understand, this is one of the categories of rules in the Act and in the legislation that requires all – that required at that point all states and territories to agree with the Commonwealth. And it was finally agreed in – we got a final agreement from states and territories in March, I think it was, of 2017.

At that point, then the CEO directive was revoked and then the rules came into play. It's fair to say that there's – that the experience of the scheme, a lot of this scheme, because it has never been done before in the world, is – a lot of it is experiential. There are things you learn along the way that you realise you could have done better. And definitely with SDA one of the things we learnt about SDA – it might have been plainly evident now to all of us that we should have agreed – should have put some things in the SDA rules earlier, but it wasn't evident at the time.

And what we learnt from providers is that more signalling to the market would give greater investor confidence. And it was the work that way did with the SDA market that allowed us – that made us think about what more could we do. Hence the changes in the rules this year to be able to – to be able to be more explicit about SDA and people's plans so we could start signalling more to the market.

MR KNOWLES: It's just unclear to me, with respect, Ms Rundle, why that didn't happen much, much earlier.

MS RUNDLE: And I'm really sorry, Counsel, but I can't – I can't answer that.

MR KNOWLES: Do you agree that as a matter of common sense - - -

MS RUNDLE: I agree.

MR KNOWLES: - - - these things just point out obviously in the face of the projected shortfall from 2011 as ways to mitigate or alleviate that?

MS RUNDLE: I agree that in hindsight, when you look back, there are a number of things that could have been done better. Yes.

MR KNOWLES: Can I ask you just briefly, in relation to the Younger People in Residential Aged Care Action Plan, you're familiar with the action plan, of course?

MS RUNDLE: I am.

MR KNOWLES: Yes. And do you agree that the focus of the action plan, really, is action taken involving the NDIA and the NDIS? That's the focus of the plan, isn't it; the solution presented in the action plan will be one delivered by the NDIA?

MS RUNDLE: A lot of it will be. There are some aspects of the plan that are delivered by Department of Social Services, as well.

MR KNOWLES: Okay. But do you agree that, in terms of that cohort of the younger people in residential aged care that I mentioned earlier who might not have a disability and might not qualify for an NDIS plan, they're largely not contemplated at all in the action plan as it's presently termed, are they?

MS RUNDLE: For people who are not eligible, did you say?

MR KNOWLES: Yes. They're not contemplated in the action plan at all, are they?

MS RUNDLE: No, because the action plan is primarily related to people who have access already to the National Disability Insurance Scheme or who may gain access - - -

MR KNOWLES: Yes.

MS RUNDLE: - - - to either prevent them from coming into residential aged care or to move them out of residential aged care.

MR KNOWLES: So – and that's reflected, isn't it, in the sense that for the purposes of the action plan it refers to people who are not eligible or likely to be eligible as being out of scope?

MS RUNDLE: That's correct.

MR KNOWLES: So those people are not going to be helped by the action plan. Do you agree?

MS RUNDLE: The action plan, as I said, is about helping those who are eligible or who could become eligible - - -

MR KNOWLES: Yes.

MS RUNDLE: - - - because that is the intent of the action plan. There are a range of other supports that the Commonwealth more broadly and states and territories are responsible for, for people who don't come into the scheme and who don't get access to the scheme. And that's – that's – that has been agreed through continuity of support provisions or there are other mechanisms that have been agreed for those people.

MR KNOWLES: Do you agree with me that, insofar as the action plan is presented as some overall solution to the problem of younger people in residential aged care, it isn't complete? It doesn't deal with everybody - - -

MS RUNDLE: No. I don't agree with that.

MR KNOWLES: - - - who falls within that category, does it?

MS RUNDLE: No. I actually don't agree, because the purpose of the action plan is to – is actually to look at the group. It was primarily to focuses in – particularly to focus in on the group of people that we have in the scheme that are in residential aged care settings and those who may – may – are at risk of going into residential aged care settings. And so I – I think that is the purpose of the action plan. If you're asking me is the – should there have been a – additional actions, I think that is a – that is a different question - - -

MR KNOWLES: Well, I am asking you that - - -

MS RUNDLE: - - - but not one for the action plan.

MR KNOWLES: - - - in the sense that the action plan doesn't set out details of dealing with people who would not be eligible as to be participants in the NDIS.

MS RUNDLE: With respect, the – that is correct. And I would say, with respect, Counsel, the – I can't – that's true. And I – my answer is the same as it was earlier.

MR KNOWLES: That's all I'm asking.

MS RUNDLE: Yes. Yes.

MR KNOWLES: So you would agree that those people, say, for instance, who have younger people in residential aged care who have cancer, but don't have a disability

that would provide for them to be eligible to be a participant in the NDIS, they're not covered by the action plan.

MS RUNDLE: No, they aren't.

MR KNOWLES: Thank you. And that's – I think it was said in the minutes earlier – a substantial unmet need? That's - - -

MS RUNDLE: According to the AIHW figures.

MR KNOWLES: And that's not dealt with by this action plan.

MS RUNDLE: No, because they're not participants of the scheme.

COMMISSIONER BRIGGS: Are you aware, Ms Rundle, about whether or not the states are actually working to address this issue of young people with terminal illnesses in aged care?

MS RUNDLE: The – I know that the – in the – in this construction of the scheme itself, the broader construction, there are a range of areas in the bilateral agreement where States and Territories have responsibilities. It isn't – I think it isn't specific enough about this particular group. It gives me cause to think it could be. And we could be more specific about what the role is, particularly in relation to palliative care and that group that we are talking about. So I think we – I think it – I think we can do better.

COMMISSIONER BRIGGS: Yes, so it's likely you'll take it up shortly after this hearing, no doubt.

MS RUNDLE: I think so.

MR KNOWLES: Just in terms of the SDA shortfall, Ms Rundle, what – we've preferred to the Productivity Commission's report estimating that at full scheme, that is now, there will be a shortfall of 12,300 participants. What's the NDIAs present estimate of the shortfall?

MS RUNDLE: In our – in our written evidence, we – we did talk about the fact that we don't have good yet – we don't have actuarial – any further actuarial modelling, other than the Productivity Commission earlier modelling, and we are currently – we are currently working through this to work out what our methodology would be to be able to – in watching supply, understand whether that trajectory and that trend is going to meet the sort of targets that we need over the – over the course of ,particularly, in the case of the action plan the next – until 2025. So I'll give you an example of that. We – firstly, I should say the scheme, we did give some evidence in our – in our evidence, that the only actuarial data we've got that the scheme actually is able to provide for us at the moment that relates to SDA that isn't the same is SIL, and you mentioned supported independent living earlier.

The – at the moment in the scheme, our annual report at the end of June said we had 31,000 – sorry, 21,000 people in the scheme that were receiving SIL supports but we only 13,000 – have a bit over 13,000 people receiving SDA supports with SDA in their plan. The difference is because many people receive SIL supports in other settings other than in SDA settings. And so it's a fairly – whilst it's one way, we can – whilst it's one way of helping us to try to estimate the demand of participants, it's not the best – it's not the best source of demand.

MR KNOWLES: Well, for instance, you might seek supported independent living supports in connection with living at home?

MS RUNDLE: That's right, yes. Yes

MR KNOWLES: So you don't – if you're living at home you don't need SDA at all.

MS RUNDLE: No, that's right.

MR KNOWLES: It's not a reliability proxy at all, is it?

MS RUNDLE: No, it isn't. No, it isn't. And the best estimate we've got is the Productivity estimate at the time and that is still – and at the moment the scheme, if you look at the scheme at the moment, we've got 13,000 – just over 13,000 people in the scheme to date, end of June, with – with SDA supports in their plan when the – when the commission was expecting that there would be twenty – 28,000. And we've got four point – I think it's 4.4 per cent when it estimated there would be six per cent so we've got a way to go.

MR KNOWLES: So you might even – the figure of 28,000 might, on that basis that you've just described, actually be a bit conservative now. It might even be above that if you accept the six per cent estimate.

MS RUNDLE: Yes, it could be over or under and this is the thing about the scheme in had the experience of the scheme we're – we need to watch carefully and monitor the trends to be able to try to project the growth into the future.

MR KNOWLES: But that, as I understand it, has not occurred at the present time - - -

MS RUNDLE: No.

MR KNOWLES: - - - in relation to SDA on either the supply or demand sides?

MS RUNDLE: No, and - - -

MR KNOWLES: There are no projections into the future about projected supply or demand for SDA?

MS RUNDLE: That's correct. And – at the moment that's correct. However, this is work that we are – we are now getting close to be able to doing and the reason is because it's only been – we haven't fully rolled out the scheme and the scheme phased in differently in different parts of the country. So different people came into the scheme at different times. So we don't have the full scheme experience yet. So in terms of modelling, anything on what's gone by, it's not – it's not a reliable modelling approach because we – we know that there was very – there was very differential entry into the scheme. But we are getting closer - - -

MR KNOWLES: You do know also there's been – sorry, pardon me, Ms Rundle.

MS RUNDLE: My apologies. We do know that we are getting close to those, to being able to now say, well, once we have the majority of people in the scheme, in the full scheme, we can now say we've got a set of data that should be able to be reliably used to be able to start predicting trends.

MR KNOWLES: You do know, obviously, as we've already discussed that there's been a shortfall in SDA and it's a longstanding shortfall and it's been predicted for a long time. In the face of that, knowing that whatever would be done might – would not necessarily overshoot that shortfall, what targets were set in the past for amounts of SDA to be developed by the NDIA? What targets were set internally for the amount of SDA that needed to be in existence at particular times?

MS RUNDLE: I - - -

MR KNOWLES: Were there any targets?

MS RUNDLE: No.

MR KNOWLES: Well, why not?

MS RUNDLE: We need to set targets. This is work we're doing. The reason we have not done that is because we – it's – we've had little experience until very recently, particularly in SDA. So if you look at the quarterly report data at the end of June and you look at the last year and you look at each quarter successively you'll see there's been a significant percentage increase, though off the base of small numbers in SDA.

MR KNOWLES: Yes.

MS RUNDLE: I think it was three thousand one hundred and something at the end of June for our total properties in older dwellings. The – when you look at those though, if you – that – if you used a figure like that, it wouldn't be a reliable way to approach it because many of those are legacy properties that have come into the scheme and these are properties that we – they are larger properties, you know, larger group homes. They – and some of them are smaller congregate settings, smaller institutional settings, disability, residential settings, not residential aged care, and so

we – we, you know, we're trying to move people out of those, and so we're not counting – it's not reliable to look at those, but it is more reliable to look at the new builds and the refurbished news which are the – which are a much more accurate predictor of the – of the newer supply that's coming into the market.

And when you look at those, even quarter on quarter in the last year, there were in most cases in – in every single – in the last three quarters there was more than 100 per cent increase in all of those new builds and refurbishments and in the last quarter I think it was over 200 per cent. What we're seeing is a lot more confidence in the market, and what – what we can now do is we can now – we can now start thinking about what are the sort of – what do we think supply will look like and what more do we need to do? And in terms of setting targets we now have enough scheme experience, or shortly, to be able to set targets for the broader SDA cohort – that's everyone, the 13,000 and growing. For residential aged care we now need to take that information and use it to think about what are the – the dwelling targets, how does that inform the dwelling targets for people in residential aged care. So it's work that we haven't done.

MR KNOWLES: Yes, in some ways you got a target through the action plan goals, haven't you?

MS RUNDLE: We do. We do.

MR KNOWLES: I mean, although it's cast in terms of supporting people to leave residential aged care if they wish to do so, which, would you agree, is somewhat vague language?

MS RUNDLE: Yes.

MR KNOWLES: Would you agree with that, by the way, that those goals - - -

MS RUNDLE: Well, I think - - -

MR KNOWLES: - - - insofar as they're expressed as supporting people is somewhat vague.

MS RUNDLE: Yes, I shouldn't have said yes, because in a way that's too flippant an answer. It was deliberately designed because of the choice and control aspect and the respect that we need to observe with participants, because we heard yesterday some people don't want to move out of that residential aged care.

MR KNOWLES: Of course. But you understand that the goal is couched in terms of supporting a person to leave residential aged care if that is their goal to do so.

MS RUNDLE: Yes.

MR KNOWLES: In that context the word "supporting" does seem to be somewhat vague and lacking in concrete terms, doesn't it, where the goal actually refers to people, only those people who have the goal of leaving?

MS RUNDLE: Well, I mean, I suppose one could debate that the words could have been a lot – you know, could have been said differently. But I need to just be really clear that it's our intent that everybody living in a residential aged care setting would be encouraged to think about other options. Understanding that some may well choose to stay, but in the planning process, that is one of our – one of our fundamental questions which is where do you live now and where do you want to live, are you happy with where you live.

MR KNOWLES: And for all those people that are in residential aged care presently who do express a desire, a well-informed and clear desire, even knowing that there may not be viable options immediately to leave residential aged care, the target is that they'll all be out by 2025; is that right?

MS RUNDLE: Yes, we've said that everybody under 65 by 2025 will, if they choose to leave, will be able to leave a residential aged care setting.

MR KNOWLES: So knowing that target, what sort of projections and targets have you set along the road to that, because that will be a decided figure that you'll know, presumably, or have a fair estimate of that you're going to need, if history is any guide, 6000 places by then and on an ongoing basis one to 2000 places each year; do you agree?

MS RUNDLE: I do agree with that. And we've done – we have done some early thinking so whilst we haven't provided any modelling at the moment because we haven't completed it, and nor have we provided targets because then we'll be able to set the targets, we – if you think about these – as you've just said, if you think about the number of people over five years entering at about 2000 people per year, and halving that number as well as getting people out in residential aged care, and you look at the current float of people in the current number, in residential aged care, and you total those and you – you consider the – the growth of the new and refurbishments and the trend, we started – we believe that setting aside other legacy properties, we believe that we would be able to – the market is likely to reach that target in that time.

MR KNOWLES: Yes.

MS RUNDLE: We believe but I have to - - -

MR KNOWLES: You believe that without any projections, without any modelling and without any internal targets.

MS RUNDLE: Yes.

MR KNOWLES: That belief at the moment seems to be hopeful - - -

MS RUNDLE: Yes, but - - -

MR KNOWLES: - - - one might suggest, rather than one that you could confidently have; do you agree?

MS RUNDLE: Yes, I absolutely concede that we do not have, at the moment, targets and we haven't done – we haven't done any modelling that is publicly available to anyone and we haven't – indeed, it's very early work, because as I just described we just – we're in – we've just reached full scheme. In fact, we're still continuing to roll out in this year and so perhaps "belief" is a very strong word and I shouldn't have used it, but what I can say is that, yes, we know we need to do that work and we're doing that work.

MR KNOWLES: But at the present time, it's fair to say without that work, the projections, modelling and the targets, you couldn't have any confidence in actually achieving the action plan goals at the moment?

MS RUNDLE: Well, again, I'm trying to avoid using the word "belief", counsel, because obviously I can't say that so strongly. We are – if you look at the market and the trends in the market, we are reasonably confident that the market and particularly with some of the additional incentives we've provided recently, particular with pricing, we are confident that the market will grow, but it is true to say that I can't confidently say – sit here now and say that we will absolutely without doubt meet that goal.

MR KNOWLES: Yes. It may grow, but you couldn't have confidence one way or the other as to whether or not the relevant target that needs to be met in the action plan to ensure that all younger people who choose to do so are able to leave residential aged care or not live there by 2025 will be met?

MS RUNDLE: I can't confidently say that.

MR KNOWLES: And that's highlighted, isn't it, in terms of the NDIAs project plan which presents this as a high risk, doesn't it, that there won't be enough SDA by 2025 to meet the goals of the action plan? Perhaps I will go to that. Do you agree that, in terms of the project plan for the NDIA – and this is at tab 140 of the general tender bundle – that that sets out various matters, including the project milestones and the like. You will see that there on the screen, Ms Rundle. And this is the version – the latest version dated 20 August 2019. If one goes to page 0017, there is risks that are set out. And do you see the second risk is:

A lack of SDA stock for NDIS participants.

MS RUNDLE: Yes, I do.

MR KNOWLES: Yes. and it has got a likelihood of four. What's the likelihood score out of?

MS RUNDLE: Five.

MR KNOWLES: So four out of five. So there's 80 per cent chance that there are will be a lack of SDA stocks for NDIS participants?

MS RUNDLE: When – can I please provide some context?

MR KNOWLES: By all means.

MS RUNDLE: When – you would expect that we would identify all of the risks. And indeed you would expect that this would be a very high risk, for the reasons you've talked about earlier, which are that we – we've yet not done the modelling to – and to assure ourselves of the market – the growth in the market – and to assure ourselves, and also to set targets for that growth along the way. And so at the moment without mitigation, without that mitigation that I've just talked about, that is – that is high, with a likelihood of four at the moment.

MR KNOWLES: Yes, four out of five. And what's the consequence rating of D mean?

MS RUNDLE: Look, I would need to – I would actually need to check that, I'm really sorry.

MR KNOWLES: Yes.

MS RUNDLE: Consequence - - -

MR KNOWLES: Well, perhaps I might ask you to do that.

MS RUNDLE: Normally, consequence is high and – so it's just expressed - - -

MR KNOWLES: The overall rating is high, so I take it - - -

MS RUNDLE: Yes.

MR KNOWLES: - - - that the consequence is regarded as serious, obviously.

MS RUNDLE: Yes. Yes.

MR KNOWLES: Because it's an important contributing factor - - -

MS RUNDLE: Yes. Yes.

MR KNOWLES: - - - to solving the issue.

MS RUNDLE: Yes.

MR KNOWLES: But perhaps if you could clarify what D is and what it's out of - - -

MS RUNDLE: Yes.

MR KNOWLES: - - - in terms of a rating. That would be helpful.

MS RUNDLE: Yes. I know – I do understand it's significant; I just can't remember what the D stands for, but it is a significantly serious consequences.

MR KNOWLES: Yes. There's also a reference in the risk profile to:

Service delivery resources are not adequate to meet demand and targets.

And that's also got a likelihood rating at present of four out of five. Do you see that's R3?

MS RUNDLE: I do.

MR KNOWLES: Is this somehow related to the fact of anticipated shortfalls in workforce for the – to ensure that supports can be provided in connection with NDIS funding?

MS RUNDLE: When that plan was developed in August, it was the case that we had let little – we had less people doing the planning. We've now got considerably more. We've increased our planning – our complex planners, the numbers of our complex planners. And we also have – we had 20 – I think that's referring to the YPIRAC planners, the specialist planners for residential aged care. We've now got 39. We've just increased that number, with the ability to draw on our broader complex planners, should we need to. And if we need to increase that, we will.

MR KNOWLES: Yes. Just on a perhaps related workforce topic, you mentioned earlier – or we discussed earlier supported independent living supports, and that if a person is in specialist disability accommodation, that will often run in tandem with supported independent living supports. Do you agree?

MS RUNDLE: I did.

MR KNOWLES: So while there is a specialist disability accommodation provision, there's also the need for somebody to be there to assist the person sometimes in activities of daily living, other times in other ways.

MS RUNDLE: Yes.

MR KNOWLES: And you would be aware that in terms of anticipated workforce shortfalls, the NDIA made a submission to a joint parliamentary committee, I think in September last – around September last year, that anticipated workforce shortfalls were in the order of 70,000 people. Are you aware of that?

MS RUNDLE: I think you're referring to the – the general disability workforce.

MR KNOWLES: Yes.

MS RUNDLE: And not the NDIA workforce.

MR KNOWLES: Yes, I am. I am.

MS RUNDLE: Okay. This was a – possibly – it may – yes. It may have – was it our submission or was it a DSS submission?

MR KNOWLES: It's an NDIA submission.

MS RUNDLE: It's an NDIA submission. Right.

MR KNOWLES: But do you agree that that's something that you are aware of and perhaps even concerned about in relation to the disability workforce shortfalls that are anticipated at the time of full scheme implementation, being now?

MS RUNDLE: Yes. The workforce shortages have been acknowledged for some time. And quite a lot of work has actually gone on over time. And Department of Social Services is the policy lead for this. And – and they would be better placed to also provide more detail. But, broadly, I could say that there'd been a range of initiatives that the government have worked on to try to build the disability workforce more broadly, so not the NDIA workforce, but the disability workforce.

MR KNOWLES: I understand.

MS RUNDLE: And - - -

MR KNOWLES: These are the providers of the services - - -

MS RUNDLE: Correct.

MR KNOWLES: - - - that go to the supports that are funded by NDIA.

MS RUNDLE: Yes. Yes.

MR KNOWLES: But do you agree that that anticipated shortfall will have a bearing on whether or not people are even able to leave residential aged care and live in supported disability accommodation in future?

MS RUNDLE: Yes. The workforce is also another important consideration.

MR KNOWLES: Yes. And are there projections of the shortfall in that disability workforce going forward over the life of the Younger People in Residential Aged Care Action Plan?

MS RUNDLE: The – I'm trying to recall the recent projections. I think 70 might be the most recent – 70,000 may well be the most recent projection that anyone has done. And that will have been taken from the work, I think, of Alpha Beta, who did some work for DSS. The – and so I acknowledge that that supply – workforce and supply – workforce supply is very, you know, key, alongside of dwelling construction for this particular group. So it's both a general issue for NDIS and it's also an issue, therefore, for this particular group.

MR KNOWLES: So where does one see anything in the action plan that goes to those issues of the availability of workforce in support of independent living to accompany specialist disability accommodation for the purposes of ensuring that people are able to leave residential aged care if they wish to do so?

MS RUNDLE: The – again, I think the action plan is very focused particularly on, as you noted earlier, the goals in the action plan and the – and the – and the NDIA, particularly the NDIA efforts in that. But there – the action plan needs to be seen within the context of many other broader activities that are happening. So it isn't in the action plan. I concede that. But it – but there are a range of other things which are going on that support the action plan that are concurrent activities. And this one is one that particularly is run by DSS. So there's a range of initiatives happening which will support workforce development. I acknowledge it's not in the plan itself, but it's – I shouldn't say this. It implies I take it lightly, but it's almost a given that all of the other work that is going on supports the action plan. It's nested within that broader environment.

MR KNOWLES: But are there projections as to how that shortfall might affect the ability of younger people in residential aged care to leave, if they choose to do so, and live in supported disability – specialist disability accommodation?

MS RUNDLE: I can't answer that, because I haven't been involved. If anything – if anything has been undertaken by DSS. But I know that that's not a function that we have undertaken.

MR KNOWLES: In relation to the availability of SDA, the approach that's been taken is one that is market-based, that is, that, essentially, supply will meet demand. Now, you've, obviously, accepted that there's been a longstanding shortfall and it's continuing.

MS RUNDLE: Yes.

MR KNOWLES: Do you agree on that basis that as things stand there is market failure in relation to the provision of SDA?

MS RUNDLE: The – if you look at the – if – it depends what the test – how you answer that. The – which lens you look through. If you ask me, by the fact that there are not sufficient properties to – for people to live in alternatively, then the market is – is failing at the moment. If you ask me is there market failure more broadly in terms of where the scheme is at and what you'd expect to see with market development in a scheme like this, the scheme – the market is actually responding to all of the initiatives and is growing. The market is growing considerably, not just the existing providers coming into the market, but new markets – new and innovative markets.

And so, for example, at the beginning of – in July of 2016 the market – there were just over 5000 providers in the market and now there are over 21,000 providers in the market at the end of June. And when you look at the – when you look at registered providers of SDA, that's been one of the biggest growth areas in the last few quarters of the scheme. So the – there's – I think the market is responding. And – and it's very – it's looking very positive. But I acknowledge that there are not sufficient SDA properties right now.

MR KNOWLES: Yes. And, also, there are various kinds of SDA properties that are required and they are in particular locations they might be required where it might not be financially viable for an individual private developer to enter into provision of that service there. Do you agree that in those circumstances markets are thin in particular places and it's difficult to see how a market-based approach will succeed overall?

MS RUNDLE: I – firstly, I would – I would make a point that price is one of our biggest leaders in encouraging the market. And price – price is made up of a number of factors. And if you look at SDA alone and if you were to go – you may have done this – if you have a look at our website and price guide and indeed all of the framework, the SDA framework, you will sigh that there are a variety of options in terms of dwellings, and not just the dwelling, type like a unit or an apartment or a house, but also the type of construction, whether it's robust or whether it's accessible – various – various different configurations.

And, as well as that, we also allow for where properties are – are in rural remote areas. We also allow for expensive land prices in the middle of big cities. So we've adjusted – what we've done is our SDA prices take all of those things into account to provide the sort of incentive, so that in a rural area, for example, the prices have been constructed in such a way that they're – at the moment the market is telling us there is sufficient – there appears to be sufficient incentives. Now, we can – we've got the ability to use price as a lever further to pay more of a premium if we need to for a market-based solution in those areas. But I would also add that, and acknowledge that in rural areas, and remote areas where you have small numbers of participants

needing SDA, the market isn't always confident, that it – that it will – it will get a return.

Now, the actual SDA investment, the prices for SDA are one of the most significantly – providers will tell you that they receive quite a return on the prices for SDA properties. So it's – it's set very high with very high returns and we've done that – we've done that in response to quite a lot of feedback about where the previous SDA prices weren't set.

They needed to be tweaked and, indeed, we're currently now doing what we're calling a limited assumptions review of SDA where we are looking again at some feedback we've received from the market and where we think we need to increase the prices again. And so in some areas, so we are – you know, we use price as one lever but it is not the only lever and this goes to your question of, do I acknowledge that there are thin markets where the market won't exist; and I think the answer is yes, and I mean, I think we - - -

MR KNOWLES: So does that then follow, going back to my initial question, that there are difficulties in putting all one's eggs in a market-based approach?

MS RUNDLE: Well, I think we're not doing that. So there are a range of other things that we will need to do and have started – started doing and working locally at local levels with participants on. So yesterday we heard about the role of the support coordinator in a participant's plan and the – and some of the other initiatives we are putting in place to make sure that support coordinators, we have more specialised support coordinators in this particular market who can help people match participants up to local builders, local providers who might be interested in – in building for that group of participants or that participant.

Equally, there are – if you look at a remote indigenous community, we need a completely different solution for that community in many instances because many indigenous families will want to look after their own and we will need to find other ways of doing that. So this is where, again, home modifications and the ability to be more innovative with what we do with other dwellings comes into play and we're starting to see that innovation.

MR KNOWLES: Do you think this approach, though, is going to be one – you've talked about iterations of price levers - - -

MS RUNDLE: Yes.

MR KNOWLES: - - - and having to respond to market signals and then apply different approaches in terms of pricing, but do you think this is the quickest way to resolve the shortfall that's been known about since 2011 in respect of SDA?

MS RUNDLE: In – in – I think the – the – in some of those areas, what we do is we do look at the areas of supply, and where supply is low. So we understand – we're

starting to do – we're again, this gets to the maturity of the scheme and the growth of the scheme and the ability now for us to do this now because we have more data, but we are now starting to look at, if you like, a map, a heat map of where we believe we've got areas where there are market risks, and indeed they're – they're not just in rural areas. They're in some urban areas as well. And we are – we're starting to – to look at well, what other market interventions may we need besides price to be able to incentivise, not just the market but to be able to find solutions for – for people.

I would add that for this group of participants, for YPIRAC – excuse me I'll just have a glass of water – we are – we are – I think we've been giving this quite a bit of thought lately. I think in those rural areas where we know the location – when we know the location of participants and if they are – they are very small in number that that areas, we really will have to look at individual bespoke solutions for those YPIRAC participants and that I actually think that is going to be one of our main solutions, and not market. So I'll give you one example; the other day - - -

MR KNOWLES: So is it right to say then that the market-based approach is one which will not be the only solution to the question of dealing with getting younger people out of residential aged care?

MS RUNDLE: It's correct to say that in some places we will need other solutions beside market solutions because the market won't necessarily be the only answer. The market-based solution won't be the only answer, that's right.

MR KNOWLES: Yes, thank you. Can I just ask you, you've already given some evidence about data that's held by the NDIA, particularly in relation to projections and targets and the like. In terms of understanding about younger people who are actually in residential aged care, is it right to say that the main source of data received by the NDIA in that regard is the quarterly reports from the Department of Health?

MS RUNDLE: That's correct.

MR KNOWLES: Yes. And so it may be that – it's not until three months after the fact that the NDIA actually knows about a person being in residential aged care; is that right?

MS RUNDLE: At the moment that's the case.

MR KNOWLES: Yes. Are there steps afoot to try and improve that information gathering process and, if so, to get that information in a more real-time way?

MS RUNDLE: Yes, we – I should add to my earlier answer that it could be that a participant does make an application to the NDIS separate – separate to the data that comes through from the Department of Health.

MR KNOWLES: Sure.

MS RUNDLE: The – it would be better to get more timely data. I understand – and I may be wrong here, but I understand that the reason for the quarterly data is really the way in which Department of Health collect from all of the many residential aged care settings the data and then, you know, they cleanse the data no doubt and need to put it together in a way that they can give it to us, and so that is, you know, that is more a factor of just the time that it takes to be able to undertake that function, but I – that is an assumption. I couldn't be sure of that and - - -

MR KNOWLES: Yes. And so what ways is it anticipated that the NDIA will get more timely data about the people who are in or entering into residential aged care?

MS RUNDLE: No, I didn't say it is anticipated. I said it would be - - -

MR KNOWLES: Good to have that.

MS RUNDLE: It would be desirable. Yes.

MR KNOWLES: It being desirable, are there any plans to obtain data in that more timely fashion by the NDIA?

MS RUNDLE: I can't answer that with certainty. It's possible that that – that has been a question that we have asked the Department of Health and it might be that someone who manages – you know, someone else in the organisation may know the answer to that, but it is something that I will – it's something that I am going to follow up on.

MR KNOWLES: That data in relation to what's provided by the Department of Health on a quarterly basis, it's limited, isn't it, in terms of what it tells you. It doesn't tell you, for instance, the pathway by which a person entered into residential aged care?

MS RUNDLE: No, it doesn't. No, it doesn't.

MR KNOWLES: It doesn't give you any insight into ways in which you might – that data itself at least, ways in which you might go about preventing a person entering into residential aged care?

MS RUNDLE: No, it doesn't.

MR KNOWLES: And do you agree that by and large, data in Australia about younger people in residential aged care, and analysis of it, has been lacking over the years?

MS RUNDLE: It has, though I would add that – you referred earlier to advocates and others, I would add that many of the peak organisations or particularly a couple of them, the Young People in Residential Aged Care Alliance and also the Summer Foundation and particularly – and Youngcare, but Youngcare is slightly different.

The latter – the earlier two, you know, they've also made a range of attempts to do that and produce some really good qualitative information particularly, but information – but both.

MR KNOWLES: But it's left – you're saying that it's – they're getting the information rather than the NDIA or others.

MS RUNDLE: No, I – I'm acknowledging that they have done that.

MR KNOWLES: Yes.

MS RUNDLE: But it is true to say that we don't understand very much about the group of people that are coming into the agency, into the NDIS when we get the data from Health and we don't understand the pathway.

MR KNOWLES: And that would hamper you in understanding how to prevent people entering into residential aged care and possibly how to get them out of residential aged care?

MS RUNDLE: It's true that that, and not having that information at that point, that information isn't available at that point. For the only – only other way that we know that a person may need access to the NDIS is if they put an application in separately or if they're in a hospital awaiting discharge. And there is a risk of them being discharged to residential aged care. That – that's one of the pathways. But other than that – and it's probably a significant pathway in the past.

MR KNOWLES: In terms of that significant pathway via a hospital, am I right in understanding that at present the NDIA has, I think, is it three hospital liaison officers in South Australia?

MS RUNDLE: That's correct.

MR KNOWLES: And otherwise how many are there elsewhere around the country?

MS RUNDLE: There are – we're - - -

MR KNOWLES: At the moment.

MS RUNDLE: We're currently employing five in Victoria. Again, if I might provide a bit of context. The relationship between the four participants with significantly high needs, for example, this group of participants in a hospital at the moment, the – the main relationship between the agency and the – the participant and the hospital will be with our complex planning – our complex planners, not only but in the main with our complex planners. And so we – we – to say – when we rely on – we talk about health liaison officers, we're talking about some positions that we put into place specifically to do a particular task but that's not to say that there aren't a

great number of planners around the country who still – who already connect with their local hospitals, and I know for a fact that that's the case.

MR KNOWLES: But this is – the hospital liaison officer is a new initiative to try and prevent the steady stream of people who have been entering into residential aged care, younger people over the years that's sat pretty steadily at around two to two and a half thousand people each year.

MS RUNDLE: The hospital liaison officer was put in place in South Australia because it was agreed it would be one mechanism to try to run a project to – to – to improve our processes and learn some things about the pathway, and what could be done to improve people's discharge from hospital into the scheme because we know it's been – hospital discharge was a problem long before the NDIS came into being. I think most people would acknowledge that. But it is – we've sort of planted ourselves in the middle of this, this ecosystem and it is similarly an issue for people wanting to come into the scheme and gets supports from the scheme.

When they leave – want to leave hospital and some supports in the scheme aren't ready for them it is therefore a blocker for them to leave in the broad – in the broad sense. In the – in the specific sense of people who might have a pathway into residential aged care then it equally applies to that group. For the liaison officers, they were put in place specifically to run a project, if you like, a proof of concept or a project to try and look at where the blockers are and where we can improve the pathway of people out of hospitals generally.

MR KNOWLES: Sorry, where the what were?

MS RUNDLE: Where we could improve the – I may have said that incorrectly – where we could improve the pathway and the timeliness of people leaving hospital back into the community.

MR KNOWLES: Where the blockers were; is that what you said?

MS RUNDLE: And looking at the – looking at the things which would prevent that, the barriers to that, and looking at how we could overcome those barriers.

MR KNOWLES: Just finishing up on this topic, in terms of the hospital liaison officers, you say there are three in Adelaide, five in Victoria, none elsewhere.

MS RUNDLE: There are not five yet in Victoria. We are – I don't think they're in place yet. What we've agreed to is a hospital action discharge plan with all States and Territories. That was agreed as well at the last Disability Reform Council. In that plan, we will – we have, like them, committed to try and reduce the delays of discharge from hospitals and the right pathways for people out. So in – in rolling out that, we will consider how many more, either liaison officers or complex planners – and sometimes they will be the same, they will wear the same hat – we will need around the country to be able to match the hospitals.

MR KNOWLES: So at the moment, aside from three people in Adelaide who are there as part of a pilot, there's nobody else who's actually dedicated to being in a hospital, liaising with the people in a hospital to work out appropriate discharge options to - - -

MS RUNDLE: No.

MR KNOWLES: - - - prevent them possibly entering into residential aged care; is that right?

MS RUNDLE: No. That's not what I said and it's not correct. What I said earlier was the hospital discharge liaison officers were put in place for a particular project. We can give them any other name, we call them that name, but the function is the same. And that function currently is being undertaken by planners all around the country. What I think we need to do, though, is we need to be much clearer that – the increased effort we need here is to be clearer about which people in which areas would – will, you know, would be – have those roles, so that everyone knows – all parties know who those people are, be they complex planners or someone else. We just need to mature that model a little bit more. But that is already in place.

MR KNOWLES: So what model, in terms of what you're describing as maturing, exists nationally for the NDIA in terms of preventing hospital discharges of younger people into residential aged care?

MS RUNDLE: So that's a different question - - -

MR KNOWLES: Yes.

MS RUNDLE: - - - than the one you just asked.

MR KNOWLES: Yes.

MS RUNDLE: The - - -

MR KNOWLES: Is there a model?

MS RUNDLE: The – well, the – the – all of the work we're doing around hospital discharge to – to make sure that we know about people early who are in hospitals, if we don't already know about them, identify whether they're in the scheme or not already. If they're not in the scheme, identify whether they are putting an access decision in and need a quick access decision if they're eligible to the scheme, working out what they need once they're medically fit for discharge, what they need to go out into the community and – including home modifications or SDA setting and other supports that they might need in their plan. All of those things are efforts that we've been putting in place since the scheme started to roll out. And we've – that is – they are still all of the efforts that we've put into place for people who currently reside in hospitals - - -

MR KNOWLES: Yes.

MS RUNDLE: - - - who might have a pathway into a – into a setting we don't wish them to go to, like a residential aged care setting.

MR KNOWLES: Yes.

MS RUNDLE: In South Australia - - -

MR KNOWLES: Just before you go on to that, though, but in terms of saying that they've existed at all times, there hasn't been a decline in the number of people, including people who are NDIS participants, going – in the number of people going into residential aged care who are younger people; would you agree?

MS RUNDLE: Well, I think – I don't have the numbers with me, but yesterday someone who gave evidence did talk about the numbers generally declining in the last, I think, couple of years of people entering in aged care. But I also know that the AIHW showed figures that were two and a-half – two to two and a-half thousand people a year entering.

What we don't know – we haven't had – your question really goes to what visibility do we have about the numbers of people that we get out of hospitals and divert them from residential aged care. And the answer to that is we haven't known that until very recently, because we haven't had the ability in our system – in our – in our information system, we haven't had the ability to track that. We've just made some changes to help us track a number of things. And – and if a person has a plan, we'll be able to track where they go if – I need to be – I need to check the detail that, for example, if a person has moved out of a residential aged care setting, we'll be able to track the fact that they have left the residential aged care setting and gone to their own home. We haven't ever been able to do that before. We've only ever known that anecdotally.

MR KNOWLES: Right. I see. So, in terms of my question, there has been a period where the numbers, accepting for the moment if the numbers haven't diminished, what has changed in relation to the way that the model exists, if there is a model, for identifying people who are at risk of entering into residential aged care who are younger people at a very early stage at hospitals?

MS RUNDLE: Well, the – I think it's fair to say that the action plan – the action plan is – has only just started to be implemented for the young people in residential aged care. The efforts before – before that time go to my more general answer before, which is the efforts for everyone – the efforts for residential aged – people going into residential aged care were – were the same as they might have been for everyone. That is to say, we would do our very best to make sure that they've got the supports they need to divert them into going into residential aged care.

And because we don't have the numbers, but anecdotally I know that we have done that. We have actually diverted people from going into residential aged care, possibly not in large numbers, but anecdotally I know that to be the case. We haven't been able to track that. What is different is we've put a range of supports in place. The biggest – the largest thing that is different to the past is the scheme itself and the fact that this scheme is – the – the investment and the sheer investment, even in SDA alone, at around 700 million a year is significantly more than has ever gone before. That is one thing that's different.

The other thing that's different is that the SDA itself and the way in which we have set up SDA and the rules – and I acknowledge some of those things only recently – they are very different. The pricing arrangements that we've got in place and the incentives that we're offering and the growth that we're starting to see, that is a different feature to anything we've seen before.

So there are – the action plan is also different, new, and we've got a series of actions, as you can see in that action plan, and we ourselves have a fuller action plan to make sure that we monitor – track and monitor all of those things which we've committed to do to meet the goals of that action plan. So I – does that answer your question or have I answered the wrong question?

MR KNOWLES: I'm not sure that it does, but I don't have any further questions for you, Ms Rundle. Thank you, Commissioner.

COMMISSIONER BRIGGS: Okay. Thank you, Mr Knowles. Could I just ask you a couple of things. The first is about, I don't know, 20 minutes or half an hour ago in your evidence you alluded to something that I understand is a change in the way the NDIS is looking at accommodation for people with disabilities; namely, you're moving from congregate housing and large group homes that you might have otherwise inherited to individualised based housing units.

MS RUNDLE: Yes.

COMMISSIONER BRIGGS: I'm wondering, do you see any potential to use those congregate homes or large group homes as two things: a stepping stone that people might go to from hospital to avoid going into aged care while SDA accommodation is being developed; or as an accommodation focus for young people who are dying of cancer and a place where they could go with their families to – while they go through the process of palliation and eventual death. I suppose there's a third option that's a possibility. And that is a more innovative model of the provision of residential accommodation to elderly people more generally, because it's more community based. Have you thought about those options, Ms Rundle?

MS RUNDLE: Commissioner, some of those facilities – in a way, some of those aren't owned by us, because, as you know, we don't own our facilities. It's a good question that you ask. And I – I think when – I think in the past some of the insurance schemes have actually built smaller settings, not the larger settings, but

larger than a home for individuals as – as interim – as interim settings like rehabilitation settings and others as a transition.

COMMISSIONER BRIGGS: Yes.

MS RUNDLE: And, you know, it's fair to say that we have thought about all of those things which might help us and might give people some interim options while they're waiting for a long-term solution. The – if they choose – if they chose that. The – of course, the real risk of that – as – that becomes another long term - - -

COMMISSIONER BRIGGS: An end point. That was the point Mr Lye made yesterday.

MS RUNDLE: Yes.

COMMISSIONER BRIGGS: Yes.

MS RUNDLE: Yes.

COMMISSIONER BRIGGS: But something is better than nothing, a premature institutionalisation in aged care that can go on for years and years - - -

MS RUNDLE: Yes. Yes.

COMMISSIONER BRIGGS: - - - as we've heard in evidence in the last couple of days.

MS RUNDLE: Yes. Yes.

COMMISSIONER BRIGGS: My next question is in and around young people with disabilities accessing home care services. I gather there's around 2000 of these already accessing home care services – well, two and a-half thousand, about another 2000 who have been approved to get those services and will eventually get them. There's an issue here about why is that the case when the NDIS is there? Do you have any idea what's going on? Is there a gap here that needs to be brought out so we can understand more broadly?

MS RUNDLE: I think this came up yesterday, didn't it. And - - -

COMMISSIONER BRIGGS: Yes. I asked the question and didn't get an answer.

MS RUNDLE: Yes. I'm not sure I'm going to be able to answer it any better for you, Commissioner, but, as I understand it, because I'm not sort of – you know, I'm not involved in that area. But the – as I understand it, people can either choose to have – they can choose to be in both. And when a person gets an NDIS plan, we take into account every other supports that they receive. And so we wouldn't – we wouldn't duplicate a support that they get from another service, if that's what they

chose. But if they chose instead to have it provided by the NDIS, then we would facilitate that for them. But I can't answer the question about why is it the case.

COMMISSIONER BRIGGS: Yes. Okay. We need to investigate that further. Now, Ms Rundle, I'd like to thank you very much for your evidence this morning and excuse you from giving further evidence.

MR FREE: Sorry, Commissioner.

COMMISSIONER BRIGGS: Mr Free.

Mr Free. Just before you do excuse - - -

COMMISSIONER BRIGGS: Sure. Sorry.

MR FREE: - - - with your leave there are two very short topics that I wanted to question Ms Rundle about.

COMMISSIONER BRIGGS: Of course. Please proceed.

<EXAMINATION BY MR FREE [11.26 am]

MR FREE: Thank you, Commissioner. Can I ask the operator, please, to bring up the document at tab 146 of the bundle. Ms Rundle, this is the response which the agency prepared in response to a notice ..... from the Commission. And if I could ask the Commission please to go – the operator, rather, to go to page 0015. Just have a look on the screen there, Ms Rundle. You'll see there the first table is number of Young People Residing in Residential Aged Care Who Are NDIS Participants With an Active Plan as at 30 June 2019. And the first row is for under the age of 45 years. And the number says 18. Is it the case that that's actually a mistake, are you aware?

MS RUNDLE: Thank you for pointing that out. I - - -

MR FREE: I think - - -

MS RUNDLE: If I might – yes, that is a mistake. It's a hundred and – do you have the correct - - -

MR FREE: I'm instructed it's 177. Is that right?

MS RUNDLE: 77. And that was the figure that came to mind. And thank you for pointing that out. Yes.

MR FREE: Thank you. And just the other topic, Ms Rundle. You were asked some questions by Mr Knowles earlier about whether it might be appropriate to vary the

policy settings for young people in residential aged care so that, in effect, they all qualify for SDA by virtue of being in a residential aged care. Do you remember that - - -

MS RUNDLE: Yes, I do.

MR FREE: - - - line of questioning?

MS RUNDLE: Yes.

MR FREE: I just wanted to ask you, would you have any concerns that if you did that it might create an incentive for people to go into residential aged care?

MS RUNDLE: It's a good question. And I – I suppose in – if it were to be – if the rules were to be changed to allow for SDA to be included in all plans, we would have to think about the – yes. We would have to really think about the unintended consequences of that. It's – I mean, I – it's hard to imagine that anyone would by choice under – you know, go into an aged care residence unless they either want to for different reasons or there is just no other choice. And so you would hope that wouldn't be the case. But we would need to think about that if we were to do that. We would need to think about the unintended consequences of that policy setting change.

MR FREE: Thank you, Commissioner. That was all. Thank you.

COMMISSIONER BRIGGS: It would be a sorry situation, though, wouldn't it, Ms Rundle, if that were to occur?

MS RUNDLE: That's right.

COMMISSIONER BRIGGS: Yes. And you wouldn't want to rule out the possibility of a blanket referral straight out of aged care in order to fix that?

MS RUNDLE: That's right.

COMMISSIONER BRIGGS: That's right. Yes. We've got a timing shortfall. Have you any further questions, Mr Knowles?

MR KNOWLES: I have no further questions, you'll be pleased to hear, Commissioner.

COMMISSIONER BRIGGS: Okay. Ms Rundle, I need to formally excuse you from our hearings today. Thank you for your evidence.

MS RUNDLE: Thank you, Commissioner. Thank you.

<THE WITNESS WITHDREW [11.30 am]

COMMISSIONER BRIGGS: We need to talk time, I think.

MR KNOWLES: Yes. I believe that we have a very short adjournment now in order for the next witness to enter the witness box.

COMMISSIONER BRIGGS: Yes.

MR KNOWLES: So no more than 10 minutes.

COMMISSIONER BRIGGS: We'll take about 10 minutes. And if my colleagues are willing to agree to this and you would be prepared to put up with me doing this, I'd be happy to have a working lunch, sitting here having my sandwich as we proceed today.

MR KNOWLES: Yes.

COMMISSIONER BRIGGS: Because I wouldn't wish to cut short the evidence that people would be prepared to give. So if you want to take an early lunch, feel free, Mr Knowles.

MR KNOWLES: Yes. Thank you.

COMMISSIONER BRIGGS: With that, we'll have a short adjournment of the order of 10 minutes while people take positions.

MR KNOWLES: Thank you, Commissioner.

ADJOURNED [11.30 am]

RESUMED [11.46 am]

COMMISSIONER BRIGGS: Ms Hill.

MS HILL: Commissioner, I call Kirby Elise Littley.

<KIRBY ELISE LITTLEY, AFFIRMED [11.47 am]

<EXAMINATION BY MS HILL

MS HILL: Good morning, Kirby.

MS K. LITTLEY: Good morning.

MS HILL: Could you please tell us your full name.

MS K. LITTLEY: Kirby Elise Littley.

MS HILL: How old are you?

MS K. LITTLEY: 33.

MS HILL: Where do you live?

MS K. LITTLEY: Geelong.

MS HILL: And that's in Victoria.

MS K. LITTLEY: Yes.

MS HILL: Kirby, you've prepared a statement for the Royal Commission dated 30 August this year, haven't you?

MS K. LITTLEY: Yes.

MS HILL: Have you got a copy of that statement in front of you?

MS K. LITTLEY: Yes.

MS HILL: Are there any changes that you wanted to make to that statement?

MS K. LITTLEY: No.

MS HILL: Are the contents of that statement true and correct?

MS K. LITTLEY: Yes.

MS HILL: Commissioner, I tender the statement of Kirby Littley.

COMMISSIONER BRIGGS: Yes, the witness statement of Kirby Littley dated 30 August 2019 will be exhibit number 9-11.

EXHIBIT #9-11 WITNESS STATEMENT OF KIRBY ELISE LITTLEY DATED 30/08/2019 (WIT.1241.0001.0001)

MS HILL: As the Commissioner pleases. Operator, could I ask you please to display document IDs RCD.9999.0192.0002 and document ID RCD.9999.0193.0001. Kirby, you've provided some photos to share with the Royal Commission today, haven't you?

MS K. LITTLEY: Yes.

MS HILL: You've got a copy of those photos in front of you.

MS K. LITTLEY: Yes.

MS HILL: We've got the photos beamed up on the screens here.

MS K. LITTLEY: Yes.

MS HILL: Could you describe those photos for us.

MS K. LITTLEY: There's two. One is me playing the piano and the second one is me and my best friend.

MS HILL: And who's your best friend?

MS K. LITTLEY: Mel.

MS HILL: And how does she feel about being up on the screen today?

MS K. LITTLEY: Okay.

MS HILL: Why did you pick those photos?

MS K. LITTLEY: To show my life before the strokes.

MS HILL: In your statement, you describe your experience of living in aged care as a young person, don't you?

MS K. LITTLEY: Yes.

MS HILL: And you've asked to take the opportunity to read out some parts of your statement?

MS K. LITTLEY: Yes.

MS HILL: Operator, could I ask you to please display paragraph 27, and if I could ask Ms Abbott to join Kirby as she assists Kirby to read out. When you're ready, Kirby, could you please read from paragraph 27 to 32.

MS K. LITTLEY:

I was at Wallace Lodge from October 2014 to November 2015. I was the youngest person there.

I couldn't speak when I was in Wallace Lodge because of the tracheotomy. My only way of communicating with other people was by spelling words out with my communication board. Although I could not speak, I could understand what people were saying and what was happening around me.

I felt very isolated, lonely and mistreated while I was at Wallace Lodge.

I was isolated and lonely because I was in a different demographic to most of the residents. I couldn't speak which meant I couldn't socialise with anyone else.

When I first moved to Wallace Lodge, I had visitors but they stopped coming to see me. My friends stopped visiting me. I think it was because visiting an aged care facility was quite confronting. My room was also next to the pan room with the bed pans and the smell was off-putting for visitors.

I felt that I was mistreated at Wallace Lodge because the staff seemed to punish me if they were unhappy with me. They made me feel like I was a difficult resident because I had very high care needs.

MS HILL: Thank you, Kirby. Where did you live after Wallace Lodge?

MS K. LITTLEY: I lived with my mum and dad.

MS HILL: And now you're living in Belmont.

MS K. LITTLEY: Yes.

MS HILL: And that's not too far from Mum and Dad.

MS K. LITTLEY: No.

MS HILL: Do you live by yourself or with other people?

MS K. LITTLEY: By myself.

MS HILL: And what type of place do you live in?

MS K. LITTLEY: I'm living in accessible accommodation.

MS HILL: And what is life like for you in your unit?

MS K. LITTLEY: I have more control.

MS HILL: What do you hope to do in the future?

MS K. LITTLEY: I would like to work, talk and eat, and hopefully drive and eventually go back to work teaching.

MS HILL: Are you working with other people to step towards those goals?

MS K. LITTLEY: Yes.

MS HILL: Who are you working with?

MS K. LITTLEY: Allied health and other professionals and support coordinator and ..... and, of course, Mum and Dad.

MS HILL: We couldn't leave them out, could we?

MS K. LITTLEY: No.

MS HILL: In your statement, Kirby, you've prepared a message that you want to share to the Aged Care Royal Commission, haven't you?

MS K. LITTLEY: Yes.

MS HILL: Operator, could I ask you please to display paragraph 67 to 69 of Kirby's statement. Please read that when you're ready.

MS K. LITTLEY: Yes.

> *The main message I have for the Royal Commission is about the poor management of the aged care sector and the lack of accountability of staff. Aged care is not the place for young people.*
>
> *Nursing homes don't need more staff; they need dedicated staff.*
>
> *Residents need advocates and they need somebody helping them that's not employed by the nursing homes.*

MS HILL: Thank you, Kirby. How does it feel to be coming along and sharing a story with the Commission today?

MS K. LITTLEY: I'm happy. I will like to help by sharing.

MS HILL: And we've been talking about your mum and dad a bit. Shall we ask Carol and Kevin to join you?

MS K. LITTLEY: Okay.

MS HILL: Commissioner, I call Carol and Kevin Littley.

<CAROL ANNE LITTLEY, AFFIRMED [12.01 pm]

<KEVIN LLOYD LITTLEY, AFFIRMED

MS HILL: Kevin, could I ask you to please state your full name.

MR LITTLEY: My name's Kevin Lloyd Littley.

MS HILL: Carol, can I ask you to state your full name also.

MS C. LITTLEY: My name's Carol Anne Littley.

MS HILL: And Carol and Kevin, you live in Highton, around the corner from Kirby?

MS C. LITTLEY: Not that far away. Yes.

MR LITTLEY: Yes.

MS HILL: And Kirby has also got an older sister, and that's Cara?

MS C. LITTLEY: Yes.

MS HILL: So the Littleys are Kevin, Carol, Cara and Kirby?

MS C. LITTLEY: Yes.

MS HILL: Kevin, yourself and Carol and Kirby came along to a community forum of the Aged Care Royal Commission a few months ago at Maidstone.

MR LITTLEY: Yes.

MS HILL: And since then yourself and Carol have prepared a statement for the Commission.

MR LITTLEY: Yes.

MS HILL: Operator, could I ask you to please display the document WIT.1242.0001.0001. Kevin, you've got a hard copy of that statement in front of you. Is that your statement that you made with Carol?

MR LITTLEY: Yes, it is.

MS HILL: Were there any changes that you seek to make to that statement?

MR LITTLEY: No.

MS HILL: Are the contents true and correct?

MR LITTLEY: They are.

MS HILL: Carol, you've got a copy of your statement that you've made with Kevin there?

MS C. LITTLEY: Yes.

MS HILL: Were there any changes you seek to make to that statement?

MS C. LITTLEY: No.

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

MS C. LITTLEY: Yes.

MS HILL: Commissioner, I tender the statement of Carol and Kevin Littley.

COMMISSIONER BRIGGS: The witness statement of Carol Anne Littley and Kevin Lloyd Littley, dated 30 August 2019 will be exhibit number 9-12.

EXHIBIT #9-12 WITNESS STATEMENT OF CAROL ANNE LITTLEY AND KEVIN LLOYD LITTLEY DATED 30/08/2019 (WIT.1242.0001.0001)

MS HILL: As the Commission pleases. How are you feeling, Kevin?

MR LITTLEY: Fine, thanks.

MS HILL: And, Carol, how does it feel, having sat in the hearing room, listening to Kirby tell her story?

MS C. LITTLEY: Very emotional for me, seeing the photos of how she was before.

MS HILL: Carol, Kirby has talked about the goals and her plans for the future. How is Kirby going achieving her goals?

MS C. LITTLEY: She's going really well. She just works really, really hard. Whenever any of the allied health team give her something to do, she does it, and she does it to the best of her ability. So she has been-she's been making incredible progress, and since moving into her home she has actually made even more progress

because it's suitable for her. So it's set up so that she can do the things she needs to do without too much assistance. So, yes, we're very – we're very proud of what she's doing and the achievements. We never – five years ago, we just didn't know where she would be so it's amazing.

MS HILL: Carol, can I take you to Christmas 2013. What was life like for the Littley family at that point in time?

MS C. LITTLEY: Well, we had Christmas at our house and I have a photo of Kirby holding her dog. She'd just had her hair coloured so it was half blond and half green, very interesting. We had all the family there, we had Kevin's family and we had had Christmas – we sort of have two Christmases. One with our family, because of all the to and fro, and they all get along, but it's just different days. And it had been just the usual busy celebration. Kirby was – she'd been feeling unwell and she was telling me that day she didn't feel that well. And I actually said to her, we'll organise a doctor's appointment with my doctor and I did that the next week after Christmas. I was a bit concerned that she was still getting the headaches but she was joining in. She wasn't her usual healthy self, just a little bit off-colour, but we just a good day. They gave out the presents and it was a good day, wasn't it?

MS K. LITTLEY: Yes.

MS HILL: Kevin, I want to ask you some questions about Kirby's diagnosis. Can I take you to 3 January 2014 and ask you to tell the Commissioner what happened on that date.

MR LITTLEY: I'm not good at the actual dates but the – to sort of precis what happened was, Kirby met Carol and myself at the movies on – was that the 3rd, Carol?

MS C. LITTLEY: Yes.

MR LITTLEY: Yes. And - - -

MS C. LITTLEY: No, the 2nd, I think.

MR LITTLEY: Yes, on the 2nd. And she had been for an eye test with the optometrist and it was discovered by the optometrist that she had swollen optic nerves. Which we weren't sure what that meant now, what the significance of that was. So she – he – the optometrist obviously had got in contact with Kirby's doctor straightaway and she was called to go straight to the doctor. Subsequently, the next day Kirby had an MRI which discovered a huge tumour at the – in her brain. Yes, base of her – at the base of her brain stem, yes.

MS HILL: And, Carol, as a result of that tumour, Kirby had surgery?

MS C. LITTLEY: Yes. She was taken that night to – she was in Geelong Hospital and they took us straight up to the Royal Melbourne and she was to be operated on the next morning. So – and it went all day, the operation went, and we got a call about quarter past 6 that she'd made it through the operation.

MS HILL: And then what happened, Carol?

MS C. LITTLEY: Well, I just got on Facebook because her friends were all contacting me, and I was saying she's out, she's fine, and we got a phone call 20 minutes after that to say could they take her back into surgery because she had had a bleed and they needed to operate. So they took her back into surgery and she had had a stroke. So we didn't get up there till – they said don't come up and they called us about 10.30 and said she was out and we drove up to the hospital. We got there about 11.30 that night and went in to see her, and she wasn't actually doing – moving, she was obviously out to it. And just looked terrible.

MS HILL: And Kirby ultimately had another stroke and you just - - -

MS C. LITTLEY: She had a stroke three weeks later to the other side of the brain. That was called a vaso-something spasm I think that-

MS K. LITTLEY: Yes.

MS C. LITTLEY: Yes. The blood vessels collapsed and blocked the blood getting into her brain and that was very dire. Actually, that was pretty life and death for a few days. That was quite scary, and after that she couldn't move at all. She could only move her head. So she's come a long way.

MS HILL: And you don't have much memory of this time, do you, Kirby.

MS K. LITTLEY: No.

MS HILL: In your statement, Kevin, you describe that Kirby ultimately spent about 10 months in various hospitals; is that - - -

MR LITTLEY: Correct.

MS HILL: That's correct? And can I turn then to what's happening at the end of that 10-month period, so October 2014? Carol, how was Kirby going at that time?

MS C. LITTLEY: She was – well, she was in the Austin Hospital and she was making some progress. They had, they had some rehab there, but she'd been there for 19 weeks and she was supposed to have left 18 weeks before that. So she was a bit – I suppose we were all a bit down as to what was going to happen to her, because she wanted to get rehab and we just could not get anyone to take her for rehab.

MS HILL: Was she at a particular – was Kirby at a particular stage of her rehabilitation?

MS C. LITTLEY: Well, she hadn't really had rehab except in the hospital. So she was – she had a speech pathologist at the Austin who was amazing. She was the first person who put a little speech valve on her tracheostomy and we could actually talk. Very basically, obviously, but we could – she could communicate back with us, which was amazing. So this – because it was a VRSS, it was all about speech and breathing, she had done – she just kept persevering and she was making some progress. And they had also – the physio had got her up one day with a few people helping her to take a few steps with a walking frame. So we were thinking that there was – it was an optimistic outlook, but it wasn't the proper rehab that she needed. She needed slow stream rehab.

MS HILL: That's something you address in your statement, Kevin. You talk about the importance, and being anxious for Kirby to receive proper rehabilitation, slow stream rehabilitation. Why was that a priority for yourself and Carol?

MR LITTLEY: Well, because we could see that that would be the only way that Kirby could really reach the potential that we – we – the outcomes that we expected. And she hadn't had any, or apart from what Carol was just saying about limited rehab, she hadn't had a good program of rehabilitation to sort of, to kick her along so that she could reach that potential. But - - -

MS HILL: What were the options for Kirby at that time to receive that rehabilitation?

MR LITTLEY: There were no options. No one was offering Kirby any rehabilitation in any setting whatsoever, which was really concerning.

MS HILL: So what did you do then?

MS C. LITTLEY: I was – I was ringing places. I rang the – the Royal Melbourne Hospital Gardenview and we got the Austin to put in an application, and I rang them and they said the board meets on Monday nights, we'll decide. And I rang them after the Monday and they said the board met and they're not taking Kirby. And Royal Talbot, we were trying them. She was supposed to be going to McKellar, that's why she was getting ready. She was sent up to the Austin to get the ventilator put onto a tube and that's where she was originally going, but they said they wouldn't take her. Royal Talbot said they wouldn't take her, they may take her, but they didn't know why Barwon Health wouldn't take her.

I rang a private hospital in Geelong and asked them if they would provide rehab but it was costly, but we were thinking that – they would only do it for six weeks. So I was desperate and I ended up – I ended up calling A Current Affair to try and get someone to help us because I just didn't think she was ever going to get rehab and I just wanted to have a chance. So I called them and then the next day we got a call

from Barwon Health to say that we'd made a mistake and we'd got it wrong and that they were going to try and help us. And the funny thing is the Austin Hospital also got it wrong because they – they knew that Kirby wasn't getting rehab so they were trying to do something to help us so – but, and then we had a meeting with the Barwon Health CEO and some other people to try and come to a resolution.

MS HILL: Was there a resolution arrived at?

MS C. LITTLEY: No. What they offered us was a place in Northcote which was able to look after people with ventilators and tracheostomies because they said no one could look after Kirby with the ventilator and the tracheostomy. But it was not – it didn't offer rehab; it was actually a nursing home, and they said they could possibly get some people to come in and give her rehab, but we knew that wasn't what she needed. She needed rehab – proper rehab on a, you know, a regular basis.

MS HILL: So what did you do?

MS C. LITTLEY: I – I got quite upset and I – I just said we're not doing that. And we had an advocate from a group in Geelong, a solicitor with us who'd come along and he just said no, that's not an option, and we left. And we didn't know what was going to happen. And then we got a phone call a few days later to say that they wanted to meet with us again and we had a meeting with just the CEO and the COO, I think, and she had done a lot of work, and she'd come up with a report telling us why Kirby couldn't go home, Kirby couldn't go into rehab and the best option for her and the safest option was aged care at Wallace Lodge and then she could access rehab.

MS HILL: So pausing there, if I can ask you to reflect on that time when you're trying to work out what to do, would you have liked assistance at that time, guidance at that time?

MS C. LITTLEY: We would have loved it because we were still driving to Heidelberg every day which on a good day was a one and a half hour trip, and on a bad day in peak hour was two and a half hours. We were exhausted. We were calling people. We really felt – we just felt like we were so alone. We felt like no one cared and it was a horrible experience and if we had had someone to talk to, to help us, and just let us vent because we just – we felt like we'd been deserted and we didn't know what to do. It was just a horrible, horrible time. And my mother was also in aged care as well; she'd just been put into aged care at that time so I was going from Mum and then going trying to sort things out. It was just a nightmare. It would have helped to have someone to talk to.

MS HILL: Would you like to respond to what Carol said?

MR LITTLEY: Yes, well, the issue there also was that we – when Kirby initially left University Hospital in Geelong, we were told it was only for three or four days to go to the Austin to get the ventilator attachment so that it fits onto her tracheostomy,

and then they would be taking her back to Geelong Hospital with the aim eventually then to go to McKellar Centre for rehabilitation. We actually asked if they would write something down, a legal document to suggest that that would happen that way. They said no, we don't need to do that. And as it turned out we did because they refused to take her back. They said they couldn't take her back with the ventilator on her tracheostomy.

MS C. LITTLEY: Even to the hospital. They wouldn't even take her back to the hospital.

MR LITTLEY: Unless she went to ICU which was stupid.

MS C. LITTLEY: And they said they won't do that.

MR LITTLEY: So she was taking a high needs bed at the Austin for 19 weeks when really she could have quite easily have come back to her own home town and that's where she should have come, really. So it was a worry, a very worrying time, obviously, and Kirby got very desperate. She said to us one day, she was in tears and she said "Nobody wants me" which was a pretty sad but true fact.

MS HILL: You've given evidence about how Kirby had the option of Wallace Lodge or what Wallace Lodge had made available to Kirby. What did you then do once that was presented?

MS C. LITTLEY: Well, we thought that that was the only option to Kirby having rehab so we didn't have much choice and we didn't know how to tell Kirby. We had to tell her and I said to her, "Look, the option is aged care, it's going to be better for you, it's going to be safer". And she started to cry. But I said "You have to do this because you have to get rehab." If we hadn't done it she wouldn't be where she is now, she wouldn't be doing anything, she wouldn't be talking, she wouldn't – she wouldn't even – she really wasn't hardly able to sit up in a chair at that stage; there was very little Kirby could do and that's where she would have stopped if we hadn't done that.

MS HILL: What did Kirby say to you at this time; what did Kirby say to you about going to Wallace Lodge aged care?

MS C. LITTLEY: She just cried. She just said, she was just so – she was upset about it. I don't think she really wanted to go but she didn't say much more. I think – I think she'd been there so long at the Austin she thought she was never going to leave. And it was a very – it was a ward of four beds that were highly needed. So Kirby was watching people coming and go, some passed away, and I think we all knew we need that we needed – we needed to leave that bed for other people. It was an important bed, you know, they needed it. And they were so wonderful there; they never said anything to us but we just had to get Kirby out of there so - - -

MS HILL: Whilst Kirby is living at Wallace Lodge, what observations did you make – I'll turn to you perhaps, first, Kevin; what observations did you make of Kirby at the time in had aged care?

MR LITTLEY: She was very depressed during that time, she was – her demeanour wasn't good. She – you could tell she didn't really like that she was, you know, the fact that she was there. She didn't socialise, obviously, because the people that – the other people that – other residents were much older than Kirby so she – and she wasn't communicating well anyway because she wasn't speaking so she was virtually, as she said in her own statement, she was isolated in her own room and as also she said in her statement she – visitors tended to drop off after a while because it wasn't a pleasant experience for them either.

So, yes, she was pretty much – very lonely. If it wasn't for Carol and myself and her sister, she wouldn't have had any visitors and any outside contact because she was pretty much in her room, apart from her therapy sessions which she got a lot of joy out of those, because she could see herself improving and she saw that as – obviously living in Wallace Lodge was a means to that end of getting the therapies that she required.

MS HILL: Carol, Kevin has touched on the therapy that Kirby required and received. What care and support did Kirby need while she was at Wallace Lodge.

MS C. LITTLEY: She often needed suctioning. She still had a tracheostomy, so she needed suctioning, and she needed to be taken over to the actual facility which was next door and she needed – she needed, back when she was in the aged care, the staff to allow her to try to do things. The physio made a recommendation one day of using a standing hoist that she didn't need to be hoisted anymore so she could start to stand, and unfortunately those things often didn't happen, so yes.

MS HILL: Did Kirby receive rehabilitation in the aged care?

MS C. LITTLEY: She received rehabilitation – an absolutely fantastic team at McKellar.

MS HILL: But that's separate to Wallace Lodge.

MS C. LITTLEY: Yes. That was where she went for the rehabilitation but when she got back it was like she was a 90-year old. They treated her like she was a 90-year old. So – I know that one day the physio came in and she wrote on the white board that they were to now use a standing hoist which we didn't know what that was, but anyway, and she signed it and when the staff came in that night, I said, "The physio has written a note there" and she said, "I'm not doing that". And I said but the physio has written a note. She said, "I'm not doing that until she tells me herself". I said, "She's gone on leave". She said, "I know" and she just wouldn't because they – they thought – I think they thought we'd written the note but we didn't know what a standing hoist was.

So I went down to the NUM and I said, "Look, she has to use this hoist" and they went and got it, but they didn't want to use it because they had to walk down the hall to get it and bring it back every time so it was inconvenient. But we got it – we got it done and then we still – it was really great because it stands you up which was wonderful. So there were just a lot of things. It was a rush in the mornings. They had – they put on an extra staff member who was supposed to take the time so Kirby could try to do things for herself, because in aged care people are at the end of life; Kirby was trying to get better.

But they ended up absorbing that staff member into the routine and so Kirby didn't get the opportunity as often to do things – to try to do them because it was time consuming. She had a couple of staff members who would do it; they were great. But the majority just pushed her through the production line of showering in the morning and dressing and she didn't get that opportunity so that was – that was disappointing.

MS HILL: You referred, Carol, to the NUM; is that the nursing unit manager?

MS C. LITTLEY: Yes, manager. Yes.

MS HILL: And McKellar was the rehabilitation centre that Kirby was able to access.

MS C. LITTLEY: Yes.

MS HILL: And that was a separate facility to Wallace Lodge?

MS C. LITTLEY: Yes. They do have – you can live there – live in there, but Kirby, they didn't suggest, they didn't think that was the best place for her and that's why she wasn't there.

MS HILL: How was Kirby's rehabilitation facilitated between moving between Wallace Lodge and McKellar?

MS C. LITTLEY: Well, sometimes they wouldn't take her; they didn't have someone to take her over. If they didn't have a nurse to suction her they wouldn't go and the staff over there couldn't suction her so they couldn't give her rehab. So a lot of times we would go in and do those things. I know one day they were angry with Kirby because they said she had thrown a tantrum, I think, and they – her punishment was that they didn't send her to – it was physio that day and then in front of her the nurse said – or the staff member said, "And don't bother about OT either". And that was awful for Kirby because that's why she was there, to have rehab; so her punishment was she didn't get rehab that day.

MS HILL: Kirby, you've described in your statement with some detail the experience that you had with staff and the feeling of being punished when your needs weren't understood; is that - - -

MS K. LITTLEY: Yes.

MS HILL: Kevin, in your statement with Carol you describe finding out about the NDIS in May/June 2015.

MR LITTLEY: Yes.

MS HILL: Carol is nodding so I think I've got the dates right.

MR LITTLEY: Yes.

MS HILL: How did you find out about it?

MR LITTLEY: I don't know. I think that would be better directed at Carol; I can't recall.

MS C. LITTLEY: Well, the first time I heard of the NDIS was when Kirby was in – she was coming from the Royal Melbourne to Geelong and a social worker from Geelong called me before she'd even left and said, "You need to get into the NDIS, you need to get your daughter into the NDIS". I didn't know what the NDIS was. And then I found out it was about disabilities and I just – I thought Kirby is going to get better. She doesn't need the NDIS, she's going to get better; being a mum just hoping that was going to happen. And then later on we met Kirby's support coordinator. I went to a group called MAINH that tries to get young people out of aged care – we met – who is now Kirby's support coordinator.

But at that stage on our initial meeting they said they would have to let us know if Kirby would be accepted into the NDIS. So we sort of thought well, if Kirby's not accepted into the NDIS, who is? We just – we were stunned at that. But as it went on, she was accepted and we were in a trial site so that was – that was a blessing, you know, that was something positive out of this whole experience.

MS HILL: How long had Kirby been at Wallace Lodge at that point in time?

MS C. LITTLEY: I think she'd been there about – she went there in the November. I think this was – I think it was about May. I mean, thinking back, it's confusing, but I know we started having meetings then because Wallace Lodge were telling us Kirby needed to go, and that was by the June they wanted her to go. So they were trying to get her out by June, but that didn't eventuate so - - -

MS HILL: How did Kirby get out of Wallace Lodge?

MR LITTLEY: Well, the NDIA. When Kirby had an NDIA plan, obviously they – they helped with home modifications to our home, which enabled Kirby to come home. That took some time to get that all completed. So yes, bathroom modifications and widening of doors and all the things that Kirby needed to access

our home. So she was still in Wallace Lodge while that was – those works were taken on.

MS HILL: Kirby has told us that she lives in her own unit these days.

MR LITTLEY: Correct.

MS HILL: How did that come about?

MR LITTLEY: Well, again, that was something that just was suggested to us by Kirby's support coordinator, I think. That there was a gentleman in Geelong, a very philanthropic gentleman that was building accessible homes for people, and that Kirby might be interested in applying for SDA and purchasing one. Which Kirby saw – from a plan stage, it was still in construction at the time – and Kirby decided that she was interested in one of those units. And – and so she applied for SDA and she got the SDA funding and purchased the property. So Kirby is – as far as we know, she's one of the – if not the – one of the few, she might be the only person in Australia that is a SDA provider and participant.

MS HILL: And that's because Kirby owned her own unit before.

MR LITTLEY: That's right, yes, which she sold to aid in the purchase of this new property, yes.

MS HILL: SDA being specialist disability accommodation, you describe that in your statement, Carol and Kevin, and you also talk about supported independent living or SIL as we've heard it referred to here today. Carol, could you explain how this works presently for Kirby?

MS C. LITTLEY: The SIL?

MS HILL: Along with the specialist - - -

MS C. LITTLEY: The SDA? The SDA is the payment that the person who has the property receives, so as the owner, Kirby receives the SDA payment – sorry, payment to pay for her property and then the SIL is the supported independent living. So what that means for Kirby, during the day Kirby has her own workers that come in, support workers, because she needs quite a bit of assistance throughout the day. But because Kirby had lived independently before this all happened, she wanted to live independently again. So the SIL are on-site. They have their own little – like a motel unit, and Kirby can buzz them. So from 6 o'clock at night until 8 o'clock the next morning, it's just like Kirby's living the life she used to, where she's in her own place, there's no one there. You know, she can watch TV and there's no one sort of around. It's just a little bit back to the normality, so it's a great idea because it gives the independence, but it also gives you that security of having someone there when you need them.

MS HILL: And that's that control, Kirby, that you talked about earlier.

MS K. LITTLEY: Yes.

MS HILL: Kevin, could I ask you to turn to the statement that's there in front of you, and turn to page 11.

MR LITTLEY: Yes.

MS HILL: Could I ask you to look to paragraphs 98 and 99 and read them to the Commission, please.

MR LITTLEY:

> *We are grateful that Kirby received assistance from the NDIS which enabled her to leave aged care. However, it felt like an ongoing fight to move her from aged care and we advocated for her as hard as we possibly could.*
>
> *We don't think we should have needed to advocate so hard to get Kirby rehabilitation or to get her out of aged care, because she should not have been there in the first place. We were experiencing the most traumatic event we had ever had to face, and it took a great toll on our health to have to fight the system which should have been supporting our daughter.*

MS HILL: Kevin, what did your family need at this time?

MR LITTLEY: I would just – would have liked, as we said before, that somebody was there to sort of guide us through all this. The whole process of transitioning from aged care to – to our home or to wherever Kirby was going in as a next stage, and it was – it wasn't made – it was not an easy process.

MS HILL: Carol, reflecting on what Kevin said and what you've set out there in your statement – of course, that's just two paragraphs of it – is there anything you'd like to add?

MS C. LITTLEY: I'd like to add that Kirby should have been given rehab. She should have been brought back the three nights after she went there that we were promised and she should have been given the rehab she was promised. And it should have been made available to her in Geelong. It could have been done. It wasn't. If that had happened, she would have had – 18 weeks earlier she would have started her rehab. Who knows how much more she would have achieved? I don't think that anyone ever should go into aged care. There should be places for people to have – to go to whether it's rehab or whether it's somewhere that they can live in the interim. It's just – it's almost like a punishment for having a disability or a chronic illness. I mean, this is what we're doing to people. This is what we're doing in Australia.

We're putting people into aged care because we have nowhere else in 2019 to put them. Is that seriously the country we want to live in? I can't believe it. I'm stunned by this whole experience because I know there are other Kirbys out there now that haven't got people to advocate for them and they're stuck somewhere. And they could be where Kirby was before we got her into aged care. They could be now able to achieve what Kirby has, and they're not doing it. And they're the people that we're here talking, speaking for, because there are people out there that have no one to speak for them, and that really concerns me.

MS HILL: Commissioner, that concludes my examination.

COMMISSIONER BRIGGS: Thank you. Might I say that I read both of your statements with a great degree of interest. And I have to say, Kirby, I nearly cried when I read yours to see what you had gone through, and how much, as your father says, you had to fight the system to get there. But the great thing is that you're doing it, you're getting there in spite of all of these things. The fact that you've got your own accommodation, you've left aged care and you've got a future that you're planning ahead of you is a terrific thing. So thank you for that and thank you to your parents who clearly spent a lot of time and emotional energy supporting you on this pathway.

MR LITTLEY: Commissioner, could I just make a statement?

COMMISSIONER BRIGGS: Sure. You could, yes, Mr Littley.

MR LITTLEY: I'd like to commend the NDIA and the NDIS as one of the greatest initiatives that is this country has ever seen. And although it is – we all should be proud of it as a – you know, on a worldwide thing. The only problem I see is that it, in its implementation, is a bit clunky and needs a lot of overhaul of the process itself, but as an initiative it's something as Australians we should be very proud of.

COMMISSIONER BRIGGS: I agree absolutely. It's something that takes us to a world class - - -

MR LITTLEY: Yes.

COMMISSIONER BRIGGS: - - - standard of supports for people with disabilities. And one of the things this Royal Commission is trying to do is ensure that that happens for those people in aged care more generally. So if I may thank the three of you for attendance and I would like to officially excuse from further appearing before this Royal Commission Kirby Littley, Carol Littley and Kevin Littley. Thank you very much.

<THE WITNESSES WITHDREW [12.34 pm]

COMMISSIONER BRIGGS: I gather we're going to continue on after a brief pause - - -

MS HILL: Yes, Commissioner.

COMMISSIONER BRIGGS: - - - with further evidence before lunch. That's good.

ADJOURNED **[12.34 pm]**

RESUMED **[12.40 pm]**

COMMISSIONER BRIGGS: Mr Knowles.

MR KNOWLES: Thank you, Commissioner. I call Mario Amato.

<MARIO AMATO, SWORN **[12.40 pm]**

<EXAMINATION BY MR KNOWLES

MR KNOWLES: Mr Amato, you've prepared a statement for the Royal Commission.

MR AMATO: Yes.

MR KNOWLES: Yes. And is there a copy of your statement before you there in the witness box?

MR AMATO: Yes, there is.

MR KNOWLES: And that's the statement dated 29 August 2019.

MR AMATO: That's correct.

MR KNOWLES: That's document WIT.1244.0001.0001.

MR AMATO: Yes.

MR KNOWLES: Have you read your statement lately?

MR AMATO: I have.

MR KNOWLES: Yes. And are there any changes you wish to make to your statement?

MR AMATO: No changes.

MR NUTT: And are the contents of your statement true and correct to the best of your knowledge and belief?

MR AMATO: Yes, they are.

MR KNOWLES: Yes. I seek to tender the statement of Mr Amato dated 29 August 2019, Commissioner.

COMMISSIONER BRIGGS: Yes, the witness statement of Mario Amato dated 29 August 2019 will be exhibit 9-13.

EXHIBIT #9-13 WITNESS STATEMENT OF MARIO AMATO DATED 29/08/2019 (WIT.12044.0001.0001)

MR KNOWLES: Mr Amato, you're presently 59 years old.

MR AMATO: Yes, I am.

MR KNOWLES: And you live in the Australian Capital Territory.

MR AMATO: Yes, I do.

MR KNOWLES: Yes. You've had type 1 diabetes since you were a young child; is that right?

MR AMATO: That's right, 41 years now.

MR KNOWLES: Right. And you presently have some damage to the frontal lobe of your brain.

MR AMATO: I do.

MR KNOWLES: Yes. And you have some trouble with balance and stairs, but otherwise you're physically able.

MR AMATO: That's correct.

MR KNOWLES: Now, in 2013, you owned your own tax accounting business and you lived in your own home with your former wife and your two children, didn't you?

MR AMATO: I did.

MR KNOWLES: Yes. Now, by early 2015 you had been admitted to a mental health ward of a public hospital with depression.

MR AMATO: I was.

MR KNOWLES: Yes. What were the circumstances that led up to you finding yourself in that mental health ward in early 2015?

MR AMATO: My wife had left me and I'd become depressed and I was trying to kill myself by having insulin and not eating.

MR KNOWLES: And when you had insulin and you didn't eat, what happened?

MR AMATO: I'd have hypoglycaemic attacks and be sent to hospital. 144 times that happened.

MR KNOWLES: Over the span of how long did those 144 attacks occur?

MR AMATO: A year.

MR KNOWLES: What happened to your tax accounting business?

MR AMATO: I sold it because I was incapable of running it.

MR KNOWLES: And how long were you in that mental health ward in the hospital from early 2015 onwards?

MR AMATO: Nine months.

MR KNOWLES: Right. And was it around that time that you acquired the frontal lobe damage?

MR AMATO: Yes, in hospital.

MR KNOWLES: And how did that come about?

MR AMATO: I was in the mental health ward going to have dinner and I had collapsed with a grand mal, with epilepsy, which I had also, and a hypo – hypoglycaemic attack.

MR KNOWLES: So you had a grand mal seizure; is that what you say?

MR AMATO: Seizure. That's correct.

MR KNOWLES: Yes. And that led to what? Did you - - -

MR AMATO: Brain damage.

MR KNOWLES: Yes. I see. And how has - - -

MR AMATO: And I had two strokes also.

MR KNOWLES: Right. I see. And was that also as a result of the hypoglycaemic attacks, the strokes?

MR AMATO: Yes, correct.

MR KNOWLES: Yes. And how has that frontal lobe damage affected you, Mr Amato?

MR AMATO: It has affected me a lot but I've recovered quite well.

MR KNOWLES: Yes. What's the main effect that you would experience now?

MR AMATO: Main effect is memory loss.

MR KNOWLES: Yes. And in your – in that regard, is it your long term, short term; what aspects of your memory do you struggle with now?

MR AMATO: Long term.

MR KNOWLES: What are some aspects of your life that you have difficulties remembering now?

MR AMATO: My children growing up, and going on holidays overseas with my ex-wife. I don't remember those at all.

MR KNOWLES: Now, while you were in that hospital, you were visited in April of 2015 by an advocate from the ACT Disability Aged and Carer Advocacy Service, or ADACAS.

MR AMATO: Yes.

MR KNOWLES: Is that right?

MR AMATO: That's right, yes.

MR KNOWLES: Yes. Now, was that a visit that was planned or organised in some way for you?

MR AMATO: No, it wasn't.

MR KNOWLES: So it was just by chance that this person happened to visit you.

MR AMATO: It was by chance.

MR KNOWLES: And what did you discuss with the advocate when you first met them?

MR AMATO: She mentioned to me that I could be a member of the NDIS.

MR KNOWLES: And did she help you in some way in pursuing that?

MR AMATO: Yes. She filled out an application for me to become a member.

MR KNOWLES: And did you eventually become a participant in the NDIS?

MR AMATO: Yes, in April 2016, from memory.

MR KNOWLES: All right. And what happened after you became a participant in the NDIS?

MR AMATO: Well, they – they funded caring for me.

MR KNOWLES: Yes. Did you prepare a plan when you first became a participant in the NDIS?

MR AMATO: Yes. We had a meeting with the NDIS managers and we prepared a plan for me.

MR KNOWLES: And did the plan set out your goals, Mr Amato?

MR AMATO: Yes, it did.

MR KNOWLES: And can you recall what your goals were at the time in the NDIS plan back at that time?

MR AMATO: Yes, to get out of the aged care facility, mainly.

MR KNOWLES: Yes. Now, just going back a step in terms of how you actually came to be in the aged care facility after nine months in hospital, your brother was appointed your guardian; is that right?

MR AMATO: That's correct.

MR KNOWLES: And that was by the ACT Civil and Administrative Tribunal.

MR AMATO: Correct.

MR KNOWLES: Yes.

MR AMATO: Because the Public Trustee didn't want to manage my affairs.

MR KNOWLES: And on what basis was it considered necessary for you to have a guardian at that time?

MR AMATO: Because the doctors determined that I needed a guardian because I didn't have the capacity to make decisions.

MR KNOWLES: And why were you regarded as not having the capacity to make decisions at that time?

MR AMATO: Because I had front lobe damage.

MR KNOWLES: Have you subsequently received any neuropsychological report that goes to be capacity to make decisions?

MR AMATO: In August 2018 I had another neuropsychological report done. Yes, I did.

MR KNOWLES: And what did that say about your capacity to make decisions?

MR AMATO: It said I had the capacity to make decisions and do other things myself, take care of myself on my own.

MR KNOWLES: Now, after the appointment of your brother as your guardian, and after the period of time in hospital, why was it that you actually ended up going to residential aged care rather than some other type of accommodation?

MR AMATO: Because there was no other accommodation available for me in Canberra.

MR KNOWLES: Yes. And you say in your statement that you were effectively put into residential aged care against your will in September 2015.

MR AMATO: Correct.

MR KNOWLES: So I take it from that, you were not wanting to go into that type of accommodation.

MR AMATO: No, I didn't want to go.

MR KNOWLES: When you went into residential aged care, how old were you, Mr Amato?

MR AMATO: 55.

MR KNOWLES: Can you tell the Royal Commission how you felt when you started living at the residential aged care facility?

MR AMATO: I got more and more depressed, seeing the elderly in the aged care facility and what they were going through.

MR KNOWLES: Did you – in terms of those elderly people, what was the general age group of the people who were in the facility with you?

MR AMATO: Above 80 – 80 and 90 and up, getting older.

MR KNOWLES: And what was their state of health like?

MR AMATO: Not very good.

MR KNOWLES: In what way, Mr Amato?

MR AMATO: They were dementiaed or Alzheimer's.

MR KNOWLES: Did you share common interests with the people who were in the aged care facility as well?

MR AMATO: Other than talking to them, no, not much.

MR KNOWLES: How did your interests differ? Can you give some examples of how their interests and yours were not the same?

MR AMATO: They spoke to me about World War I, the Boer War and World War II. I wasn't even born then.

MR KNOWLES: What about other tastes, music and the like? Did you have similar - - -

MR AMATO: I liked pink Floyd and I like the Beatles and things like that. And they talked to me about Mozart and other piano-type music, way out of my league. I didn't understand that, what they were telling me.

MR KNOWLES: How did you end up spending your days in the residential aged care facility?

MR AMATO: I'd go walking to get out of the place.

MR KNOWLES: Now, did you make any friends while you were there?

MR AMATO: Yes, I did.

MR KNOWLES: And was it difficult for you to form friendships with people at the aged care facility?

MR AMATO: No, I'm an outgoing person. It wasn't difficult for me.

MR KNOWLES: Yes. And what happened in terms of those friendships?

MR AMATO: Well, most of the people would die. There was one there for a week at least, which would make me more depressed, being there, and that would sort of cause me a lot of – I'd go to my room and burst into tears each – each time that happened, and yes, it – it just wasn't a place for me. That's why I walked out a lot.

MR KNOWLES: And where would you walk to?

MR AMATO: Well, from the suburb I was in, to the city and back. I went to the city to buy food or a coffee and walk back to the nursing home.

MR KNOWLES: Now, all up, how long were you in the residential aged care facility?

MR AMATO: Over three and a half years.

MR KNOWLES: And how do you feel about those years of your life?

MR AMATO: They were a waste of time. Waste of my life.

MR KNOWLES: How did you find, in terms of the residential aged care facility, the staff there?

MR AMATO: They were good to me.

MR KNOWLES: Yes.

MR AMATO: I couldn't complain about that at all.

MR KNOWLES: Did you find them to be busy at times? Did you find them to be busy at times?

MR AMATO: Yes, they were certainly busy.

MR KNOWLES: Yes.

MR AMATO: Because all the elderly needed help constantly.

MR KNOWLES: And did you find them attentive to your particular needs as somebody who was not in that age bracket?

MR AMATO: Look, the only example I can give that they didn't take care of me is when I cut my hand. Otherwise, they took care of me well.

MR KNOWLES: What happened when you cut your hand?

MR AMATO: Well, I cut my hand on a glass frame, it dropped onto my hand and cut my hand open, and it was bleeding profusely for a long time. I wrapped it in a towel to stop it bleeding and I pressed the buzzer to get that carer to come and help me. It took – she didn't turn up, or they didn't turn up, and I eventually just picked up the phone and went – sorry, to say this – bugger it, and I rang the ambulance and they come and took care of me.

MR KNOWLES: Were you taken to hospital at that time?

MR AMATO: No. No. They just stitched me up and left me at the nursing home.

MR KNOWLES: What were the doctors like that visited the nursing home?

MR AMATO: Not very good.

MR KNOWLES: And why do you say that, Mr Amato?

MR AMATO: I say that because a lot of the elderly would complain about the doctors that would come, and I didn't like them anyway. I found my own doctor to take care of myself, someone that could understand diabetes and epilepsy.

MR KNOWLES: And did you find that, in terms of the food that was provided to you, there was an understanding of your condition of having diabetes?

MR AMATO: No. They had no idea.

MR KNOWLES: And what's an example of that that you can tell the Royal Commission, in terms of the food that was given to you as a type 1 diabetic?

MR AMATO: Feeding me ice-cream, full of sugar. Do you think that's appropriate? I don't.

MR KNOWLES: What did you do in response to that occurring?

MR AMATO: I rang the Aged Care Commission.

MR KNOWLES: The Complaints Commission?

MR AMATO: No. The Aged Care Commissioner - - -

MR KNOWLES: Yes.

MR AMATO: - - - in the ACT to lodge a complaint over the phone.

MR KNOWLES: And what happened after you did that?

MR AMATO: They rang the – the office rang the aged care facility and they told them to make meals appropriately for me. And then it was okay after that, but the manager at the nursing home told me never do that again because it causes this place a lot of problems, if you do that.

MR KNOWLES: The manager told you that about making a complaint to the Aged Care Complaints Commissioner?

MR AMATO: Don't make complaints.

MR KNOWLES: Now, in the middle of 2006, you say in your statement that – pardon me – you, after getting – you also – sorry. Pardon me. You also complained to the Aged Care Complaints Commissioner about the fact that you were even living there in the first place, didn't you?

MR AMATO: Yes, I did.

MR KNOWLES: And what was the response to that complaint?

MR AMATO: He said nothing – they could not do anything because not in their – their – their authority. It's in my guardian's authority and in the nursing and my doctors to have to make a decision about where I lived, not them – not them.

MR KNOWLES: And how did you feel when you got that response from the Aged Care Complaints Commissioner?

MR AMATO: I felt let down.

MR KNOWLES: And what did you do after getting that response?

MR AMATO: I went to the Human Rights Commission and lodged a complaint with them.

MR KNOWLES: And what was the response from the human rights commission?

MR AMATO: They said, "No. It's out of our – out of our league."

MR KNOWLES: Did you ever try to run away from the aged care facility?

MR AMATO: I did.

MR KNOWLES: Yes. And how did that end up?

MR AMATO: The – the manager at the nursing home rang the police. They – they tackled me as I was walking away and they called the ambulance. And the ambos came and gave me a tranquilliser and took – put me back and – took me to hospital.

MR KNOWLES: Now, you've said in your statement that your mood started to improve in around September 2016 after you'd met your now partner Jane.

MR AMATO: Correct.

MR KNOWLES: How did you meet?

MR AMATO: Through mutual friends.

MR KNOWLES: Right. And can you tell the Royal Commission what it was like having a partner and at the same time living in residential aged care?

MR AMATO: Not very good.

MR KNOWLES: And there are obvious reasons for that, but can you elaborate on why you say it was not very good.

MR AMATO: Well, I wasn't allowed out even to go to have lunch with her. Had to have lunch at the nursing home and dinner and breakfast at the nursing home. I wasn't allowed out.

MR KNOWLES: Why was that?

MR AMATO: Because of my medication. They wouldn't let me do it myself.

MR KNOWLES: And when you say your medication, do you mean injectable insulin? Is that what you're referring to?

MR AMATO: Correct.

MR KNOWLES: Yes. Now, across this time while in the residential aged care facility, you maintained contact with the advocate from Atticus.

MR AMATO: Yes.

MR KNOWLES: And also your NDIS support coordinator; is that right?

MR AMATO: Correct.

MR KNOWLES: Yes. And, at this time, was this when your plans for NDIS were such as to include a desire to leave the aged care facility if you could?

MR AMATO: Correct.

MR KNOWLES: And did you ask your advocate for help in getting out of residential aged care?

MR AMATO: I sure did.

MR KNOWLES: And what did she do to help you to do that?

MR AMATO: She talked to the facility manager a number of times and to my guardian at the time, my elder brother, but the doctors wouldn't allow me to move out at that stage.

MR KNOWLES: And did – is that - - -

MR AMATO: Because I didn't have a – up to date neuropsychological report.

MR KNOWLES: And was there any approach made? Or how did you go about trying to get an up to date neuropsychological report?

MR AMATO: Well, my guardian at the time, my elder brother, said he couldn't fund one and, therefore, one couldn't be done, because I didn't have money at that stage. It cost about two and a half thousand dollars to do and I didn't have that. I had $10 a week that I had in my pocket.

MR KNOWLES: After you met Jane and your relationship developed, where did you want to live?

MR AMATO: With Jane.

MR KNOWLES: And did she have her own place?

MR AMATO: Yes, she did.

MR KNOWLES: And, in terms of getting that neurological assessment, what did you have to do in order to get that?

MR AMATO: My two guardians at that time were Jane and my good friend Roger. They said they would fund one for me. I said to them, "No. Wait for my settlement to come through and we'll get it done then." But that hadn't come through and the NDIS stepped in and said they would fund it.

MR KNOWLES: And when you say Jane and your friend Roger were then your guardians, had there in the interim been an application made by you to replace your brother with them as your guardians?

MR AMATO: I did, but I made my brother – I told my brother I would do that because him being my guardian – he was a four hour drive away from me. If I needed things done, that would – couldn't be done, so I said to him, "Sorry,

[SUBJECT TO NON-PUBLICATION DIRECTION]. I have to get you replaced, because it's impractical at the moment. I'll put my two good friends on as my guardians."

MR KNOWLES: Yes. And, in terms of their guardianship and the neurological assessment that came after that, is that the neurological assessment that you referred to earlier that said that you did have capacity to make decisions for yourself?

MR AMATO: Correct.

MR KNOWLES: And that was the one that was finalised in August of 2018; is that right?

MR AMATO: Correct. Correct.

MR KNOWLES: Now, you've described in your statement that one of the obstacles for you in leaving the residential aged care facility was the level of trust shown in you and your ability to self-administer insulin.

MR AMATO: Correct.

MR KNOWLES: Can you talk about that a little bit for us to understand precisely what you mean.

MR AMATO: Well, before I went to hospital in 2015, I was injecting insulin into myself and not eating. That's a no-no for a type 1 diabetic – with the intention of committing suicide. I was trying to do that. So when I went into aged care, they didn't trust me that I mightn't – wouldn't do that again if I – that – I was allowed to self-administer. I can see their point now in doing what they did. But I had to go through the process of proving to them and proving to everyone that I could take the insulin without supervision and I wouldn't try and kill myself again.

MR KNOWLES: Did you have other people, though, that were prepared to supervise you with that outside of residential aged care?

MR AMATO: Yes, I did, my two guardians.

MR KNOWLES: Yes. And, despite that, though, how long did it take for the residential aged care facility to allow you to self-administer insulin at the premises under the supervision of a nurse?

MR AMATO: November 2018 was the first time.

MR KNOWLES: Yes. And when had you first been told by a doctor – your doctor – that you were able to do that under supervision?

MR AMATO: In July 2018.

MR KNOWLES: So there was a five month period before you were allowed to actually do that?

MR AMATO: Yes. Correct.

MR KNOWLES: In terms of being able to self-administer insulin offsite, outside of the residential aged care facility, why was that important to you?

MR AMATO: Because that would mean that I could go out with anyone, have a meal, go out to be a normal person, live a normal life away from the nursing home.

MR KNOWLES: And what sort of events had you had to miss or either make special arrangements for because of your inability to – or your perceived inability to self-administer insulin?

MR AMATO: Have a registered nurse around me when I had to do it, to supervise me.

MR KNOWLES: Yes. Did you have to make those sort of arrangements, as I understand it from your statement, at attendances at weddings and funerals?

MR AMATO: Yes. Correct.

MR KNOWLES: Now, after you were able to self-administer insulin, under supervision of your guardians, what other steps did you take to regain your independence so that you were able to leave the residential aged care facility?

MR AMATO: Go away with my girlfriend for weeks at a time – a week at a time, go to movies, go to concerts, like normal people do, go to the movies with her. I couldn't do that in a nursing home, because I was on a four hour structure for my medication, had to be back every four hours to get my medication done. I know their system – like, it's to stop elderly that Alzheimer's – like, for example. They don't know how to do those sorts of things, do they? So I know why they have those rules in place, but I wasn't Alzheimer's. I could do it myself.

MR KNOWLES: You finally left the nursing home earlier this year. Where did you initially live after you left?

MR KNOWLES: With my girlfriend in Queanbeyan, New South Wales.

MR KNOWLES: And where do you live now?

MR AMATO: I live in Melba, ACT with my girlfriend.

MR KNOWLES: And that's Jane; yes?

MR AMATO: Yes. It was 17 May 2019 that we had settlement.

MR KNOWLES: And do you have a guardian anymore?

MR AMATO: No.

MR KNOWLES: When did you stop having any guardians?

MR AMATO: In about April 2019. I think – I'm just guessing. Okay? Around that time.

MR KNOWLES: But around that time you were seen as suitably self-sufficient not to require - - -

MR AMATO: Yes.

MR KNOWLES: - - - any guardian?

MR AMATO: Yes. The Administrative Appeals Tribunal in the ACT allowed me to be my own self-guardian.

MR KNOWLES: Yes. Do you have anybody acting as an advocate for you anymore or assisting you with navigating the system?

MR AMATO: No.

MR KNOWLES: Would you like to have a person like that still?

MR AMATO: I would, yes.

MR KNOWLES: And do you still have contact with the same NDIS support coordinator?

MR AMATO: Yes, I do.

MR KNOWLES: Yes. And what's presently funded for you by the NDIS?

MR AMATO: My funding has been cut a lot because of the – moving out of the nursing home but it's appropriate enough to fund things I need, like a four hour a week carer; that's enough for that.

MR KNOWLES: And that four hours a week, what does the carer do for you during that time?

MR AMATO: Take me shopping, we go and have a coffee. I go to swimming lessons and things like that which I need.

MR KNOWLES: What other things have happened for you in your life since you left the residential aged care facility?

MR AMATO: I've got a job.

MR KNOWLES: Yes. And where are you working?

MR AMATO: I'm a tax accountant again.

MR KNOWLES: And how many hours a week - - -

MR AMATO: So be careful.

MR KNOWLES: How many hours a week are you working now, Mr Amato?

MR AMATO: About 15 to 18.

MR KNOWLES: Yes. And had you worked at all while you were in the residential aged care facility?

MR AMATO: No, not at all.

MR KNOWLES: Okay. What about transport; have you been – do you drive a car or anything of that nature?

MR AMATO: I'm on my L-plates at the moment.

MR KNOWLES: So you're seeking to regain your driver's licence.

MR AMATO: Yes, on 27 September hopefully I will. Not far away.

MR KNOWLES: Yes.

MR AMATO: So watch out on the road, okay.

MR KNOWLES: Did you ever contemplate trying to get your driver's licence - - -

MR AMATO: Yes.

MR KNOWLES: - - - while were you in a residential aged care facility?

MR AMATO: Yes, I did.

MR KNOWLES: You did think about it then.

MR AMATO: Yes.

MR KNOWLES: Yes. But did you ever make steps toward doing that then?

MR AMATO: Yes, I did.

MR KNOWLES: Okay. And what are your interests in life, Mr Amato; what do you like doing in your spare time?

MR AMATO: Following Carlton Football Club.

MR KNOWLES: Well, I feel sorry for you in that respect, I must say, but anyway.

COMMISSIONER BRIGGS: I do, too. There's no mention of the Canberra Raiders in there.

MR AMATO: No, they're a waste of time.

MR KNOWLES: Do you see your kids?

MR AMATO: Yes, I do.

MR KNOWLES: How is your relationship with them?

MR AMATO: Very good.

MR KNOWLES: Yes. And what about other family members?

MR AMATO: Yes, I talk to both my brothers now and that's good. I still don't talk to my sister but she's been off my scope for a fair while because we've had an argument so you know how family is, but the – I talk to my friends a lot, joke around a lot. My brain is coming back okay, I follow Carlton.

MR KNOWLES: And do you have any plans for the future for you and Jane: do you intend to travel or do other things like that?

MR AMATO: Yes. For my 60th birthday next year I want to take Jane to Italia.

MR KNOWLES: Are these the sorts of things that you felt like you were able to pursue when you were in aged care?

MR AMATO: No, not at all.

MR KNOWLES: In terms of your life now, do you think you could have had that life while you were in residential aged care?

MR AMATO: No.

MR KNOWLES: Okay. Is there anything else that you wish to tell the Royal Commission yourself, Mr Amato?

MR AMATO: Look, the thing is I know why the aged care facilities are there, Commissioner. They're there for the elderly, that are on their last steps in life but

they're not for a young person. And we need something else for younger people like me and the previous person, somewhere else for us to be in. I know that will cost the government a lot of money but we need to make adjustments to the system. That's all. And younger people shouldn't be in aged care facilities.

MR KNOWLES: Thank you, Mr Amato. I have no further questions for Mr Amato.

COMMISSIONER BRIGGS: Thank you, Mr Amato. I couldn't agree with you more that younger people shouldn't be in aged care facilities. I was struck by the delicacy which you told your story and the very personal nature of that story, but I think my takeaway from what you're saying is that you've now found a new life and that's a good thing.

MR AMATO: Yes.

COMMISSIONER BRIGGS: And that the aged care system didn't provide you with the life or the control over your circumstances or the opportunities that you needed to have that life. So that's quite an important message for the Royal Commission.

MR AMATO: Yes.

COMMISSIONER BRIGGS: So thank you very much for your evidence today. I really appreciate it and I look forward to hearing about the holiday to Italy for your birthday. With that said, you're now officially excused from giving further evidence before this Royal Commission. Thank you.

MR AMATO: Thank you.

<THE WITNESS WITHDREW [1.15 pm]

COMMISSIONER BRIGGS: Now, it looks like we're ahead of time again, or we've caught up a bit, Mr Knowles.

MR KNOWLES: Yes, Commissioner. It may be possible to take lunch away from this room.

COMMISSIONER BRIGGS: I'd like to have some lunch, I have to say. So how about we resume at around 5 to 2 and we'll see if we've got everyone in the room at that time. Is that okay?

MR KNOWLES: Yes, if the Commission pleases.

COMMISSIONER BRIGGS: All right. Thank you very much

ADJOURNED **[1.16 pm]**

RESUMED **[1.57 pm]**

COMMISSIONER BRIGGS: Good afternoon. Mr Knowles.

MR KNOWLES: Thank you, Commissioner. Before proceeding with the next panel of witnesses, I understand there are some parties which wish to announce their appearances.

MR McLAY: If it pleases the Commissioner, my name is McLay. I appear on behalf of the State of Victoria and the Transport Accident Commission as a statutory authority.

COMMISSIONER BRIGGS: Thank you.

MR GOLDING: May please the Commissioner, name is Golding, and I appear on behalf of the State of South Australia pursuant to leave that has previously been granted, and in particular, Ms Tamara Tomic, who is here on behalf of the Lifetime Support Authority which is a statutory authority in that State.

COMMISSIONER BRIGGS: Thank you, Mr Golding.

DR PRITCHARD: May it please - - -

COMMISSIONER BRIGGS: Dr Pritchard.

DR S. PRITCHARD SC: - - - ..... prior appearance. I also appear with MR FRASER of junior counsel for the State of New South Wales.

COMMISSIONER BRIGGS: Thank you, welcome back.

MR KNOWLES: Commissioner, perhaps if each of the witnesses might now take the oath or the affirmation.

<TAMARA RUTH TOMIC, AFFIRMED **[1.58 pm]**

<DEBORAH HOFFMAN, AFFIRMED **[1.59 pm]**

<SUZANNE MARGARET LULHAM, SWORN **[1.59 pm]**

<ELIZABETH CAIRNS, AFFIRMED [1.59 pm]

MR KNOWLES: Can I start by asking each of you, perhaps starting with you, Ms Cairns, to tell the Royal Commission your full name.

MS CAIRNS: It's Elizabeth Cairns.

MS LULHAM: Suzanne Margaret Lulham.

MS HOFFMAN: Deborah Hoffman.

MS TOMIC: Tamara Ruth Tomic.

MR KNOWLES: Ms Cairns, can you tell the Commission what your present position is.

MS CAIRNS: I'm the head of the independence division at the Transport Accident Commission here in Victoria.

MR KNOWLES: And Ms Lulham, your position.

MS LULHAM: I'm the general manager, care innovation excellence at icare, New South Wales.

MR KNOWLES: Ms Hoffman.

MS HOFFMAN: I'm the general manager of care services at icare.

MR KNOWLES: And Ms Tomic.

MS TOMIC: Chief executive, Lifetime Support Authority of South Australia.

MR KNOWLES: Thank you. Now, can I start with you, Ms Lulham, if I can take you to a statement that you prepared for the Royal Commission dated 28 August 2019? It's document WIT.0433.0001.0001. I understand you have a copy of your statement with you there. Have you read your statement lately?

MS LULHAM: Yes, I have.

MR KNOWLES: And is there anything you wish to change your statement?

MS LULHAM: No, it's fine.

MR KNOWLES: Are the contents of your statement true and correct to the best of your knowledge and belief

MS LULHAM: They are.

MR KNOWLES: Yes. Thank you. I seek to tender the statement of Ms Lulham.

COMMISSIONER BRIGGS: The witness statement of Ms Suzanne Lulham dated 28 August 2019 will be exhibit number 9-14.

EXHIBIT #9-14 WITNESS STATEMENT OF MS SUZANNE LULHAM DATED 28/08/2019 (WIT.0433.0001.0001)

MR KNOWLES: Ms Hoffman, if I can take you to your statement, do you have a copy of that there with you?

MS HOFFMAN: Yes, I do.

MR KNOWLES: Yes. And that is the statement dated 28 August 2019.

MS HOFFMAN: That's correct.

MR KNOWLES: Yes. And it's document WIT.0432.0001.0001. Now, can I take you in that statement to paragraphs 11 and 13, and you may be able to check this by reference to Ms Lulham and the statement she's holding beside you. Is there anything you wish to correct in relation to paragraphs 11 and 13 in your statement?

MS HOFFMAN: Yes, I note that the order of the numbering in 11 and 13 is incorrect. It should have started with 0433.0001.0001 in both 11 and 13.

MR KNOWLES: You mean the ordering of the numbering referring to the document ID for Ms Lulham's statement; is that right?

MS HOFFMAN: That's correct, yes.

MR KNOWLES: Yes. Subject to correcting that numbering of her statement, is there anything else that you wish to change in your statement?

MS HOFFMAN: No, there's nothing else.

MR KNOWLES: And are the contents of your statement true and correct to the best of your knowledge and belief?

MS HOFFMAN: They are.

MR KNOWLES: Yes. Thank you. I seek to tender the statement of Ms Hoffman, subject to those minor changes.

COMMISSIONER BRIGGS: Subject to those minor changes, the witness statement of Deborah Hoffman dated 28 August 2019 will be exhibit number 9-15.

EXHIBIT #9-15 WITNESS STATEMENT OF DEBORAH HOFFMAN DATED 28/08/2019 (WIT.0432.0001.0001)

MR KNOWLES: Ms Cairns, you've prepared a statement for the Royal Commission dated 26 August 2019, and it's document VIH.0023.0001.0001. Sorry, pardon me, I see that I've got the number wrong. It's as on the screen, WIT.0421.0001.0001. Pardon me. Have you had an opportunity to read your statement lately?

MS CAIRNS: I have.

MR KNOWLES: Thank you, and is there anything you wish to change in your statement?

MS CAIRNS: No, there's not.

MR KNOWLES: Are the contents of your statement true and correct to the best of your knowledge and belief?

MS CAIRNS: They are.

MR KNOWLES: Yes. Thank you. I would seek to tender the statement of Ms Cairns dated 26 August 2019 with the document number WIT.0421.0001.0001.

COMMISSIONER BRIGGS: Thank you, Mr Knowles. The witness statement of Liz Cairns dated 26 August 2019 will be exhibit number 9-16.

EXHIBIT #9-16 WITNESS STATEMENT OF LIZ CAIRNS DATED 26 AUGUST 2019 (WIT.0421.0001.0001)

MR KNOWLES: And Ms Tomic, you've also prepared a statement for the Royal Commission. That's dated 29 August 2019.

MS TOMIC: Yes.

MR KNOWLES: And that's WIT.0393.0001.0001. Have you had a chance to read your statement lately?

MS TOMIC: Yes.

MR KNOWLES: Yes. And is there anything you wish to change your statement?

MS TOMIC: No.

MR KNOWLES: And are the contents of your statement true and correct to the best of your knowledge and belief?

MS TOMIC: Yes.

MR KNOWLES: Thank you. I seek to tender the statement of Ms Tomic dated 29 August 2019, Commissioner.

COMMISSIONER BRIGGS: The witness statement of Tamara Ruth Tomic dated 29 August 2019 will be exhibit number 9-17.

EXHIBIT #9-17 WITNESS STATEMENT OF TAMARA RUTH TOMIC DATED 29/08/2019 (WIT.0393.0001.0001)

MR KNOWLES: Thank you, Commissioner. Now, I've asked you in short compass about your positions now. Can you tell the Commission, each of you, starting with you, Ms Cairns, what is actually entailed in fulfilling the role that you are presently in?

MS CAIRNS: Certainly. The independence division is one of three claims divisions within the Transport Accident Commission. The client group, client cohort that the independent division is set up to support are people who sustained a significant or permanent disability. They – those types of injuries are typically spinal cord injury, moderate to severe brain injury and we have a smaller group of clients with injuries such as significant burns, multiple amputations and blindness. The general expectation of the client group is that they will require a long term if not lifelong need for support from TAC.

MR KNOWLES: Yes.

MS CAIRNS: The role that I've got is leading the division in terms of its performance, in terms of the client experience, client outcomes and making sure that we are also managing the scheme on a financially sustainable basis.

MR KNOWLES: Yes, thank you, Ms Cairns. Ms Lulham, can you explain your position to the Royal Commission.

MS LULHAM: Yes. My role is responsible for a range of duties from managing the complaints and disputes area, looking at legislation and guidelines, as well as different service initiatives like our My Plan, looking at our self-management of our participants, looking at any gaps in services that there are and trying to, I guess,

create new services in the market to meet our particular client groups and also a role around provider management of our service providers in terms of the quality and services they deliver.

MR KNOWLES: Yes, thank you. Ms Hoffman your role at icare.

MS HOFFMAN: Yes, I'm responsible for the day-to-day operations and delivery of services to those individuals who have had a severe injury as a result of a vehicle accident or in the workplace. So it's really leading the day-to-day operations of the delivery of those supports and services.

MR KNOWLES: Yes. Thank you. And Ms Tomic.

MS TOMIC: As chief executive, I oversee the delivery of the lifetime support scheme so my role includes ensuring we've got appropriate service planning to provide care and support to participants, ensuring we have appropriate quality and safety frameworks and protocols and also ensuring the sustainability and governance of the scheme.

MR KNOWLES: If I can return to you, Ms Lulham, can you just describe in broad compass the nature of the scheme, or the schemes that icare manages and what icare's role is in connection with those schemes.

MS LULHAM: Okay. So icare, I guess, is a combination of the different insurance schemes within the New South Wales Government so it comprises lifetime care. It can work as insurance. The Treasury managed funds, the insurance – New South Wales insurance funds, Dust Diseases Commission which is people who have a dust disease from an exposure in a workplace as well as a home builder's warranty fund. But I guess in this group we're pertaining to the lifetime care and what we call the workers care scheme, so the model that we apply to lifetime care we now also apply to workers who've got the same injuries as our lifetime care cohort.

MR KNOWLES: And just to clarify, in terms of the cohort in lifetime care, who are they?

MS LULHAM: So they are similar to what Liz has described, so they are people who have got a mild to – a moderate to severe brain injury, spinal cord injury, multiple amputations, blindness and severe burns.

MR KNOWLES: And are they similar to what Ms Cairns has described in connection with the basis for having those injuries at the outset?

MS LULHAM: Yes, so if you meet – yes, the reason for looking at that injury group was they're a group that have a lifelong need for services over their time, yes.

MR KNOWLES: In connection with a motor vehicle accident.

MS LULHAM: Or a workplace accident.

MR KNOWLES: Or a workplace accident but that's a separate scheme.

MS LULHAM: Yes, separate schemes, separate funding source. But the model we use in terms of the service delivery goes across both, yes.

MR KNOWLES: I understand. And Ms Tomic, in terms of the Lifetime Support Authority, can you just explain what it does and how it does that.

MS TOMIC: So the Lifetime Support Authority is responsible under legislation for delivering the lifetime support scheme which is lifelong treatment, care and support for people seriously injured in motor vehicle accidents in the State of South Australia on or after 1 July 2014. The injury criteria is quite similar as described to the – by my colleagues here so we cover mild to severe brain injury, spinal cord injury, amputations at a relatively broad level as well as blindness and burns.

MR KNOWLES: And Ms Tomic, in your statement there at paragraph 9, you say that:

> *The scheme fulfils the State Government's bilateral agreement with the Commonwealth with respect to the State's responsibilities associated with the NDIS and the NIIS.*

Can you just perhaps elaborate a bit on that and explain what you mean by that.

MS TOMIC: As part of the State's – the State of South Australia's agreement with the Commonwealth for the rollout of the NDIS, the State agreed that they would have a scheme in place that met minimum benchmarks with respect to injury criteria as I described and making sure that we would provide lifetime care and support to that cohort if they were injured in a motor vehicle accident.

MR KNOWLES: And can I ask the other panel members, is that really what is behind the schemes ultimately that you are involved in yourselves?

MS LULHAM: Yes, the reason why we've combined the workers into our scheme is it meets the benchmarks for the National Injury Insurance Scheme.

MR KNOWLES: Ms Cairns, I see you contemplating that. The TAC is a longstanding authority insofar as its existence. I take it it's really something that predated the NIIS but it nonetheless fulfils those obligations on the part of the State of Victoria.

MS CAIRNS: Yes. The Transport Accident Commission gets its legislative mandate from a piece of legislation from 1986 so we've been in existence since 1987. We also do manage on a contractual basis the support for the people from the Victorian WorkSafe organisation that have sustained a catastrophic injury through

consequences of work too. It's a no fault scheme so we already meet the benchmark requirement for the NIIS.

MR KNOWLES: Yes. And in terms of the eligibility criteria to be a scheme participant, I think you've referred to the types of injuries that will qualify a person to be a participant, and at least in respect of the motor vehicle schemes, the fact of it having to relate to road trauma as such. Are there any other eligibility criteria in order for a person to be a scheme participant?

MS CAIRNS: So road trauma, it's a definition of road trauma under - - -

MR KNOWLES: A motor vehicle accident.

MS CAIRNS: Or a transport accident. We're covered by the relevant state legislation.

MR KNOWLES: Yes. But beyond that, are there any other eligibility criteria other than geographic connection to the State in question?

MS LULHAM: Well, in – for New South Wales the accident can be anywhere in New South Wales, and it doesn't matter if the vehicle is a registered vehicle from another state. The accident just has to be geographically in New South Wales.

MR KNOWLES: And does the same apply in respect of the other schemes in Victoria and South Australia?

MS CAIRNS: In Victoria it's linked to the registration of the vehicle so we have a number of clients who have incurred their accident interstate, but the link is back to the registration of the vehicle being Victorian-based.

MR KNOWLES: Yes.

MS TOMIC: For South Australia, in addition to the injury criteria we have criteria which defines what we mean by a motor vehicle accident so that is clear, and we also cover only accidents that occur within the state boundaries of South Australia.

MR KNOWLES: I see. And what are the entitlements of a scheme participant under each of the schemes, provided they meet those eligibility criteria? Can I start with you Ms Tomic, in that regard.

MS TOMIC: For the lifetime support scheme, when you are eligible based on your injury and accident criteria you're accepted, generally speaking, as an interim participant for the scheme. That interim – from that point of acceptance we will make sure you get all necessary and reasonable treatment, care and support in relation to your motor vehicle injury. So that includes medical, rehab, support for what you need to go back to living in home in the community, aids, that full range of what we would consider care and support for an injury. Usually an interim

participation period will last two to three years and the purpose of that period is for us to be able to make sure that you will continue to be eligible on a lifetime basis for the care and support you need. An assessment is done and most of our participants will then go on to be lifetime participants which entitles them to that care and support for the rest of their lives.

MR KNOWLES: Yes, thank you. Ms Hoffman or Ms Lulham, is there anything that you would say in your scheme is distinctly different from what Ms Tomic has described?

MS LULHAM: The only difference is our interim period is two years if – and it can't extend beyond that point in time. And just to make the comment, that's mainly that the people with a brain injury may recover sufficiently. People with spinal cord and an amputation, burns, usually stay.

MR KNOWLES: Yes.

MS LULHAM: But a certain number of people with a brain injury do recover.

MR KNOWLES: And Ms Cairns, in terms of entitlements of scheme participants?

MS CAIRNS: So, yes, TAC doesn't have an interim participant status. We've organised ourselves through the three claims divisions so we do get a bit of movement through the three claims divisions. The entitlements include you can – we will pay you effectively weekly benefits. If you're a child or a student at the time and you reach a 50 per cent impairment level and that's not going to change, you may be entitled to a loss of earnings potential payment. We pay common law when someone other than you has been at fault. There's an impairment payment scaled up depending upon the percentage of whole body impairment, and we pay for treatment and disability supports. And they range from personal care and supports right through to things like equipment, modified motor vehicles, modified houses and supported accommodation as well.

MR KNOWLES: Sorry, the last thing you said was supported accommodation?

MS CAIRNS: Supported accommodation, yes.

MR KNOWLES: Yes. Okay. Thank you. Do the other schemes also pay for supported accommodation as well?

MS LULHAM: We don't pay accommodation expenses, except for what we would call interim accommodation which is while perhaps we're waiting for some home mods to be done, so people can get out of hospital for that period of time, we'll pay interim accommodation.

MR KNOWLES: But home modifications are part of the entitlements that a person might receive.

MS LULHAM: Home mods, yes. Yes.

MR KNOWLES: And Ms Tomic in South Australia.

MS TOMIC: Yes. We will pay for supported accommodation and that is accommodation in respect of what someone needs related to their motor vehicle injury.

MR KNOWLES: Yes. Thank you. Now, in terms of the funding arrangements of each of the schemes, are they broadly the same? And perhaps if I can start with you, Ms Cairns, as to what the source of funding is for the scheme?

MS CAIRNS: The primary source of funding is the TAC component of the annual registration fee for a motor vehicle in Victoria. We also – as an insurance scheme, we offset our running expenses through investment returns as well, and that's managed for us in Victoria through the VMIA.

MS LULHAM: We collect a levy on the CTP policies and a proportion of that - - -

MR KNOWLES: Compulsory third party policies? Yes, thank you.

MS LULHAM: Compulsory third party. And it's what we would call fully funded, so we collect that levy for that injury cohort for that year to last their lifetime.

MR KNOWLES: And is it the same situation in South Australia?

MS TOMIC: Yes, very similar in South Australia. Our lifetime support levy is calculated as a standalone levy by the Lifetime Support Authority under the legislation and that is also for life – to fund the lifetime liabilities estimated for the cohort of participants likely to enter in the year ahead.

MR KNOWLES: Yes. And so can I ask each of you what you see is the key differences between these State insurance schemes on the one hand and the National Disability Insurance Scheme on the other. Recognising, of course, that you're dealing with injuries on the one hand and disabilities on the other, and you're also dealing with a specific cause of injury, if we just deal with the motor vehicle cause of injury, and you're also dealing with limited types of injuries as distinct from a broader range of injuries or a broader range of disabilities. Can you just, each of you, perhaps if I start with you, Ms Hoffman, reflect on how that affects day-to-day differences between your scheme and the NDIS.

MS HOFFMAN: I think one of the key differences of our scheme is that it's not age-related so we have people of all ages entering our scheme. There is no age cut-off point at all, so regardless of when you have your injury and what type, it's not related to age. It's not related to your residency as well. That would be another difference. It's just related to when – if you had the accident in New South Wales. That would probably be the two key differences in terms of age and residency.

MR KNOWLES: Yes. Ms Cairns, do you have anything that you wish to say in terms of differences between – because you – can I just ask, you've had previous experience working for the NDIA; is that right?

MS CAIRNS: Yes, that's right.

MR KNOWLES: Can you perhaps just tell the Royal Commission what that experience is.

MS CAIRNS: Certainly. I set up the Victorian trial site in Barwon for the first two and ran it for the first two years of the trial site. The status of that was from 2013 to 2015 and then I moved into a dual manager role with the headquarters of the NDIA moved from Canberra to Geelong and I moved from there to TAC in late 2015.

MR KNOWLES: Right. And bearing on those respective experiences, can you describe what you perceive to be the key differences between the NDIS and the TAC beyond that which I've just already alluded to earlier?

MS CAIRNS: Yes, certainly. I think probably some of the key things are that we – we provide a range of benefits so we can purchase – well, people receive their income support from us. If there's a common law entitlement, which can be significant, that is something that the TAC is responsible for assisting in paying. Impairment allowances are also an additional benefit. And we also have a direct funding relationship with Health. So if someone moves through, the – particularly in my client cohort, when someone moves through their rehabilitation journey, which can take many months in some cases, we pay – we have a direct contractual relationship with the Health Services in Victoria.

MR KNOWLES: Can I just ask you to elaborate on that direct contractual relationship and how it actually works and what benefits you perceive it has for the TAC and its scheme participants?

MS CAIRNS: Okay. So we have significant data sharing arrangements with the hospitals in Victoria, including the trauma hospital, the primary one being the Alfred, but also Ambulance Victoria, so that gives you information very early on after the accident. And we use that primarily to make sure that people who require our support and are eligible as TAC clients get access to the scheme very quickly. So early identification and then we can effectively intervene and get close to the clients and their family very early on as well. The direct funding relationship that we've got, particularly in the inpatient rehabilitation stage means that we get access to clients and their families and work collaboratively with the health treating team to make sure that we stay in close to the discharge planning. That starts very early on in the admission when it's done well.

So the outcome of that means that we've got to – I guess because we're paying money, we've got a – we get a seat at the table, for want of a better word, and we get to learn a lot about the client, get to understand what the client's and their family's

preferences and goals are, make sure that there's good strong linkages between the client, between our staff and the treatment team, the rehabilitation team. So that the discharge planning, I guess there's no surprises and it can often take very many months to understand what a client needs, what their recovery or independence levels are going to be upon discharge. And that really helps inform what it is that we need to do at our end to make sure that the client is going to the best place possible.

And also making surely that we work as quickly as we can to make sure that they get the right equipment and the right – for instance, the right attendant care supports. But also, where they're going home, that we've got an opportunity to do health and modifications. Now, sometimes housing modifications, particularly with our client group, are extensive. It's a long drawn-out process. You've got a whole lot of considerations around funding, subcontractors. We do have a housing team within our structure that manages all of that. But that doesn't keep the client in hospital. We have an arrangement in Victoria where we can support and fund the client to go into interim accommodation whilst they're waiting for their own home to be modified. Typically that is something like an accessible apartment unit.

MR KNOWLES: Yes, and do you have formalised arrangements in terms of provision of those apartment units in place?

MS CAIRNS: We tend to use one provider.

MR KNOWLES: Yes.

MS CAIRNS: Not on a contractual basis, because they don't have a state-wide footprint, but we certainly, within the Melbourne metropolitan area we have a working arrangement, it's not a formal contractual arrangement.

MR KNOWLES: Right. And can I ask each of you on the panel otherwise, how do your respective schemes – and I start with you, Ms Tomic. How do your respective schemes get early access to people who are or may be eligible to become scheme participants?

MS TOMIC: The primary way we would find out about potential participants for the scheme is through the hospital network, so we have close relationships with South Australia's major trauma hospitals, which in particular are the Royal Adelaide, Women's and Children's and Flinders Medical Centre. By having close relationships with those hospitals and the particular units who we would expect to see potential participants of the injury types accepted into the scheme as well as relationships with the social workers on the wards. We usually get notifications relatively soon post-accident. If it is an injury that is perhaps not as apparent – like, a brain injury may not be apparent at the time of being in hospital – we would generally find out through community services or potentially through other rehabilitation providers.

MR KNOWLES: And just in terms of those close relationships, I take it that they're not akin to what Ms Cairns has described as existing in Victoria, that is, that they're not contractual in nature.

MS TOMIC: That's correct, they're not contractual in nature. So we have that relationship because both the treating teams and the Lifetime Support Authority are interested in getting the best possible outcome for participants. And that means where they're able to move through the hospital system and into acute rehabilitation and then back through discharge planning into their home or into the community. It's in the best interests of all the parties to work closely together.

MR KNOWLES: An so how, particularly, are those close relationships formed between scheme staff – or I should say Lifetime Support Authority and the actual hospitals themselves as the key source, as I take it, of people who may be participants in the scheme?

MS TOMIC: So we have one manager, who is our intake officer. And she will do my on the groundwork that's associated with making contact with the participants and their families in the early stages after injury. So we're in the position – given the size of our scheme, we expect about 50 people to be eligible per year, but we do have one manager who's primarily responsible for that intake planning and acceptance process.

Once someone is accepted into the scheme, they are allocated an in-house service planner to oversee their discharge planning and understand what the participant's injuries are, their immediate needs and then over the long term their goals for the future. So we find that in our in-house model where we have service planners who are allied health professionals working with participants then enables them to understand and then make contact with the treating teams and be involved in those conversations and discussions.

MR KNOWLES: I see. And in New South Wales do you also have relationships with these sources of potential participants for your schemes?

MS HOFFMAN: We do. We have quite strong relationships, very similar to what Tamara has said in regards to relationships with major hospitals and the brain injury unit, spinal injury units, as well. So we've really established that quite well. We have regular conversation was with them. We have a similar pathway in terms of allocating a staff member who will be responsible for actually liaising with hospitals on a regular basis, so they're well known. They're a known face, as well. And so the social workers will know them quite well. The cleaning team will know them quite well. We call them a community liaison officer. And it's a function that is performed by our single point of contact staff. Yes.

MR KNOWLES: Now, in terms of the NDIS as such – well, pardon me. Perhaps, before I go to the NDIS, you've referred to this, Ms Cairns, how that can lead to an early intervention in respect of discharge planning and how beneficial that can be.

Obviously, this hearing is relating to younger people in residential aged care. How does the TAC in that early intervention discharge planning come to avoid, if that is what it does, young people entering into residential aged care?

MS CAIRNS: It's a combination of, I guess, the service model that we've got. So, like the other schemes, we have a dedicated team of staff. We call them independence coordinators and their job is to work alongside the client, the treatment team and the client's family. And they do that from the time that we know about the client. They follow them through their inpatient and treatment and rehabilitation and they stay with the client for about two years post-discharge. So they follow that client into their community.

MR KNOWLES: Yes.

MS CAIRNS: They're responsible for, effectively, making sure the client has access to all the entitlements that are require that we're responsible to fund. Internally, we have set up a panel. It has been running for about 18 months of senior staff. So where someone can't go back to their own home, either in the shorter or longer term or, in fact, permanently, we have, effectively, an accommodation panel that's been set up that takes into consideration all of those circumstances. And one of the principles behind that panel is that someone who's under 65, an aged care facility is really the last – the last option. So it's something that we actively work to avoid.

We do have a number of clients that achieve supported accommodation after interim care. We do support, as I said before, people in interim accommodation. And the panel very, very much makes a decision taking into account the client's needs, the family's circumstances, the client preferences, family preferences, and guides – effectively, guides the – the thinking and the support around the discharge destination, but the belief and approach that we have that an aged care facility is the last resort for someone who's younger.

MR KNOWLES: And how successful has the TAC been in terms of people under 65 not entering into residential aged care?

MS CAIRNS: We've got 13 people under 65 in residential aged care across the state. And only one of those is under 45.

MR KNOWLES: And can you give some indication of what that represents in terms of the overall cohort of people in supported accommodation or otherwise in accommodation that has been modified?

MS CAIRNS: So about – about 95 per cent of our clients go back either to their own home or to family homes. We – and that's several thousand. We actively – we have about two and a-half thousand clients that we regard as actively – that we're actively working with and are deemed by us to have claims requiring administration and management. And we've got about another 1500 clients in the independence

division who we're not actively engaged with, because they've been with us for a very long time and they come and go as things change. We don't want to be overly intrusive, but we want to stay close enough to the people that need us when they need it. We had 97% of people living in independent supported accommodation. And we had very small numbers in SRSs in the State. And we had - - -

MR KNOWLES: SRSs being?

MS CAIRNS: They're sort of a boarding house arrangement. So typically in past years they've been used by people who've required supported accommodation at a level – it's typically regarded as a mental health cohort, typically.

MR KNOWLES: I see.

MS CAIRNS: And then we have about 32 people living in our operated Shared Supported Accommodation properties.

MR KNOWLES: Yes. And they're properties that are operated by the TAC.

MS CAIRNS: Yes. They are owned by an independent subsidiary of the TAC that does the bricks and mortar. And my division supports those clients with their everyday supports as they are needed in the same way that we would if they were living in any other environment.

MR KNOWLES: And, just to be clear, so of the 2600-odd active participants in the scheme you only have 13 who are in residential aged care?

MS CAIRNS: And one of those 1300 is under 45. So some of the others are approaching 65.

MR KNOWLES: Yes. And you've provided as exhibit 6 to your statement, as I understand it, a de-identified description of people who are in residential aged care.

MS CAIRNS: I have.

MR KNOWLES: Thank you. And, Ms Lulham and Ms Hoffman, can you say how successful you have been in terms of scheme participants who are under the age 65 not entering into residential aged care?

MS LULHAM: Well, we currently have two participants out of around about 1470 in residential aged care. One of them is reasonably young, but it would be fair to say that actually she went home first and, because of family circumstances and at the family's wishes, she is now in a residential aged care. So she wasn't discharged into residential aged care.

MR KNOWLES: I see.

MS LULHAM: We would – if a person – it's mainly if the person doesn't have a home to go home to or the modifications required are too extensive for a rental property that you might look for a supported accommodation place, perhaps, rather than a residential aged care. I guess residential aged care just really doesn't come up in the discussion at all.

MR KNOWLES: Yes. So for your scheme, like Ms Cairns, it's a case of that being an absolute last resort - - -

MS LULHAM: Yes.

MR KNOWLES: - - - in every instance.

MS LULHAM: Yes. And a decision that's reviewed regularly. It isn't you're in there and that's it. I think we have had a few other people over time who have gone in for a period of time and then moved on as well.

MR KNOWLES: Yes. Ms Tomic, can I ask you about how successful your scheme has been in terms of avoiding younger people entering into residential aged care.

MS TOMIC: In terms of numbers, we only have one participant out of about 207 active participants who are currently in an aged care residential facility. There are a number of complexities associated with this participant. He was already living in that facility at the time he was accepted into the scheme and it's in a small country town, which also makes, given his needs, as well as his circumstances, including pre-existing illness, were challenging to find the right option. For him, this was also a decision based on family and family needs and wants, as well.

MR KNOWLES: Yes. And can I ask each of you, how much do you put this down to, these relatively small numbers of younger people entering into residential care, your involvement at an early stage in the hospital system after a person has been identified as a potential scheme participant? Can I start with you, Ms Tomic.

MS TOMIC: I think that's really vital to the outcomes that we're able to achieve. So because we start that discharge planning and those conversations quite early and we get to know the participant and their family really well, as well as what their needs be going to look like once they're discharged and likely into the future, our first preference, similar to my colleagues, is also to make sure we give someone the option to go back home. So we're looking at home modifications, properties that could be modified to enable them to go back to living in the family unit that they came from.

If that is not an option, then we would look at other supported accommodation arrangements and really put the net out there with our providers to understand what options there would be. It would be a last resort to consider a residential aged care facility for someone who didn't need that because of their age.

MR KNOWLES: Yes, thank you. Ms Hoffman or Ms Lulham.

MS HOFFMAN: I think the small numbers that we have allows us at the moment to have a dedicated person, so a single point of contact for people in hospital, which is great. As we grow, we grow our numbers to make sure that we continue to have that single point of contact that can actually be – almost be that person that can help navigate the scheme for somebody and look at all of those options. And I think that's a critical philosophy that we have, that all of our participants have a single point of contact. They can stay with the participant and their family and do that. And at the moment our numbers are relatively small, but as they grow we grow that resource to ensure that that happens.

MR KNOWLES: Yes. Ms Cairns, do you have anything to add beyond what's already been said?

MS CAIRNS: I think the opportunity for early identification and early intervention is critical. Having said that, when I talked to the support coordinator, even though we've got that in place, it's not uncommon that, because of the way the hospital system works and kind of the concept of bed blockers, that it's not uncommon that they have the conversations with the treatment team and – where residential aged care is prompted as a discharge destination. Or it might be an interim discharge destination.

So, even with these relationships and the direct funding relationship that we've got and the fact that we've got a client sitting with the support coordinator, there's still things in the system more broadly that place pressure on hospital and rehabilitation beds that need to – some of those conversations in the discharge planning process indicating that if we weren't there and able to influence that discussion, that, in fact, more people than we've got would be being discharged into residential aged care.

MR KNOWLES: I can actually see the other panel members nodding. Is that an experience that you're conscious of in respect of your own schemes, that but for a fairly significant presence in the hospitals more people might well be discharged from hospital into residential aged care when it's not appropriate?

MS HOFFMAN: I think it's possible that it might happen, yes.

MS TOMIC: And I think, also, the way that our scheme is funded also plays a part in that, in that because we're working with people early and we're going to have these people with us for their lifetimes, we're very conscious that their quality of life and their independence and their ability to recover in those early stages post-injury, by making sure that they're living in accommodation that suits their needs and their goals is really important, because there's not only how we get better outcomes for participants, but we can manage our long term funding and sustainability for the scheme. So that the ability to ..... things up front and early has, I suppose, benefits both for outcomes in the long-term sustainability of the scheme.

MS CAIRNS: And can I clarify - - -

MR KNOWLES: Yes.

MS CAIRNS: - - - I'm not meaning to convey that anyone in the inpatient rehabilitation treatment team necessarily thinks that residential aged care is an appropriate discharge destination, but hospital systems in terms of demand, the length of time that people stay in inpatient rehabilitation creates a real capacity issue for hospitals. And when someone is coming close to the point that they can be discharged, then that becomes a focus of the treatment team, because they know that they've got 20 other people waiting to queue up who need that service. So I would not like the Commission to think that there's anything inappropriate in that.

It's just the way the system works. And there isn't a nice kind of downstream transitional opportunity or accommodation option for many people. So the advantage that we've got in our schemes is when we're operating in that context and we've got the level of uncapped funding that we've got available to us, we can actually intervene and influence that discharge destination in a way that I suspect if we didn't have those close working relationships, didn't have that focus, the outcome for that client may be different.

MR KNOWLES: Can I ask each of you, perhaps starting with you, Ms Cairns, to just – reflecting on the experiences of your schemes and, of course, acknowledging the fact that they are very different in many respects to the NDIS, what lessons the NDIS might possibly learn from your schemes and how that might be of benefit to eliminating entirely, or at least in the short term mitigating the problem of younger people entering into residential aged care?

MS CAIRNS: Well, if I think about the things that we have come to understand works for us in Victoria, and clearly I think the experience across – with the two other States is similar, it's really important that the need to understand that the client is requiring rehabilitation. So if I think about a young person with a stroke for instance, early identification and the opportunity, because you know about that client as they are in the inpatient setting, the opportunity then to make sure that you've got a service response in the same way that we do in Victoria with our ready support team is, I think, critical. Now, we effectively can achieve that because we have a direct funding relationship. So this – for me this is something about the health and NDIS interfaces that are really important. If you – it's a really hard job for everybody.

If you hear about the client and they've been here for months and you hear them kind of the week before they're due to be discharged, you've got little, really, that you can effectively bring to the table with a week's notice. And that is a reality, certainly in the way that I understand how, in some cases, the health and the NDIS are interfacing. So early identification is really important. Because these situations are complex and you need time to first of all understand the client but also organise supports to wrap around the client so that they end up not going into an inappropriate

environment. Early identification, and I think a dedicated team of planners. I'll call them planners or liaison officers or whatever the phrase may be, that can do what our staff are doing in terms of being known and trusted. I guess colleagues of the rehabilitation teams, that's really important.

The relationships here are as important as the contractual arrangements that we may have. But also the ability the influence that discharge destination, and that goes to kind of the housing supply. So if someone doesn't have a home to go to, where do they go? And I think that's probably another part of the system response here as well.

MR KNOWLES: Yes. Can I ask each of you to add anything that you see fit to add.

MS LULHAM: I think, just to pick up on Tamara's point, is that because we actually have these people for life, we view that early stuff as an investment in them. So – and we invest very heavily in the rehab side of things and acknowledge that for some of these people they will be recovering for four to five years post-injury. And so because we pay for both the treatment, the rehab and the support, we don't have any delineations about who's paying for what. We pay for it all. So you can invest in rehab with a view that you may save in support in the longer term. So it's being able to take a slightly more holistic view about the whole thing as well.

MR KNOWLES: I think you've also indicated in your statement that sometimes you may have to deal with different governments through your scheme because although the injury occurs in New South Wales geographically, the closest hospital that the person might be taken to is outside the State.

MS LULHAM: Yes.

MR KNOWLES: And how are those relationships managed with the health system in another State?

MS LULHAM: Well, it's certainly made things easier now that all the States have a similar scheme, so they – all with the same injury criteria. So they will – they know our contacts and we similarly have a contact within Lifetime Care that is responsible for each of those States itself. The majority of those people will move back to New South Wales but not all of them. Some of them do live interstate and some of them live overseas. So it is about having a group of people who know the services in that area where those people are going back to. So that they've got a good knowledge about what's around and what you can build around the person as well.

MR KNOWLES: Yes. Ms Tomic?

MS TOMIC: I would just echo the comments made by Ms Cairns and also Ms Lulham, that it is about that interaction as a State-based authority with our health system. It's about our focus on recovery in that early intervention and also the

ability to be able to say see our rehabilitation and treatment in a holistic way as an investment in someone's outcomes for the rest of their life.

MR KNOWLES: Ms Cairns, can I just ask a – following up from something you said there, in terms of the liaison officers that the TAC has, how many of them are there in Victoria? To your knowledge.

MS CAIRNS: So the liaison officers are, that's the patient liaison officers.

MR KNOWLES: Yes.

MS CAIRNS: So they're not TAC employees.

MR KNOWLES: Right. I see.

MS CAIRNS: They are employees in a range of hospitals.

MR KNOWLES: I see.

MS CAIRNS: So it's a hospital function not funded by TAC. The role that we have, it's called early support coordinators, so they are TAC staff and they are the group of people – and I've got them around our four Offices, the group of people who work with the inpatient rehabilitation and treatment teams with those clients and their families at that phase of their rehabilitation and recovery. They also follow the clients out into the community for about a two-year period.

MR KNOWLES: Yes.

MS CAIRNS: So we don't – that relationship doesn't stop at the point of discharge because we know that that's a really key transition in someone's life. And so that staff member stays with that client and their family, on average, for about two years post-discharge.

MR KNOWLES: How many people of that nature are employed? Do you - - -

MS CAIRNS: I would need to actually check that. That was remiss of me not to have that at my fingertips. But we could – look, we would have several dozen. Their case loads on average are around about 25 - - -

MR KNOWLES: I see. Yes.

MS CAIRNS: - - - at any point in time and we get about 120 to 140 new entries a year. So the number of staff and the caseloads reflect the new clients coming in in any year plus the clients that they're continuing to work with.

MR KNOWLES: I see. Thank you for that. Now, you may have heard the evidence that's been given in this hearing of the Royal Commission that there has

consistently been about 6000 younger people in residential aged care, and of them, I think there is about 4000-odd that are scheme participants in the NDIS. Do you have any sense yourselves as to why that figure of younger people in residential aged care has persisted for so long and hasn't actually diminished? Can I open that to anybody who wishes to answer the question or provide a view?

MS CAIRNS: If I may. I – look, this is not a simple problem. It's quite a wicked, complex problem. If it were simple it would have been solved pretty quickly, I would hasten to say. There is – the previous funding models, if somebody was going to be supported in the community under the previous State and Territories Disability Scheme, it was a rationed system. So often, even if you did have a home to go back to, you simply could not access the level of services and support you needed to return to home. So you might not have been able to get the level of attendant care you need, the budget for high cost equipment might have run out for that year. The money available for housing modifications was very limited.

Now, the NDIS has certainly changed that and changed that for the better in my view. But these arrangements, the 6000 clients that are often talked about, many of them have been with us for many, many years, so that – and when you start to unpack that, it's so they've lost contact sometimes with their family, so therefore there isn't a home to go back to in all cases, and even now the NDIS can fund that money, there simply isn't a house to go to. So we are looking with, I guess, some optimism towards the what is a growing market with the specialist disability accommodation funding that the NDIS is putting into the market. But that's kind of at the beginning of that journey. So housing supply is definitely an issue.

There's something in some cases about family views on this too. So when I was – when I talked to clients and their families, they've often had to go through a number of very difficult decision points and there's some degree of, I guess, unacceptability about a young person being in a residential care home. But they're there, and certainly some of the clients that we've got, they're there because their connection to their community and their family, when they're living in a more remote part of the State, is actually important for them. And I think that's true probably of some of the people living in residential aged care as well. This a real legacy issue. These numbers haven't suddenly appeared over the last four to five years, but they do seem to be persistently high. It requires a particular planning approach. It requires comprehensive funding. It requires a lot of support of clients, and where families are still connected with them, to grow the confidence about moving out.

And they've got to see something that is sufficiently attractive for them to think that that's a worthy thing to do. Previously, it was residential aged care or a congruent care environment, a pretty old-fashioned group home arrangement. So there wasn't kind of a lot of opportunities or different living arrangements that might then get someone who's been living in residential aged care or, in some cases, their family who make decisions on behalf of some of them, to think that there was anything better out there. So there's multiple layers to this. And then, of course, you do have clients who've got really high and complex nursing needs. One of the clients in the

table I presented is in a semicomatosed state because of his brain injury. He requires access to 24 hours a day nursing care, regular suctioning, and it's very difficult to get that delivered into the community.

And in his case he's got very elderly parents who simply would not manage. By their own admission, would not manage in their home. Now, in time there will be other more age-appropriate living environments for people like him. But at the moment there isn't. So it's a mixture of all of these things that need to be understood in terms of how people came to be there, the choices that were, or the limited, very limited range of options that were available to them and, until recently, in most of our states there's been very limited other options too. So if you're making a choice between residential aged care or congruent care, where you might be living with six to 12 other people, they're not really good choices either.

MR KNOWLES: Ca.

MS LULHAM: I think Liz is right in the way she's outlined all the problems. And I think too move things on it is very complex and you almost need to have very skilled, dedicated workers to do that who, you know, even – and we have similar case loads of 25 to 30 as well, but really for this group it's probably even smaller than that. It's a really dedicated effort to look at all the options and to navigate all the systems. And it's not just the NDIS system, it's the Centrelink systems, it's the housing systems, and to have – that's a very skilled person to do and you've almost got to develop those skills in a group of people to do that. But I do think some of the changes they've made around the SDA, the very recent changes, I think will also assist moving some of these people on. But it really does take a very, very skilled person to plan, to get someone out and to bring all of that into play and coordinate it all really, really well.

MS CAIRNS: And to build the confidence of the client and their families as well. Certainly in all our cases, all of these people that we – our services support, have had arguably kind of a near death experience. And the family dynamics are really important to understand. I'm not suggesting that's any different with maybe someone who's had a catastrophic brain injury because of a stroke, for instance, but families – the family dynamics typically – not in all cases, but typically become very protective of their person. They've just about lost their son or daughter typically, and they – mums and dads often, in our context, or spouses become quite wary of situations where they think there's an element of risk involved. So in addition to what Suzanne said, navigating multiple complex systems is a real challenge and will require a very skilled workforce, but the other job that that workforce has is gaining the confidence and building up the trust and capability of both the client and their families to look at alternatives.

MR KNOWLES: Yes.

MS HOFFMAN: And I think the alternatives in terms of models as well, what we now face which we didn't have 10 years ago was an opportunity to look differently

about somebody's home in terms of what we can do in a homelike vocation space. There's technology that can build independence for people where we didn't have that sort of – those sort of options prior, and I think it's important that, you know, we had two extremes to some degree and we didn't have much in the middle in in terms of innovative housing models that would allow people to stay at home and be able to be safe, confident and be as independent as possible, and it think we've now got that opportunity to explore that much more.

MR KNOWLES: Ms Tomic.

MS TOMIC: Look, I think Ms Cairns, Ms Hoffman and Ms Lulham have described it perfectly and I think that it is exactly that. We've got now opportunities that we can now take advantage of in the way we can think about care and support for people and accommodation and that understanding of how a holistic approach to looking at someone's needs is not just about, well, who is going to – how much is that, how is it going to be funded and what options there are, but just to know when you've got people and families at the centre of this it is a – as well as the system issues, it's very difficult to navigate.

MR KNOWLES: Now, each of you have described the very small numbers of scheme participants for each of your schemes that are presently in residential aged care and under the age of 65 so in that regard, clearly all of these schemes have been very successful in avoiding that scenario. You would each be aware, of course, that the Australian Government announced its Younger People in Residential Aged Care action plan in March of 2019. Can I ask each of you whether, having regard to the successes that each of your schemes have had, were any of your organisations, to your knowledge, consulted by the Commonwealth about the development or implementation of that action plan? And perhaps if I start with you, Ms Tomic.

MS TOMIC: The Lifetime Support Authority wasn't contacted but other State organisations may have been.

MR KNOWLES: But you don't know.

MS TOMIC: No, that's correct.

MR KNOWLES: The Lifetime Support Authority was not contacted or consulted.

MS TOMIC: That's correct.

MR KNOWLES: Yes. And icare.

MS LULHAM: That's the same. We weren't contacted. That's not to say that that may not have contacted FACS or one of the other - - -

MR KNOWLES: But you don't know about that one way or the other.

MS LULHAM: But – don't know. And certainly we weren't.

MR KNOWLES: Yes.

MS CAIRNS: It's the same situation in Victoria; TAC wasn't contacted directly.

MR KNOWLES: Yes. Thank you. No further questions for the panel witnesses, Commissioner.

COMMISSIONER BRIGGS: Thank you very much, Mr Knowles. And let me say I found that a very, very interesting presentation and I think some of the foundational aspects of the NDIS must well be generated from the very good work that you're doing in these areas in the States. So thank you very much for what you've had today and for your generosity of spirit in letting us know some of the ways things are done, some of the shortfalls and some of the challenges. I think it's provided a very useful nuance to, certainly, my considerations and where we go from here. So thank you very much and I need to officially excuse you. So may I officially excuse Ms Tomic, Ms Hoffman, Ms Lulham and Ms Cairns from giving further evidence before this Royal Commission and thank you, of course, very much for doing so today.

MS TOMIC: Thank you.

MS CAIRNS: Thank you.

MS LULHAM: Thank you.

MS HOFFMAN: Thank you.

<THE WITNESSES WITHDREW [2.58 pm]

MR KNOWLES: I understand there will be a short adjournment to prepare the video link for the next witness.

COMMISSIONER BRIGGS: That's sounds very good. Let's have a break of five to 10 minutes while that link is set up.

ADJOURNED [2.59 pm]

RESUMED [3.07 pm]

COMMISSIONER BRIGGS: Mr Knowles, we have a connection to Switzerland, I think.

MR KNOWLES: We do, and on the other end of the line I call Dr Ben Gauntlett.

DR GAUNTLETT: Hello.

COMMISSIONER BRIGGS: Hello, Dr Gauntlett, nice to meet you.

MR KNOWLES: Now, you're just going to be asked to take the oath or the affirmation. The associate is just - - -

DR GAUNTLETT: Oath.

<BEN GAUNTLETT, SWORN [3.07 pm]

<EXAMINATION BY MR KNOWLES

MR KNOWLES: Thank you, Dr Gauntlett and thank you for attending to give evidence despite being overseas. You are the Disability Discrimination Commissioner. You've held that position since 7 March this year.

DR GAUNTLETT: 7 May this year, yes.

MR KNOWLES: Pardon me, 7 May this year. You're also a quadriplegic yourself following a schoolboy rugby union accident when you were 16 years old in Perth.

DR GAUNTLETT: Yes, that's correct.

MR KNOWLES: And what are the positions you've held prior to assuming in May this year the position of Disability Discrimination Commissioner?

DR GAUNTLETT: It's possibly easier if I just trace through my university career. After finishing high school, I did two years of medicine before transferring into law. I then went overseas to study at Oxford where I did a doctorate in law and at the same time then did a Masters in Law at NYU. Following that I commenced as a solicitor in private practice. I then went to become an associate at the High Court of Australia, counsel assisting the solicitor-general, and a barrister in Melbourne and Perth where I was working before I became Disability Discrimination Commissioner.

MR KNOWLES: And am I right in thinking that in 2003 you were the Rhodes scholar for Western Australia as well, Dr Gauntlett?

DR GAUNTLETT: That's correct.

MR KNOWLES: Now, the Australian Human Rights Commission provided a submission to the Royal Commission on 18 July 2019. You may not have that

before you, but it is for us here at tab 197 of the general tender bundle. Do you have a copy of that document otherwise available to you, Dr Gauntlett?

DR GAUNTLETT: I do, thank you, I have it on a soft copy on my iPad in front of me.

MR KNOWLES: Yes. And were you involved in the presentation of that document, Dr Gauntlett?

DR GAUNTLETT: I was not involved extensively but I certainly had input into the content of the document that I felt that I had sufficient expertise to comment in relation to.

MR KNOWLES: Yes. And for present purposes, can I go to what is paragraph 56 in the document. It's at the page -0012 for those of us here.

DR GAUNTLETT: Yes.

MR KNOWLES: We're just bringing the document here.

DR GAUNTLETT: Yes, I've got it.

MR KNOWLES: So paragraph 56. Now, there you were dealing with younger people in aged care and the relevance of the Convention on the Rights of Persons with Disabilities. You say - - -

DR GAUNTLETT: Yes.

MR KNOWLES: - - - at the end of that paragraph, you refer to the Royal Commission's terms of reference, including the term - - -

DR GAUNTLETT: Yes.

MR KNOWLES: - - - of reference going to how best to deliver aged care services to people with disabilities residing in aged care facilities, including younger people and you say:

> *That includes the implicit assumption that there is a place for young people in aged care and that that assumption is misguided the Commission is strongly of the view that there is no place for young people in aged care in Australia and extensive regulatory safeguards and provision of age appropriate care should be put in place to prevent that occurrence.*

DR GAUNTLETT: Yes.

MR KNOWLES: Could you just elaborate on that for the Royal Commission, Dr Gauntlett.

DR GAUNTLETT: Certainly. Aged care, I would say, has within it a series of elements, ways that you are living with people over a certain age. Another is that you are living in institutional arrangements. And under the Convention on the Rights Of Persons With Disabilities, article 19, which can be informed by general comment number 5, there is a clear mandate that people with disabilities should be able to live independently in the community, and the critical issue is the choice and control that they have. That is, that a person can choose where they wish to live and who they wish to live with, in circumstances where they are not in an institution, but rather they have control over their own lives.

And so it was felt that – or at least my reading of what was written there, is that the premise of the terms of reference is that there is a place for a young person in Australia in aged care, and the position I would advocate is that from a human rights perspective, that is incorrect.

MR KNOWLES: Just on that, Dr Gauntlett, obviously the Royal Commission has heard evidence, direct evidence this week, about – from people, younger people who have lived in aged care or their loved ones who have seen them live and die in aged care. This morning, the acting chief executive officer of the National Disability Insurance Agency, Ms Vicki Rundle, was asked about whether or not, having regard to those people who gave evidence, they had had the ability to enjoy their rights under article 19 of the convention. And she agreed that in the main it was right to say that they had not.

DR GAUNTLETT: Yes.

MR KNOWLES: Does that come as any surprise to you to hear that coming from the acting CEO of the NDIA?

DR GAUNTLETT: No, it doesn't.

MR KNOWLES: And why is that?

DR GAUNTLETT: I think for a long time in Australia we have let this issue lapse in terms of the ..... people with, particularly young people with complex care needs in the community, their arrangements once they're discharged from hospital. Because often the people involved cannot advocate for themselves in a forthright manner, it has meant that they have, in a sense, drifted into, or fallen into cracks in the system. And the easiest way for their care needs to be taken care of is for them to have been placed in aged care institutions in Australia, rather than independent living arrangements in the community.

MR KNOWLES: Thank you, Dr Gauntlett. The Australian Human Rights Commission has also recently made a submission to the United Nations Committee on the Rights of Persons with Disabilities. That submission is dated 25 July 2019. For those of us here, it's found at tab 143 of the general tender bundle. Do you happen to have a copy of that document available to you as well, Dr Gauntlett?

DR GAUNTLETT: Yes.

MR KNOWLES: And that document goes to Australia's compliance with obligations under the convention, doesn't it?

DR GAUNTLETT: Yes, it does.

MR KNOWLES: Yes. And I've read out to the Royal Commission earlier today the terms of article 19, and you have effectively summarised them earlier, that it goes to choice about where you live, and the ability to do so as independently as possible.

DR GAUNTLETT: Yes.

MR KNOWLES: Yes. Now, can you perhaps go in the submission, if you have it there, in respect - - -

DR GAUNTLETT: Yes, do I.

MR KNOWLES: - - - of compliance with article 19, to paragraphs 81 and following, which will be found in the version here at pages 20 to 21.

DR GAUNTLETT: Yes, I have it open in front of me.

MR KNOWLES: Yes. Thank you, Dr Gauntlett. So at the bottom of page 20 one sees the heading Living Independently and Being Included in the Community.

DR GAUNTLETT: Yes.

MR KNOWLES: Did you have involvement in the preparation of this document?

DR GAUNTLETT: Yes.

MR KNOWLES: Yes. Thank you. And you've referred at paragraph 81 to the NDISs rules and operational guidelines for specialist disability accommodation, SDA.

DR GAUNTLETT: Yes.

MR KNOWLES: And across the page at the top of the next page you've described some concerns on the part of the Commission about those guidelines, in particular the concern that:

> *The SDA framework facilitates and encourages the establishment of residential institutions and will result in people having to live in particular living arrangements to access NDIS supports.*

Can you explain why - - -

DR GAUNTLETT: Yes.

MR KNOWLES: - - - that concern is held by yourself and the Australian Human Rights Commission?

DR GAUNTLETT: The SDA for Specialist Disability Accommodation arrangements, which is set forth within the rules, are premised on there being a market for the supply of both complex care in the community but also the built environment, relating to a person's needs. And the challenging aspects to this policy is that a lot of what's referred to is – does not presently exist. And so what can occur is that an individual seeking to live independently in the community can in a sense be stuck where they have chosen to initially move to, or with the people they choose – they have been initially allocated to. The concern I have is that a person will not be able to – will not be able to execute – sorry, will not be able to show appropriate choice and control as to their everyday life. This includes where a person has a significant intellectual or cognitive disability that the person's needs are considered in a supported decision-making framework, so that that person can decide what it is they want to, in terms of do with their life and someone who's not making a decision on their behalf.

The Specialist Disability Accommodation arrangements set forth in the rules, whilst premised on a number of market criterion, do require that there be a significant supply, both physical assets and care support in a number of locations without – throughout Australia and dealing with a number of individuals that may, as I said before, have complex support needs. They may have an intellectual disability but they also may come from a culturally or linguistically diverse background or be an Aboriginal and Torres Strait Islander. For that reasons I think there is a very real concern that what could happen is people get stuck in group arrangements where they're forced to live with people under one roof. And the reality of the situation is it just becomes a mini-institution, rather than independent living arrangement.

MR KNOWLES: In paragraph 82, if I can take to you that in the document - - -

DR GAUNTLETT: Yes.

MR KNOWLES: - - - you've there referred to concerns about the lack of appropriate and accessible housing in Australia, which I think you've just gone to a moment ago, but is there anything else that you would say to elaborate on that in addition to what you've already said?

DR GAUNTLETT: Yes. I would. The term accessible housing there includes people that would not be within the Specialist Disability Accommodation cohort. For example, it includes wheelchair users, people with mobility issues, people of age, etcetera. And so by having a shortage of accessible housing throughout the community, it puts pressure on people to, in a sense, use specialist disability accommodation housing because they cannot potentially live elsewhere. So there's

just a general shortage of overall housing and appropriate housing for people with disabilities in Australia.

MR KNOWLES: And in that regard, do you perceive potential problems with a purely market-based model to deal with that shortfall in housing for people with disabilities in Australia?

DR GAUNTLETT: I think that when dealing with people with disabilities, and their care requirements in the community, and ensuring that they can live full and independent lives, it is dangerous to rely upon purely market models, because the people that you're dealing with often have difficulty advocating effectively for themselves, and that can mean that they are taken advantage of or that the market develops in a way which is not always in their best interests.

MR KNOWLES: Can I take you, Dr Gauntlett, now, to paragraph 83 of the submission to the United Nations. And there you've referred to the younger people in residential aged care action plan, about which there's been much discussion during this hearing, and the Commission has welcomed the action – I shouldn't say you, but the Australian Human Rights Commission has referred to the plan and welcomed the action plan but stated:

> *However, the action plan should be revised to provide that no person aged under 65 years should enter or live in residential aged care by 2025.*

Can you just explain to the Royal Commission the basis for seeking a revision of the action plan in those terms?

DR GAUNTLETT: Yes. The action plan, from my understanding, has three goals, one of which is halving the number of people aged under 65 entering aged care by 2025.

MR KNOWLES: Yes, that's correct.

DR GAUNTLETT: I would say that that is inappropriate because, from a human rights perspective, no person being discharged from hospital or having a disability, should be living in aged care whatsoever. That by 2025 we should have developed sufficient resources to ensure there is no young – in aged care with a disability in Australia, as it is clearly inappropriate from a human rights perspective. And there is sufficient time to ensure that issues with market development can be dealt with within that timeframe.

MR KNOWLES: Thank you, Dr Gauntlett. Lastly, you already referred to people needing support in terms of access and advocacy for the purposes of getting the accommodation that's appropriate to them. In paragraph 84, you've mentioned again that role of advocacy – or I shouldn't say you. The Australian Human Rights Commission has mentioned that role of advocacy and recommended a specific stream of funding be introduced. What would - - -

DR GAUNTLETT: Yes.

MR KNOWLES: - - - that be directed to, particularly in this context where you're addressing concerns about compliance with article 19 of the convention?

DR GAUNTLETT: I think when we – when you consider the people who will – who are eligible or who do have specialist disability accommodation entered into their plans under the National Disability Insurance Scheme, it needs to be remembered that many of the people involved are – have intellectual or cognitive disabilities and/or they are in extremely challenging circumstances from a socio-economic perspective, given what has occurred to them.

Therefore, it is easy for those individuals to be placed in a situation where they just accept what's suggested to be a good outcome. That may not be any fault of the person asking them the question. It may just be that they do not know what they're otherwise entitled to and the benefits of it. And so when they're asked to consider whether they wish to move out of old age facilities or they wish to move from where they're living, they're not always aware of the benefits of doing so or why they might wish to, or what supports they might wish to have in this different location or the different arrangement in which they're living.

The best way to ensure that a person is properly represented in those situations is to have some form of independent advocacy for them, where the person is not the holder of either to the care provider, the National Disability Insurance Scheme, or the accommodation provider. That means that there is a clear voice for that individual to enable them to live the life in which they choose. Often, the individuals who are placed in aged care are placed there because they do not have family supports. They may be too old to have family supports, that their parents may be of a certain age. Their siblings may have gone off and started their own families. But there is a very real and important role for a systemic advocacy to ensure that people in this situation are properly protected.

And in a sense, if the Younger People in Residential Aged Care Action Plan is to work appropriately, there must be a clear mandate for independent advocacy to take place to ensure that a person with a disability knows the rights that they have to seek alternative accommodation options in the community.

MR KNOWLES: Thank you, Dr Gauntlett. There is one last paragraph in the submission that I do wish to take you to. And that concerns what is said by the Australian Human Rights Commission in respect of the action plan's focus, and that it seems, from its wording at least, to focus on those who are eligible to access the NDIS. Can I ask you to just elaborate on the recommendation and concern there that's set out at paragraph 85 of the submission.

DR GAUNTLETT: Certainly. From my understanding, the younger people in aged care plan and the figures from the National Disability Insurance Scheme indicate there are some people in aged care settings who are not eligible for the National

Disability Insurance Scheme. And I'm not 100 per cent sure why or how that occurs, but I do think it is critical that a proper assessment take place to enable these people to transition into the community to assess what their needs are and to find a way to ensure they're properly supported.

MR KNOWLES: Now, this is, obviously, a relatively recent submission, having been prepared on 25 July 2019, beneath those paragraphs I've taken to you are a number of recommendations which reflect the terms of those paragraphs. Has there been any response from the Australian Government in respect of the recommendations that have been made by the Australian Human Rights Commission?

DR GAUNTLETT: No, there haven't.

MR KNOWLES: Dr Gauntlett, is there anything further that you wish to say to the Royal Commission, whether from your personal or professional experience, about younger people in residential aged care, specialist disability accommodation or supported independent living?

DR GAUNTLETT: Yes, please. The ultimate role of the Australian Human Rights Commission is to shine the brightest light into the darkest places. And younger people in Australia living in old age care institutions, because of their disability or medical condition, is a dark and inappropriate circumstance for this country to have allowed to occur. It is a significant human rights issue that we allow this position to be maintained.

We need government to act decisively. It's very easy in disability policy to get into a situation where you think of us and them, us being people without a disability and them being people – those people with a disability. But the reality of disability is it doesn't discriminate and a person can become disabled as a result of something such as a brain aneurism and that person may be your parent, your friend, your son, your daughter, your partner. But if that does occur, in a humane society what should take place is that person should be able to receive treatment in the appropriate medical institution and then be released in the community to live independently or live the life in which they choose.

To say that by 2025, that we can only halve the numbers of people entering into aged care indicates a misallocation of resources. People who are living in aged care with disabilities do not, unfortunately, have a voice. They're often in circumstances where they feel extremely challenged by the life in which they lead, they may be depressed, they may have a cognitive impairment and they may have an intellectual disability. But that lack of a voice does not mean circumstances such as the Royal Commission and the Human Rights Commission for that matter should not shine a light on the issue that exists. And it's quite simple. By 2025, we should have no people with disabilities in Australia living in old aged care institutions.

MR KNOWLES: Thank you very much, Dr Gauntlett. I don't have any further questions for the Disability Discrimination Commissioner, Commissioner.

COMMISSIONER BRIGGS: Thank you Dr Gauntlett, I don't think I could have put that better myself or indeed more clearly. It's terrific that you were able to join us from overseas today. We really appreciate it and your preparedness to come and give evidence and explain the particular issues and the requirements on our country in terms of our UN obligations. We thank you very much for that. And I think I'm – all that is left for me to officially excuse you from giving further evidence before this Royal Commission. Thank you very much.

DR GAUNTLETT: Thank you, Commissioner.

COMMISSIONER BRIGGS: Goodbye.

<THE WITNESS WITHDREW [3.34 pm]

COMMISSIONER BRIGGS: Now, there is the question, do you want us to take a short break?

MR KNOWLES: I think we are going to have, if the Commissioner pleases - - -

COMMISSIONER BRIGGS: Sure.

MR KNOWLES: - - - a very short break to just allow for the next witness to get ready to give evidence.

COMMISSIONER BRIGGS: And I might make a little statement once he has taken the oath, if that's possible. Thank you.

MR KNOWLES: If the Commissioner pleases.

ADJOURNED [3.35 pm]

RESUMED [3.44 pm]

COMMISSIONER BRIGGS: Mr Rozen, welcome back.

MR ROZEN: Good afternoon, Commissioner. Commissioner, the last witness that we will call today is Mr James Anthony Nutt and I formally call Mr Nutt to the witness box.

<JAMES ANTHONY NUTT, SWORN [3.44 pm]

<EXAMINATION BY MR ROZEN

COMMISSIONER BRIGGS: Mr Nutt, welcome here this afternoon. I know that there have been considerable difficulties for you to give your evidence before this Royal Commission this week, and I sincerely apologise to you for that. I'd certainly been looking forward to it because you were, in fact, the first witness statement I read in preparation for this Royal Commission. The problem seems to be that our national airlines have been unable to accommodate your particular needs.

MR NUTT: That's correct.

COMMISSIONER BRIGGS: I know that you arrived at airports to be told that you cannot board the flight. Late cancellations of flights have left you away from your home and your support because no suitable alternative arrangements were made by the airlines for your needs. We thank you for your persevering with this and preparedness to be with us here today.

MR NUTT: No worries. It needs to be heard, so I'm happy.

COMMISSIONER BRIGGS: Good. Well, in my view, the ability of those with disabilities to travel throughout Australia is very likely to be relevant to the Disability Royal Commission, and I intend to raise this with my counterparts at that Commission as well. Thank you, Mr Rozen.

MR ROZEN: Thank you, Commissioner. Mr Nutt, you were due to fly down to Melbourne on Sunday night so that you could give evidence for us on Monday morning; is that right?

MR NUTT: That's correct.

MR ROZEN: And how did it feel when you learnt that you were going to be unable to do that for the reasons that Commissioner Briggs has just explained.

MR NUTT: It was soul destroying, I needed to come here because people like myself, young people in residential aged care, I needed to be here to give my voice for all of those who are not able to get here to do it. And those fellows, they – my evidence was going to be trampled into the ground without being able to be heard whatsoever. And I feel that anybody – everybody with a disability living in a nursing home, we need to be heard. It was just soul destroying, Peter.

MR ROZEN: Thanks, now, would you prefer that I call you, Mr Nutt or James?

MR NUTT: James, Peter.

MR ROZEN: Okay. And I'm very happy for you to call me Peter, James. James, I just need to deal with some formalities at the outset. Can you confirm for me your full name is James Anthony Nutt.

MR NUTT: Yes, James Anthony Nutt.

MR ROZEN: And you made a witness statement for the Royal Commission which you signed for us on 24 August 2019.

MR NUTT: Yes.

MR ROZEN: Is that right? And there are a couple of minor changes that you would like to make to your statement about the age you were when you first entered aged care.

MR NUTT: Yes.

MR ROZEN: Perhaps if we can go, please, to paragraph 18, which is at the bottom of the second page. I just ask that to be highlighted so that you can see that on the screen. Is that visible to you there, James?

MR NUTT: Yes.

MR ROZEN: Where it says:

I was 22 at the time of my entry into aged care.

it should be, "I was 21"; is that right?

MR NUTT: Yes, I was 21.

MR ROZEN: We will make that change there. And in the following paragraph 19, if we can have that highlighted, please, we need to make a corresponding change at the end of the second line. Where it says:

I'm 22.

It should say, "I'm 21".

MR NUTT: Yes.

MR ROZEN: With those changes, are you happy that the contents of your statement are true and correct?

MR NUTT: Yes, I am, Peter.

MR ROZEN: I tender the tender the statement of James Anthony Nutt, dated 24 August 2019, Commissioner.

COMMISSIONER BRIGGS: The witness statement of James Anthony Nutt, dated 24 August 2019, will be exhibit number 9-18.

EXHIBIT #9-18 WITNESS STATEMENT OF JAMES ANTHONY NUTT DATED 24/08/2019 (WIT.1237.0001.0001)

MR ROZEN: Commission pleases.

Mr Nutt, where did – James, I'm sorry. Where did you grow up?

MR NUTT: Merriwa.

MR ROZEN: Where's that? For the Victorians in the room.

MR NUTT: It's a small country town halfway between Newcastle and Dubbo, so 250 kilometres west of Newcastle.

MR ROZEN: Okay. And did you grow up with brothers and sisters?

MR NUTT: Yes, I'm one of six, the third eldest.

MR ROZEN: Brothers, sisters, or a combination of the two?

MR NUTT: My eldest is Kelly, brother younger than me is Jonathan, next in the family comes Emily, Hamish and Jordan.

MR ROZEN: And went to school in that town?

MR NUTT: Yes, I went to school till secondary school, then I went to St Joseph's Aberdeen till '99, year 10, and I finished year 11 and 12 at Merriwa Central.

MR ROZEN: When you left school, what were your intentions, James?

MR NUTT: My intentions are to acquiring a job as a trainee explosive ordinance technician and being one of two civilians to ever do a ammunition technician officer's course, which entailed learning about any explosive ever made, how to approach and detonate, eval UXOs, unexploded ordinance and place detonators down and dispose of them. I then enrolled to go to Duntroon military academy.

MR ROZEN: Yes.

MR NUTT: Which I would have been doing at the start of 2004.

MR ROZEN: Now, of course, before you had the opportunity do that, in September of 2003 you were assaulted at a local footy game.

MR NUTT: Yes, rugby league football grand final after party, Peter.

MR ROZEN: Right. And that was at Aberdeen in New South Wales?

MR NUTT: That's correct.

MR ROZEN: I won't ask you too much about the detail of that, but it left you with a brain injury.

MR NUTT: Yes.

MR ROZEN: And it left you paralysed from the waist down.

MR NUTT: Nipples down.

MR ROZEN: I'm sorry?

MR NUTT: My nipples down.

MR ROZEN: Yes. And ever since then you've required support to assist you with the activities of daily living, showering and so on.

MR NUTT: That's correct.

MR ROZEN: You're currently living in specialist disability accommodation in Belmont in New South Wales.

MR NUTT: Yes.

MR ROZEN: Now, I'll ask you a bit about that in a moment but, of course, your life changed forever really, didn't it, at the time, as a result of the assault?

MR NUTT: Yes.

MR ROZEN: And you were first treated in hospital between September 2003 and May of 2005.

MR NUTT: January 2005, sorry.

MR ROZEN: January 2005, I'm sorry. And was that a combination of hospital and rehabilitation?

MR NUTT: Yes.

MR ROZEN: And I know these events are a long time ago and you're obviously doing your very best for us to remember everything about this.

MR NUTT: Yes.

MR ROZEN: But I assume you don't remember every single detail, every single day of the time.

MR NUTT: No, but I've got a fair idea of what's happened.

MR ROZEN: Indeed. If I can ask you briefly first about that. The – you were in Muswellbrook Hospital and then you were in John Hunter Hospital and ultimately Rankin Park Hospital.

MR NUTT: Yes.

MR ROZEN: Then I want to ask you about the next period, which was from May of 2005. You were admitted into the Brain Injury Unit at the Royal Rehabilitation Centre in Sydney.

MR NUTT: Yes.

MR ROZEN: I just want to ask you about how that worked for you. Where – your parents were where at that time?

MR NUTT: Merriwa.

MR ROZEN: And were they able to visit you at the rehabilitation centre in Sydney?

MR NUTT: Yes, they came down every weekend.

MR ROZEN: Right. And what about your siblings? Were you having much contact with them during that time?

MR NUTT: Not a great deal. They – four of the six lives – live in Brisbane.

MR ROZEN: Yes.

MR NUTT: So - - -

MR ROZEN: Right. And you did a period of rehabilitation at the rehab centre and then went back to Rankin Park Hospital.

MR NUTT: Yes. Just – Rankin Park ..... me transferred onto Muswellbrook Aged Care Facility.

MR ROZEN: Right. Just before we get to that point, what was your understanding of why you were ultimately discharged from the Brain Injury Unit?

MR NUTT: I believe I was – they didn't see me of having the ability yet to be able to leave hospital and care for myself.

MR ROZEN: Yes.

MR NUTT: I wasn't muscular, I wasn't improving with muscle growth.

MR ROZEN: You said in your statement that you're a sociable person, James.

MR NUTT: Yes.

MR ROZEN: Did the injury affect your sociability, your attitude to life?

MR NUTT: It didn't really affect my attitude, but it affected everybody who was sociably included with my life as soon as I moved to the nursing home.

MR ROZEN: All right. I want to ask you a bit about the move to the nursing home. So there came a point where the doctors were saying to you that they considered that the rehabilitation – you couldn't really improve that much more through the rehabilitation; is that right?

MR NUTT: Yes.

MR ROZEN: And so you began a search for alternative accommodation with your parents; is that right?

MR NUTT: Yes.

MR ROZEN: They were helping you.

MR NUTT: A little, yes.

MR ROZEN: Yes. And what was your – what was your wish? So at that time you were, what, about – how old were you by this time; 23, is that right?

MR NUTT: No, no. I was 21 when I moved into Muswellbrook Aged Care so I was - - -

MR ROZEN: I'm sorry, you were much younger. You were about - - -

MR NUTT: 20.

MR ROZEN: Yes. My apologies, James. And what was your hope; was there any possibility of returning home to your parents?

MR NUTT: I believe there was a possibility if I gained – if I was able to stay at the brain injury unit longer - - -

MR ROZEN: Yes.

MR NUTT: - - - and continue on with my rehab so that once I can get in and out of bed I would have been more able to go home.

MR ROZEN: And what did you do with your parents to find alternative accommodation at that time?

MR NUTT: Well, they took Mum, Dad and I to a few group homes.

MR ROZEN: Yes.

MR NUTT: None of these group these group homes, there was nobody with the ability to socialise whatsoever. All they could do was grunt and kind of scream out. They couldn't talk.

MR ROZEN: And where were those group homes?

MR NUTT: Around – in and around Newcastle.

MR ROZEN: Right, I take it that they weren't attractive options for you.

MR NUTT: No.

MR ROZEN: You've already told us that you're a social person; you wanted to be somewhere where you could make friends, presumably.

MR NUTT: Yes.

MR ROZEN: And so, ultimately, there was no option, really, but to go into a nursing home; is that right?

MR NUTT: That's correct, Peter.

MR ROZEN: Yes. And what did you think about that?

MR NUTT: Well, it wasn't the ideal place to be going, but compared to going to a group home where there would have been no communication whatsoever, I finally decided that old people may be better than just having people grunt at you.

MR ROZEN: And so you went to Muswellbrook Aged Care Facility and where's Muswellbrook?

MR NUTT: Muswellbrook is about 85 kilometres east of Merriwa, so it's a lot closer to my home town, a lot closer to Mum and Dad.

MR ROZEN: Yes. You were 21 at the time that you moved into Muswellbrook and in your statement you say you were the youngest resident there by at least 40 years.

MR NUTT: Yes.

MR ROZEN: And I suspect that most of the people there were considerably older than that, perhaps in their 80s; is that right?

MR NUTT: Yes, there was one man in his mid-60s, and everybody else was mid to late 80s.

MR ROZEN: James, in your statement at paragraph 19 you describe how it felt for you going into aged care. Can I ask you to read that out, if you wouldn't mind.

MR NUTT:

> *The first night I was there, I went back into my room after having my tea and I closed my door. I dropped my head into my hands and started crying as I thought to myself, 'I'm only 21 years old. I've got maybe 65 left – years left in my life, I'll be forced to live here for the rest of my life with no ability of ever getting out.' That's what I was sentenced.*

MR ROZEN: You've talked about that in your statement as a sentence. Ultimately you describe it as a seven year sentence by the time you got out of aged care.

MR NUTT: That's correct. Those seven years felt so much longer than that.

MR ROZEN: It's probably obvious, James, but what was it about being in residential aged care at Muswellbrook, initially, that made you so anguished and so depressed?

MR NUTT: The fact that I couldn't communicate, the fact of being shut in the room, watching the same John Wayne movie over and over each and every day for months and then the fact of saying hello to people, "My name is James". I find out what their name was. Two minutes later I may have forgotten them but, yes. Having not one thing to communicate with, speak about, and having no – feeling as though there was nothing – nothing left in this world for me to do because I was confined, I was incarcerated.

MR ROZEN: Were you able to leave the - - -

MR NUTT: No.

MR ROZEN: - - - premises.

MR NUTT: No, I was incarcerated. Out the back there was a smoking area maybe 10 metres by five metres; it was like a fenced backyard pool area. Out the front, you couldn't even go out the front door because the nurses hospital – station was there. And once again, full up tall fences like you'd get in the backyard pool.

MR ROZEN: Can you tell us a little bit about the other residents at the home. You told us they were considerably older than you.

MR NUTT: Yes.

MR ROZEN: Did some of them have dementia?

MR NUTT: Yes, the vast majority.

MR ROZEN: How many residents were there, approximately; do you remember?

MR NUTT: 20-odd.

MR ROZEN: Okay. And you've mentioned the repeats of the John Wayne movie.

MR NUTT: Yes.

MR ROZEN: Were there other social activities that were – that you could participate in?

MR NUTT: Once a week they played bingo. That was it.

MR ROZEN: And I take it from that, James, that that wasn't an attractive option for you.

MR NUTT: No. I locked myself in my bedroom, just having massive DVD marathons. I did this for years, probably watched the same movies, 10-plus times.

MR ROZEN: What about visitors? You told us your parents were able to - - -

MR NUTT: Yes, my parents were able to visit.

MR ROZEN: How often did they come to see you?

MR NUTT: Every weekend.

MR ROZEN: What about others, what about friends?

MR NUTT: No, I had friends visit me while I was in hospital. As soon as I moved into the nursing homes they might come two, three times and they said – they see the hell I'm going through, living where I'm living, see that I don't feel anything left to live for because any friendship I made, anything that I form there in nursing homes,

that was just gone because of death. So they didn't really like seeing me always upset due to losing friends.

MR ROZEN: Were you able to make friends with any of the other residents in the home?

MR NUTT: Yes, you make a friend or two, but within a couple of weeks, a week, that would be it. They'd no longer – they would be dead. It's very soul destroying.

MR ROZEN: Yes.

MR NUTT: You make a friend and then you mourn because they die.

MR ROZEN: At paragraph 35 of your statement, if that could perhaps be brought up on the screen in front of you, you say that you were eventually linked to a community group called Challenge.

MR NUTT: Yes.

MR ROZEN: Do you want to tell us a bit about that; how did that happen?

MR NUTT: I'm not too sure how Challenge came about, but it was an opportunity for me to get out of the nursing home.

MR ROZEN: Yes.

MR NUTT: The people that went to Challenge had brain abnormalities. So I'd go there, they might – I was very – I couldn't really remember stuff at this stage, but they had never known life, although it was good to be able to go out and see people of similar age, and then be able to go out, see people of similar age and then the same age as you supporting these people, so that was a massive sociable thing.

MR ROZEN: Yes. Improved your quality of life.

MR NUTT: Exactly. And Challenge, they took me to the PCYC gym which was a massive, really great thing I felt that I was given a chance to do. Once again, I was building my body strength - - -

MR ROZEN: Yes.

MR NUTT: - - - and socialising once again with people that went to the gym, gym instructors. And it was the best day of the week.

MR ROZEN: You say it gave you something to look forward to?

MR NUTT: Exactly.

MR ROZEN: And how did that impact on your attitude to life at that time, James?

MR NUTT: Well, on so many positive attributes. Before that – before that day of going to the gym, I went challenge maybe once, twice a week, but until going to the gym, doing something that I actively wanted to pursue - - -

MR ROZEN: Yes.

MR NUTT: - - - there wasn't really much going on in my life at the home.

MR ROZEN: Paragraph 39 of your statement, if that could please be brought up on the screen, you talk about how any improvement that you'd been experienced at the rehab centre stopped when you went into the nursing home. You say:

I think cognitively I went backwards.

Can you explain to us what you mean by that?

MR NUTT: Yes. Not using my brain, being in the nursing home, not thinking for yourself. You're being instructed. You'll go to be at this time, you get up at that time, you won't have no say. And then having no interaction with the other residents there. Your brain goes to mush, as you're not using it.

MR ROZEN: You mention in your statement you didn't even have a choice what you ate.

MR NUTT: No.

MR ROZEN: It was just presented. That was – that was your meal.

MR NUTT: Exactly. You got a two-week menu which was over – continued on and on every fortnight.

MR ROZEN: Yes. Now, in May of 2009, so after about three years at Muswellbrook, you moved to the Merriwa Multi Purpose Service. That's at paragraph - - -

MR NUTT: Four years at Muswellbrook.

MR ROZEN: Four years, was it? Paragraph 40 of your statement. Can you just tell us how that came about? Why did you move to Merriwa?

MR NUTT: I moved to Merriwa Multi Purpose Services as my family are from Merriwa.

MR ROZEN: Yes.

MR NUTT: And, yes, if I went back there, I could have a lot more visits, be able to be a lot closer to what – where they were.

MR ROZEN: It was the town where you grew up, of course, wasn't it?

MR NUTT: Yes.

MR ROZEN: How did the experience at Merriwa compare to Muswellbrook? Apart from being closer to home, which presumably was a positive aspect, what about the day-to-day living there. Was it different or much the same?

MR NUTT: It was much the same, though it wasn't such a penitentiary because there was no gates. You're not trapped on the – in the facility. So I could drive down the street if I liked.

MR ROZEN: You decided to go out to the local RSL.

MR NUTT: Yes.

MR ROZEN: On the first flight that you were there. How did that go down with the staff at Merriwa?

MR NUTT: Not too good at all.

MR ROZEN: Really?

MR NUTT: I needed to had have asked them if I could go out. There were no games, you're not going down the street. So, rather smartly I just left without letting them know. When I got back they weren't too happy about it at all.

MR ROZEN: What was the attraction at the RSL?

MR NUTT: Some raffles .....

MR ROZEN: Okay. I think you were seeing your parents there, weren't you? Is that – they were there too?

MR NUTT: Yes, they were there too.

MR ROZEN: You say at paragraph 44 that there were some improvements at Merriwa but you considered that – that you were still depressed about your experience. It really wasn't that different. You were still surrounded by people - - -

MR NUTT: Yes.

MR ROZEN: - - - considerably older than you.

MR NUTT: That's correct.

MR ROZEN: And a lot of the problems you'd had at Muswellbrook really were perpetuated at Merriwa; is that right?

MR NUTT: Yes. The problems really didn't change. They were all still there.

MR ROZEN: Ultimately, you were at Merriwa for another three years after the four that you spent at Muswellbrook, is that right? A total of seven years in residential aged care.

MR NUTT: Yes.

MR ROZEN: I wonder if you could read out paragraph 47 of your statement, James, where you sum up your residential aged care experience. It's highlighted on the screen for you there, mate.

MR NUTT:

> *I was sentenced to live in residential aged care for nearly seven years. I say "sentenced" because it felt like jail. It's not right for a younger person to get locked up in a facility like that. It is not appropriate place for a younger people to be forced to live. It was not appropriate for me, and it would not be appropriate for any other younger person. At times, the staff did not seem to care that I was a younger person with different needs to the other residents. My complaints seemed to fall on deaf ears.*

MR ROZEN: Now, from this point, the story gets a bit more positive, doesn't it, James?

MR NUTT: That's correct.

MR ROZEN: But the turning point in your story was an event that happened purely by chance, wasn't it?

MR NUTT: That's correct.

MR ROZEN: Do you want to tell us a bit about that?

MR NUTT: In 2008 when I was at Royal Rehab Centre Sydney's Brain Injury Unit, I was featured on a story in either Today Tonight or Beyond Tomorrow, the ABC program, about alcohol-fuelled violence. And by chance, Ms Trish Rutherford, a coordinator for Northcott Disabilities saw it and they were in the process of building the first villas, they were called, first four apartments for young men in residential aged care. If she did – if I didn't go to Sydney to the Brain Injury that year for rehab, I would not have gotten out of nursing home. I could still be there today.

MR ROZEN: It's just that - - -

MR NUTT: So it was purely by chance.

MR ROZEN: It was the chance, there was a series of things that lined up, weren't there? You were at the Brain Injury Unit, you got featured on the TV show and the lady from the Northcott society happened to see it.

MR NUTT: That's correct.

MR ROZEN: Is that right? And came to visit you - - -

MR NUTT: Yes.

MR ROZEN: - - - at Merriwa. Tell us about that – how that then played out. So as a result of her meeting you, what did she tell you about the options that might be available to you?

MR NUTT: She explained to mum and dad and I that Northcott were building these villas in Mount Hutton, and mum and dad and I were kind of a bit concerned that they might be like group homes.

MR ROZEN: Yes.

MR NUTT: But there was four villas, two single man units and two two-man units. Trish continued to reassure us, "No, no, there will be young people with similar-type disabilities. They will be able to communicate, they are not – their brains have – they've got acquired brain injuries, but much greater levels with their memory than what people that live in group homes were".

MR ROZEN: And you eventually moved out in November 2011.

MR NUTT: Yes, that's correct.

MR ROZEN: To accommodation in Waratah in north-west Newcastle.

MR NUTT: That's correct.

MR ROZEN: And it was quite a big place, wasn't it, that you were in on your own?

MR NUTT: Yes.

MR ROZEN: Was it a three bedroom apartment?

MR NUTT: Three bedroom apartment.

MR ROZEN: How did you feel about being there on your own?

MR NUTT: I was extremely happy. It was my house.

MR ROZEN: Yes. And were there people there who were able to assist you with - - -

MR NUTT: Yes.

MR ROZEN: With daily living. Do you want to tell us a bit about that? What sort of assistances were you receiving?

MR NUTT: Well, I had Shane and Pedro, my two disability support workers.

MR ROZEN: Yes.

MR NUTT: Every night I got to cook what I liked. They would help me do whatever I liked in the afternoon. Like go down, get a meal at the pub, go and watch the footy or anything I wished to do, I done.

MR ROZEN: How did that feel, James?

MR NUTT: When you're given the freedom of choice, that's a massive thing in life.

MR ROZEN: Yes.

MR NUTT: When you've had no choice for years and years, choice means power.

MR ROZEN: You enrolled in a TAFE course.

MR NUTT: Yes, certificate II in Community Services.

MR ROZEN: And tell us about that. How did – how was that experience?

MR NUTT: It was really good because seeing – moving out of the nursing home and being reconnected with society, and after this happening, my brain has healed each and every day due to having opportunities and taking these opportunities. This is why I was able to begin this course, to complete this course and to pass this course.

MR ROZEN: And what are your intentions with that certificate; are you intending to try and use it to get some employment?

MR NUTT: Yes. I'm going to begin doing my cert IV in drug and alcohol. Upon finishing that – I'm actually going to be starting before the end of the year, hopefully, going to – start going and giving talks, speeches at high schools relating to the use of drugs and alcohol. I was never on drugs but alcohol is why I'm in a chair, going to a rugby league football grand final after party, not knowing like what my boss was like when he was drunk, but yes. Going to these schools, if just one person out of 100

listens to me and thinks, hang on, that – I'm stopping here, that's enough beer for the night.

MR ROZEN: Yes.

MR NUTT: Or goes out, maybe I won't drink tonight. That's going to be more than worth it for me. It might only take that one in 100 to listen; if they didn't listen, perhaps they could have had something not very pleasant happen to them.

MR ROZEN: Yes. You say in your statement, James, that enrolling in the course and completing the certificate helped to switch your brain back on.

MR NUTT: Yes.

MR ROZEN: So that, the brain was switched off, I think you told us, from you time at resi care.

MR NUTT: Yes.

MR ROZEN: And is that how it felt, you were sort of living again; is that a fair description?

MR NUTT: That's correct. I wouldn't have been able to complete that course living at an aged care facility. My brain wouldn't have been able to switch on to be able to remember any of the information which was getting spoke about in the courses, lessons.

MR ROZEN: Now, after some time in that home, you moved into Mount Hutton Villa - - -

MR NUTT: Yes.

MR ROZEN: - - - in June 2013. Can you tell us what led to that? You were waiting for that to be completed; is that right?

MR NUTT: Yes. That's correct.

MR ROZEN: What was the accommodation like compared to the three bedroom place that you'd been in?

MR NUTT: Well, it was a single man unit.

MR ROZEN: Yes.

MR NUTT: It was all purpose-built so it had kitchen benches and sink that was on hydraulics, lifted up and down. A ceiling hoist so this could be connected to my sling and placed underneath me, picked up and put on the bed.

MR ROZEN: Yes.

MR NUTT: So it was a lot fancier due to the new technology than just a normal everyday house because it was purpose-built for people with disabilities like myself.

MR ROZEN: Initially that was terrific at Mount Hutton?

MR NUTT: Yes, it started off great.

MR ROZEN: Amazing, you say. But then it changed; what was the change?

MR NUTT: Probably the fact that they went through so many coordinators and then the coordinators would not offer contracts, renew the contracts of the support that were there, and the ones they didn't renew were the contracts of the good workers. They built relationships. They knew exactly how and what to do to help support you, and without their contracts being renewed, you had to teach new people coming in to support.

MR ROZEN: Yes.

MR NUTT: Had to regain trust relationships. And with this just happening over and over again, and needing to regain all these relationships, I just didn't see it as a place for me to continue to be. I was made an ambassador for a not-for-profit organisation the Summer Foundation whose goal is to get all young people out of residential aged care. Being made an ambassador for them, I found out about the Belmont units where I'm living now.

MR ROZEN: Can I just jump in there for a sec, James; how did you come into contact with the Summer Foundation?

MR NUTT: That's a good question; I'm not too sure.

MR ROZEN: That's all right. Anyway, you did, and I cut you off, they put you – they drew your attention to the Belmont accommodation.

MR NUTT: Yes.

MR ROZEN: And you became an ambassador for them. You continue to be an ambassador for them, don't you, James?

MR NUTT: Yes.

MR ROZEN: What does that involve?

MR NUTT: It involves letting the community – letting Australia know about YPIRAC, Young People in Residential Aged Care.

MR ROZEN: Yes.

MR NUTT: It's our goal to abolish that or decrease it drastically in time. As it went six and a half thousand young people in residential aged care, I believe.

MR ROZEN: Yes.

MR NUTT: When I become the ambassador it was three and a half. It's disgraceful that it's nearly doubled in so many short years.

MR ROZEN: What do you do as an ambassador, James, what does that involve? Talks?

MR NUTT: Yes, it involves talks and then media.

MR ROZEN: Yes. And tell us about the Belmont accommodation. What – be when did you move there? I think it was early - - -

MR NUTT: February 1st, 2017.

MR ROZEN: 2017. Firstly, where is Belmont?

MR NUTT: Belmont is on Lake – situated on Lake Macquarie, the largest lake in the southern hemisphere.

MR ROZEN: What's the accommodation like?

MR NUTT: It's absolutely wonderful. I couldn't expect a better unit than what I've got at the moment. I've got a penthouse with my balcony overlooking the lake. It can't get much better than that.

MR ROZEN: Living the dream, James.

MR NUTT: Exactly, living the dream.

MR ROZEN: And who's there with you; what's the setup?

MR NUTT: The setup is I'm living in my unit by myself.

MR ROZEN: Yes.

MR NUTT: So I've employed every single person that comes into my unit, I've ticked off. It's been me that decided I like Casey, I like Karen. It's my decision who comes in and who works with me. Bet.

MR ROZEN: You mentioned a moment ago about the turnover of the staff in your previous accommodation and how that was part of the problem there.

MR NUTT: Yes.

MR ROZEN: I neglected to ask you about this, but the NDIS started to be rolled out, didn't it, around about that time in that part of New South Wales.

MR NUTT: Yes.

MR ROZEN: Did that initially make much difference to your life, do you think? Did it give you more control over, for example, choosing support workers?

MR NUTT: Yes, it did, but not while I was at Mount Hutton. I had no say in who got employed. It was just the organisation going they're good, we'll put – we'll put them on.

MR ROZEN: Yes.

MR NUTT: Which isn't the way things should be done. It should be how I'm living today.

MR ROZEN: Yes.

MR NUTT: I get to run the interview. I get to say okay, Casey, you'll be a support worker. Rebecca, I want you. Sorry Mark, sorry, Peter, sorry John; I don't feel you fit the bill, rather than being the organisation saying - - -

MR ROZEN: Yes.

MR NUTT: - - - so Mark, Paul, John we feel you're going to be right; how about you just go and work with James.

MR ROZEN: You say, James, at paragraph 68 that your life in the supported disability accommodation of Summer Foundation could be defined with the words choice, control and independence.

MR NUTT: Yes.

MR ROZEN: You're in the driver's seat in your life, you say.

MR NUTT: Yes.

MR ROZEN: What else have you been able to do at Belmont during this time that's improved your life, James?

MR NUTT: Having the choice to do what I want, being able to say I'm going there tonight, going here tomorrow, are you able to support with that. It's really quite a massive thing and a massive positive about anybody's life, choice – choice and control. Without those, what is life?

MR ROZEN: You spoke a moment ago about your desire to do school talks.

MR NUTT: Yes.

MR ROZEN: About the dangers of drug and alcohol consumption and violence. Is that something you can see as being a paid role in some way or do you see yourself doing that on a voluntary basis.

MR NUTT: Maybe to start with voluntary, but hopefully I may be able to lead to some type of motivational speaking thing which will become paid.

MR ROZEN: James, you obviously had a great interest growing up in explosives and the like which is what led you to pursue that option of going to Duntroon. Do you see in the future any chance of being able to get back into that line of work; is that a possibility do you think?

MR NUTT: I'd love for that to be possible but no. You have to be continuity checked, you're not allowed to have any positive or negative forces or fields coming off you, otherwise a lot of explosive would go bang.

MR ROZEN: Yes. All right. You complete your sentence, James – sorry, your statement, James, with a message to the Royal Commission and rather than me reading it out, I wonder if I can ask you to read out the last paragraphs of your statement starting at paragraph 76.

MR NUTT:

> *I believe that no matter how severe the disability or condition, a younger person should not be in residential aged care. Just because you have a wheelchair, cerebral palsy, you might have a broken leg, an amputated arm, amputated leg, this does not mean you should be shut away and forgotten about in a residential aged care facility.*
>
> *When you put us there, we lose the ability to run our own brains. They switch off. We no longer make decisions or have to think for ourselves. We become institutionalised. There is nothing on offer for us.*
>
> *It is really important to me that the Royal Commission understands how unsuitable aged care is for younger people. I don't want anyone else, or anyone else's family to have to go through what me and my family went through.*
>
> *I was lucky in that I eventually was able to leave, and now have my own life. The quality of my life now, and what I am able to do and the things I want to with my life show just how much of a limitation aged care has put on my life. No one seemed to care. No one seemed to notice the opportunities that were being taken from me. It should not happen to anyone. Nobody else.*

MR ROZEN: Thanks very much James. They're the questions that I have for Mr Nutt, Commissioner.

COMMISSIONER BRIGGS: Thank you very much, counsel, and might I say, Mr Nutt, thank you very much. It's a harrowing story what has happened to you, and from innocently going along to a football match or a post-football match party and then finding yourself in the circumstances that you did, and then living a life of frustration and isolation and brain-dimmingly dullness must have been just absolutely awful, and our hearts go out to you for that. But it's also great to hear about the positive steps that emerged in the last few years and the way the NDIS has stepped up to the mark in helping you and getting you into that accommodation in Meriwether – no, Belmont.

MR NUTT: Belmont.

COMMISSIONER BRIGGS: Belmont. So well done. And I do want to, again, apologise for the difficulties you've had in getting here today but I have to say I'm very appreciative of the fact that you persevered, and that you came and stuck with it and came here today because your evidence has been very important to our considerations here. And I've certainly got the message about what you're saying about no young people should be in residential aged care.

MR NUTT: Yes.

COMMISSIONER BRIGGS: Thank you, and you are excused from further attendance before this Royal Commission. And I hope you have a safe trip home, and that the airlines come through with a flight in the very near future. So thank you.

MR NUTT: Thank you. I'd like to thank you and everybody for giving me the opportunity to come give my evidence which to me feels I'm very blessed. I would hope everything I say sinks in. Thank you very much.

COMMISSIONER BRIGGS: Thank you.

<THE WITNESS WITHDREW [4.31 pm]

COMMISSIONER BRIGGS: With that we'll adjourn these hearings until Friday morning, Friday, 13 September at 9.30 am.

MATTER ADJOURNED at 4.31 pm UNTIL FRIDAY, 13 SEPTEMBER 2019

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