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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

9.31 AM, FRIDAY, 13 SEPTEMBER 2019

Continued from 11.9.19

DAY 50

MR R. KNOWLES, counsel assisting, appears with MS E. HILL
MR HARRIS appears for the State of Victoria

COMMISSIONER BRIGGS: Good morning.

MS HILL: Good morning.

5 COMMISSIONER BRIGGS: Ms Hill.

MS HILL: If the Commission pleases, before I call the witnesses to start today, there's an appearance to be announced by the senior counsel for the State of Victoria.

10 MS HARRIS: Commissioner, I appear for the State of Victoria Harris.

COMMISSIONER BRIGGS: Nice to meet you, Ms Harris.

MS HARRIS: Thank you.

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MS HILL: Commissioner, further, there are two additional documents which I would seek to add to the general tender bundle of the Broome hearings of this Commission. If I could read those document IDs.

20 COMMISSIONER BRIGGS: Yes.

MS HILL: CTH.0001.1000.6769 and CTH.0001.1000.6753.

25 COMMISSIONER BRIGGS: Those documents will be added to the Broome tender document.

MS HILL: As the Commissioner pleases. Commissioner, I call Dr Bronwyn Morkham, Mr Luke Bo'sher, and Mr Shane Jamieson.

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<BRONWYN ELIZABETH MORKHAM, AFFIRMED [9.32 am]

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<LUKE RICHARD BO'SHER, AFFIRMED [9.32 am]

<SHANE CAMPBELL JAMIESON, SWORN [9.33 am]

40 MS HILL: Good morning, Dr Morkham.

DR MORKHAM: Good morning, Ms Hill.

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

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DR MORKHAM: Bronwyn Elizabeth Morkham.

MS HILL: And you told a PhD, Dr Morkham.

DR MORKHAM: I do.

5 MS HILL: And what's that PhD in?

DR MORKHAM: It's in philosophy.

10 MS HILL: And what is your role?

DR MORKHAM: I'm the national director for Young People in Nursing Homes National Alliance.

15 MS HILL: And could I ask you to describe what your organisation does.

DR MORKHAM: We work with young people living in residential aged care aged care facilities and their families. We work with young people at risk of entering residential aged care facilities and their families. We work with everybody who's concerned about this issue. We work with aged care providers, health providers, 20 disability providers. We work with all levels of government to provide answers to this complex problem and the solution to fix it.

MS HILL: Dr Morkham, you've prepared a statement on behalf of your organisation dated 30 August of this year. 25

DR MORKHAM: I have.

MS HILL: Operator, could I ask you to please display document ID WIT.0372.0001.0001. Dr Morkham, do you see a copy of that statement in front of 30 you?

DR MORKHAM: I do.

MS HILL: Are there any changes that you would seek to make? 35

DR MORKHAM: No, there are not.

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

40 DR MORKHAM: Yes, they are.

MS HILL: Commissioner, I seek to tender the statement of Dr Morkham dated 30 August 2019

45 COMMISSIONER BRIGGS: The witness statement of Dr Bronwyn Elizabeth Morkham dated 30 August 2019 will be exhibit number 9-19.

EXHIBIT #9-19 WITNESS STATEMENT OF DR BRONWYN ELIZABETH MORKHAM DATED 30/08/2019 (WIT.0372.0001.0001)

5 MS HILL: As the Commission pleases. Good morning, Mr Bo'sher.

MR BO'SHER: Good morning.

10 MS HILL: Mr Bo'sher, could I please ask you to state your full name.

MR BO'SHER: Luke Richard Bo'sher.

MS HILL: What is your role, Mr Bo'sher?

15 MR BO'SHER: I'm the CEO at the Summer Foundation.

MS HILL: Could I ask you to describe the Summer Foundation.

20 MR BO'SHER: Sure. Our goal at the Summer Foundation is that young people don't get forced into aged care because there's no alternatives for them. So the work that we do covers research, building the evidence base around the need for alternatives to aged care for young people. We do capacity building work, working with hospitals, with disability service providers, housing providers to create alternatives to aged care for younger people. We also run a series of prototypes to
25 help connect together young people at risk of aged care with housing opportunities in the community. So all of that work together is aimed at that goal of reducing the number of young people going into aged care.

30 MS HILL: And in your capacity as CEO of the Summer Foundation have you prepared a statement dated 27 August 2019?

MR BO'SHER: I have.

35 MS HILL: Operator, could I ask you, please, to display document ID WIT.0373.0001.0001. Mr Bo'sher, do you see a copy of your statement on the monitor in front of you?

MR BO'SHER: I do.

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

MR BO'SHER: There are none.

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

MR BO'SHER: Yes, they are.

MS HILL: Commissioner, I tender the statement of Mr Bo'sher dated 27 August 2019.

5 COMMISSIONER BRIGGS: The witness statement of Luke Bo'sher dated 27 August 2019 will be exhibit 9-20.

**EXHIBIT #9-20 WITNESS STATEMENT OF LUKE BO'SHER DATED
27/08/2019 (WIT.0373.0001.0001)**

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MS HILL: As the Commission pleases. Good morning, Mr Jamieson.

MR JAMIESON: Good morning.

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MS HILL: Could I ask you to please state your full name.

MR JAMIESON: Shane Campbell Jamieson.

20 MS HILL: What is your role?

MR JAMIESON: I'm the manager of the Youngcare Connect service which provides support to people trying to navigate disability in the health system.

25 MS HILL: And does that form part of Youngcare Australia?

MR JAMIESON: Yes, it does.

MS HILL: And could I ask you to describe the work of Youngcare?

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MR JAMIESON: I suppose we work across a number of areas. We build places for people with high physical support needs. We have an information referral service which I manage and we have some grants that we offer people who are at risk of entering aged care or who are living in aged care and looking to – to leave and those grants, I suppose, provide gap funding where – to enable them to either to remain at home or to return home. We do some advocacy and - - -

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MS HILL: Are you familiar with how Youngcare was formed?

40 MR JAMIESON: Yes, absolutely.

MS HILL: Could you describe how Youngcare was formed to the Commissioner.

45 MR JAMIESON: Youngcare was formed when our founder David Conry, his wife Shevaune was diagnosed with multiple sclerosis when she was 27. By the time she was 33 her support needs were so high that she needed to go into full-time care. Dave, like many people, thought that there would be somewhere appropriate for his

wife to go and live, and the only place he could find at the time was residential aged care. So, unfortunately, Shevaune had to move into aged care for a period of time. In 2005 Youngcare was formed by Dave and three of his friends, and by 2007 we had completed the first Youngcare building which became home for Shevaune and
5 16 other people.

MS HILL: And in your capacity at Youngcare, you've prepared a statement dated 14 August of this year.

10 MR JAMIESON: Yes.

MS HILL: Operator, could I ask you, please, to display document ID WIT.0371.0001.0001. Mr Jamieson, do you see a copy of your statement on the monitor next to you there?

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MR JAMIESON: Yes, I do.

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

20 MR JAMIESON: No.

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

25 MR JAMIESON: Yes.

MS HILL: Commissioner, I tender the statement of Shane Jamieson dated 14 August 2019.

30 COMMISSIONER BRIGGS: The witness statement of Shane Campbell Jamieson dated 14 August 2019 will be exhibit 9-21.

35 **EXHIBIT #9-21 WITNESS STATEMENT OF SHANE CAMPBELL
JAMIESON DATED 14/08/2019 (WIT.0371.0001.0001)**

MS HILL: As the Commission pleases.

40 Mr Bo'sher, I might start with you. How long has the Summer Foundation been saying that residential aged care is not appropriate for young people?

45 MR BO'SHER: So the Summer Foundation was formed in 2006, and from that point we've been making the case for young people to be able to live in the community and working across all levels of government to make that happen.

MS HILL: And we've heard evidence this week about the Commonwealth action plan. Is it correct to say that the Summer Foundation is a member of the stakeholder reference group that's been referred to in the context of that action plan?

5 MR BO'SHER: Yes.

MS HILL: Mr Jamieson, has Youngcare also had a role in that stakeholder reference group for the action plan as well?

10 MR JAMIESON: Yes.

MS HILL: Dr Morkham, has the Alliance – if I may refer to your organisation as that – had a role in the stakeholder reference group also?

15 DR MORKHAM: It has, yes.

MS HILL: Dr Morkham, how long has the Alliance been grappling with this issue of the inappropriateness of young people in aged care?

20 DR MORKHAM: The Alliance was formed in 2002 specifically to provide a national voice for young people in this position and their families and to find solutions to work with government to achieve that. But this issue goes back well before that. The Slow To Recover Program in Victoria, an acquired brain injury community rehabilitation program started in 1996 specifically to address this issue.
25 So this young people in nursing homes issue has been around for far too long.

MS HILL: Dr Morkham, why are we still having this discussion?

30 DR MORKHAM: We're having this discussion because there has been a complete lack of will by government to fix the problem. I think Commissioner Gauntlett's comments the other day provided substance to this; there's been a complete lack of will. The resources have not been there to provide that solution. Fundamentally, we're having this discussion again because the services and supports these young people need to live safely and with confidence in the community aren't there when
35 they need them.

MS HILL: Mr Jamieson, could I ask you to inform the Commission of Youngcare's view of the recent action plan of the Commonwealth?

40 MR JAMIESON: First and foremost, I think it's important to say that it's absolutely fantastic that for the first time we've got some targets. We don't necessarily believe that the targets are good enough, but the mere fact that there is a commitment from government at the moment to have those targets is something that we can work towards. Youngcare also believes that even though the targets are there, it's up to
45 everybody, it's not just government, it's up to the sector, it's up to developers and investors and – and that to actually – we need to start building, and we need to be part of that solution as well. So even though the target is, you know, to halve the

numbers by 2025, I think it's important that we challenge ourselves to try and beat that.

MS HILL: Mr Bo'sher, what's the Summer Foundation's view of the action plan?

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MR BO'SHER: Similar to Youngcare's view, the idea that we have targets that we can measure I think is a big step forward. I think we were all involved as the three organisations here in the development of that action plan, and I think what's become apparent to Summer Foundation during the hearings this week is that setting a target in 2025 to halve the number of young people in aged care clearly has not led to enough action over the last six months. The action plan was released in March this year but six months later we still don't have a lot of progress on the ground to show for the action plan that's been announced.

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15 So our perspective is that those targets are really important. They're a way to create energy and motivation within government to solve this issue but the scale of the target or the time of the target, being in 2025, appears too far out to have generated enough urgent activity. Similar to Dr Morkham's comments, you know, this is an issue that we can solve when governments put their mind to it, and I think bringing forward those targets, as Commissioner Gauntlett recommended, I think would lead to more action to government to solve this problem. And I think one example of that is we heard this week that only 66 of the four and a half thousand young people in aged care have specialist disability accommodation approved in their plan.

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25 I mean, six months after announcing an action plan, to have 98 per cent of young people in aged care without the funding they need to leave an aged care facility I think speaks to a lack of urgency.

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MS HILL: Dr Morkham, if I could ask you to share the Alliance's perspective of the action plan, but in your answer if I could ask you how is it that we can learn from the previous failures to address this issue?

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DR MORKHAM: Thank you, Ms Hill. The Alliance was very pleased to hear that there was an action plan in development, and as Mr Jamieson and Mr Bo'sher have indicated, we were part of a group that was called together to provide some input into development of that action plan. However, when the action plan was announced, we were quite disappointed to see that it was reiterating some of the mistakes of the past in its focus entirely on disability services as the answer to this solution. We were completely nonplussed to see a first stakeholder reference group stating that we didn't have a representative from the aged care sector there, nor did we have representation from the State health services themselves. Two fundamental stakeholders to delivering the solution to this problem.

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So we've been quite disappointed. We think the targets are not good enough. We want to see no younger person enter residential aged care by 2022. That should be perfectly enough time to stop that happening and plug that pipeline that has been mentioned in this Commission this week. We also take heart from Commissioner

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Gauntlett's comment in his evidence, we should have no one in residential aged care under the age of 65 by 2025, not hoping to stop people going in by then but stopping it. So we've been somewhat disappointed and quite appalled that there's no resourcing in the action plan, the targets are not acute enough, there's no modelling.
5 There's no consultation with young people and their families or the communities they live in as well.

Yet, we've heard this week in had the Commission's hearings, we've heard from senior government officials admit they have manifestly failed to deliver the solution
10 to this problem thus far. Yet we are being asked to trust them again with this action plan. With regard to the current action plan and the Younger People in Residential Aged Care initiative in 2006, we are seeing the same mistakes being reiterated. The 2006 initiative had no representation from aged care at all, at the direction of the then Federal Government of the day.

15 State disability services were charged with delivering that action plan with little knowledge of this group and no involvement of health services again. So we are repeating the mistakes of that plan in the current plan in 2019, 14, 15 years later, and it's unbelievable to see the same mistakes being repeated once more.

20 MS HILL: How can those mistakes be overcome?

DR MORKHAM: This is a system problem. These young people come along with integrated health and disability needs and they need concurrent services from health,
25 from disability, through the NDIS and from housing. We need those services to be delivered in an integrated or joined-up manner and we need those programs and the governments that manage them to work together. We don't want any more buck passing. We simply want people to collaborate with one another to deliver the solutions that we know are needed, we know what we've got to do. We simply have
30 to make it so.

MS HILL: Mr Bo'sher, could I ask you to respond to Dr Morkham's points there?

MR BO'SHER: So we know that, as Dr Morkham said, young people going into
35 aged care often need support from the disability system, the health system and also a housing response. It's the lack of being able to work across those different silos that see people go into aged care heard. I guess my reflection on the evidence this week was that we heard disability officials, we've heard the health system, we heard people say that they don't want to see young people going into aged care and yet that
40 problem still persists. I think one of the challenges is how do we join up those silos. I think what's pretty clear at the moment is that the key mechanism to stop young people going into aged care are aged care assessment teams who we heard have an obligation to make sure there's no other alternatives and to find those other
45 alternatives.

And yet those aged care assessment teams are not trained or skilled or have any mechanisms to be able to find alternatives to young people going into aged care. So

I think one of those system level problems is that we've put the responsibility on the aged care system to find alternatives to aged care for young people but they have no levers and no ability and no alternative funding sources to be able to make that happen. The levers, the alternative solutions, the information, they all sit with the
5 NDIA. They don't sit with the aged care assessment teams or the aged care system for those alternatives.

So I think a really fundamental thing that we need to do is bring that responsibility together in one place, bring the accountability together in one place to make sure that
10 young people don't go into aged care and I think that place has to be the NDIA and I think by having clear responsibility with the NDIA we can avoid the buck-passing, we can avoid the falling through the gaps that Dr Morkham talked about.

MS HILL: We understand from the evidence this week that the action plan is
15 focused on those individuals who – those young people who fall under the NDIA. What does that mean for young people that don't fit within that cohort, Mr Bo'sher?

MR BO'SHER: The NDIA has an obligation to determine whether younger people are eligible for the scheme. So any young person at risk of going into aged care, it's
20 reasonable to expect that they have applied to the NDIS for access to the scheme. Because the first question to make sure that we're answering properly is that the NDIA is picking up all those people who are eligible for the NDIS. So even though at the moment it appears that there are some people that have been found ineligible for the scheme, if it still makes sense for the NDIA to be the gateway – at least the
25 first pass of the gateway into aged care because the first thing we need to work out is to make sure that everyone who is eligible for the scheme is in the NDIS.

So even though on current information there are people who are not eligible for the scheme who are under 65 going into aged care, we need to make sure that every
30 single person going into aged care tests their eligibility with the NDIA. So it's still the first gate in the gateway into aged care.

MS HILL: Dr Morkham, can I turn to you and ask you a question about the information, what we know about young people and young people entering
35 residential aged care. From your position, what do we know about the numbers of young people, the data of young people in aged care or at risk of entering aged care?

DR MORKHAM: We have a large amount of anecdotal data. We don't have a great deal of data at all. The data that is collected is insufficient, it's not giving us
40 the information we need to know. The Australian Institute of Health and Welfare has an aged care data clearing house now which takes information that nursing homes submit quarterly on the number of residents they have and it provides very imperfect information about these younger people. We don't know enough about them. We don't know enough about where they came from to go into nursing homes, we don't
45 know what conditions they present with, acutely. We know something but not enough. We don't know if they would like to leave residential aged care, and if they do, where they would like to go.

We have no idea of the quantum of their needs while they're in residential aged care and how that might be best met if they were to move out. So the data is absolutely imperfect and I mention the Senate Inquiry in 2015 that had as its number 1 recommendation that a comprehensive dataset of this cohort be established without
5 delay. Four years later we have no evidence like that in hand at all. Can I also make a comment about the – Mr Bo'sher's comments about where we sort of see some solution coming from. I think the National Disability Insurance Scheme has a very important role to play, but by focusing so firmly on that, we forget again that this is a system problem.

10 Unless we have the health services who are going to be needed to provide their support to people in the community, unless we have housing in there as well; if those parts of that solution aren't integrated and available we won't have a solution at all. So while the NDIS is very, very important – and I agree with Mr Bo'sher
15 about that – they are not all of it and cannot be all of it as we've heard this week through the Commission's hearing. We have seen governments previously try to get system change across these silo programs, fail from the top down. The Alliance's view is that we need to have a case manager key worker approach, a dedicated person for every young person at risk of entering residential aged care or who is in
20 residential aged care to work with them to provide the solutions they need to live in the community.

That case manager key worker would also be responsible for wrangling those systems, for getting them to come together, to sit down and deliver what they need to
25 do. Unless we do that, we're never going to get to the solution we've got to have. And I think our past efforts in this area, these failed efforts are evidence enough of the need to bring those programs together in a different way. We need fresh thinking on this issue.

30 COMMISSIONER BRIGGS: Can I just ask you for a minute, does the NDIS have advocates who do that at the moment? Or we heard a slight softish version of that yesterday – I think it was, or the day before, I beg your pardon.

DR MORKHAM: No, the NDIS does not, Commissioner. There are support
35 coordinators who have a very poorly defined role and very poor training whose job it is to link the services funded in the NDIS plan and make them happen. These people are not well prepared and poorly equipped to travel across those program areas. They don't understand the capacities and the incapacities of those programs and really are not equipped to bring them together at all. The support coordinator group
40 could be used to be highly – to be skilled up to become key worker case managers if we wanted to but at the moment there is no – no one doing this job at all, other than the Alliance; the Alliance does it.

COMMISSIONER BRIGGS: Right. And that skillset of people, would you see
45 them being under the auspice of DSS, given it's chairing the action plan or where would they be?

DR MORKHAM: Absolutely not. No.

COMMISSIONER BRIGGS: Okay. Yes. Let me understand this.

5 DR MORKHAM: We believe they have to be completely independent.

COMMISSIONER BRIGGS: Right.

10 DR MORKHAM: Because they are going to work across systems, they need to have a clear mandate, probably at ministerial level, to go in and work with the systems and get those – require those systems to do what they are supposed to do together. But we see the need for them to be completely independent, really as acting as a third party intermediate.

15 COMMISSIONER BRIGGS: Thank you.

MS HILL: Mr Jamieson, could I ask you to share Youngcare's view of the role of advocates for young people in residential aged care?

20 MR JAMIESON: It's absolutely vital and there is not enough advocacy available to people. People who end up in aged care quite often get lost. And a really good example, we were recently up in the Northern Territory assisting people to make submissions for the Royal Commission. And we found a young lady in aged care who had been there for a number of years. She had an NDIS plan. That NDIS plan
25 was just almost 12 months old and up until a couple of months previous to that, it had not been enacted because she was given the plan but no-one to support her to – to start implementing that plan. The – she was found by chance, by an advocacy service who was visiting the aged care facility that she was in for an absolutely different reason, and it was only then that the wheelchair that she was provided for,
30 in her NDIS plan, was able to be ordered.

She had not had any community service – community access the whole time that her NDIS plan was. And she simply wanted to go and drive around the – the Darwin area that she had lived in. She had been stuck in that aged care facility for that whole
35 time and none of her NDIS plan was enacted. And that's not an isolated case. We're finding that time and time again. We receive calls almost daily from people that are in aged care or from family members of people who are in aged care. And they don't have access to the right advocacy or the support that Dr Morkham spoke about. And it's absolutely vital. And if somebody is provided with a support coordinator, more
40 often than not they don't have the skills to – to do the job that they're required to do.

MS HILL: And why is that?

45 MR JAMIESON: I don't think there's enough money associated with – with what they're doing to do that. There's not – there doesn't appear to be any accountability as far as the support coordinator sector is concerned when they are charged with linking all the services together. They can go through a 12 month plan with a person

and not actually achieve the things that the person has identified in the goals, in their plan. And that's a horrible waste of money that, you know, people are receiving up to 100 hours of support coordination and yet they're not achieving their goals that the funding is supposed to do.

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MS HILL: Dr Morkham, how would a system wrangler overcome these difficulties?

10 DR MORKHAM: The system wrangler would be a highly skilled individual who has competencies across those program areas, who understands – excuse me – the different languages those programs use, the budgetary constraints and measures they had to hand to help. Predominantly though they'd be very skilled at developing collaborative working relationships, not only with the programs themselves but with the young person and their family. We heard from Ms Cairns in her evidence that
15 the Transport Accident Commission in Victoria has, I think they were called support coordinators, that fulfil this role for that Commission and one of the more important tasks that person has is to develop a relationship of trust with the younger person they work with and their family.

20 I think that is a very important point to make, because at the moment the support co-ordinators that the NDIS has are poorly skilled. We've recently conducted a survey of support co-ordinators and found uniformly that – most of them said they didn't receive training and were thrown out into the community. These support co-ordinators through the NDIS receive funding only through the plan. If there isn't
25 sufficient funding, they stop turning up. There's no continuity of support co-ordinator under the NDIS whatsoever, insufficient funding, poor training and lack of ability to develop and sustain those collaborative working relationships across programs and with young people and their families. Fundamentally we need a very-highly-skilled worker who can deliver that collaborative working relationship, who
30 can wrangle the system, bring the processes together to deliver the joined-up responses these young people need.

35 So I think, if we can develop that sort of person, we will be very well advanced in solving this problem. That case-manager, key worker, wrangler, system-wrangler must be in place in the hospital, in our view, as soon as permanent disability is identified by the hospital treating team for someone newly disabled; that system wrangler should be actioned immediately.

40 For people in nursing-homes, we want to see a system-wrangler, case-manager, key worker, whatever we want to call it, appointed immediately to work with that younger person to develop an exit strategy to the community that should be available within six months or earlier. And that means again rounding up all the actors that are relevant to that person's need to live in the community safely and with confidence and getting that action plan in place. It also means working with the aged care
45 provider, who may need to work with the NDIS and Health to skill-up that person to gain the skills back – that they may have lost – so that they can move successfully back to the community. But we see that key worker, case-manager, system-wrangler

as fundamental to the solution of this problem. We also don't want to see that person in the purview of DSS or any government agency. We want them to be completely independent but with a mandate to act.

5 MS HILL: Mr Bo'sher, could I ask you to respond to Dr Morkham and Mr Jamieson.

MR BO'SHER: Thank you. I wanted to highlight perhaps some of the similar themes of what, we're saying, are really important in this role, because whether we
10 talk about advocacy, case-management, support co-ordination, I think what we're trying to come up with – what are the characteristics of this support to navigate the system. As Mr Jamieson said, we've seen people throughout this week who get lost in the system, who feels like the gaps in the system are letting them down. So what are the characteristics of that role? I think there's four characteristics that, it seems
15 like, our organisations are highlighting. One of those is a very skilled worker. The second is that they can work across systems and that – aren't just part of the disability system.

Two more that perhaps didn't come out as much so far – one, I think – one
20 characteristic is that we need a way of supporting people that can have a whole range of expertise that lives within that service; so we're talking about someone that can have deep expertise in how health and clinical supports work, deep expertise in engaging with the housing market, deep expertise in designing disability-support models and all the other goals that people have about returning to work, about
25 reconnecting with their family. I think finding the workforce where one individual can have all of that expertise is going to be very, very challenging, especially as we try and deal with this problem across the country.

So from Summer Foundation's perspective, whether we have one single worker, the
30 key-worker model that can hold all of that expertise in that one role, or whether we have a more-consortium-based approach, I think, needs a bit more investigation, because, certainly, what we know is that these systems are each complex, and we want someone who's expert in each of those systems, and trying to find one individual that can do all of that can be quite challenging. So thinking about – I
35 would say Government should work with the sector and people with disability to design what are those skillsets that that – that are needed to help people navigate the system, and if we can find one person to do that – that's fantastic, and if we need a team-based – multidisciplinary team that might have a key worker that engages with the person but that key worker's able to then draw on other expertise – I think that
40 would be really critical for success. And the - - -

MS HILL: Do you - - -

MR BO'SHER: Sorry.

45 MS HILL: Your fourth?

MR BO'SHER: A fourth characteristic that we haven't talked as much about is about aggregation, and that's, I think, one of the biggest problems that we've got at the moment. If we think about – if we take a group of, say, 500 young people in aged care that might be living in Melbourne and want to leave their aged care facility – those 500 people have 500 different support co-ordinators out there, each of those 500 support co-ordinators making their own phone calls to housing-providers. So housing-providers get 500 different phone calls from 500 different support co-ordinators, all for young people in aged care in Melbourne, wanting to leave. It's not a sensible program design, that you would distribute that so extensively. A much-more-effective model would be able to have a more-structured network of how that support is being provided so the housing-needs of people can be aggregated together and we can work on a systems-based solution, not going person-by-person to try and generate a new building, construction.

15 MS HILL: Do you agree? That role of the advocate should be independent of Government, as Dr Morkham suggests?

MR BO'SHER: I would say that advocacy – this is, probably, a useful point to separate out advocacy, kind of big-A advocacy, from the other supports that we're talking about. I think young people in aged care do need access to an advocate who is genuinely independent from all the other supports they're getting, because even in a model where we have a really highly-skilled support-coordination workforce or a skilled key-worker model, however that rolls out, people still need independent advocacy in the event that they're not satisfied with the way that key worker or the way that that support co-ordinator's working. So I think we do need independent proper advocacy for people.

In terms of that system navigation, that kind of case-management, that support co-ordination, that key worker – I think there is a question about how we learn from what's working in other systems. So we heard yesterday for example, from compensable insurers like the TAC, that what's really successful for them is that – they do find the health supports and disability supports that someone needs. So if we reflect on the TAC – they don't have a system-wrangler that's working across TAC and the Victorian health department to try and bring those together. The way that problem's been solved is to bring the funding together before the case-manager or the support co-ordinator even starts working with the person so they've got one single funding source they can draw on.

So I think there is a structural question that Governments and the Royal Commission need to grapple with is, which is “Can we get the systems to be integrated before we even get to the person's NDIS plan, or do we need to fund someone to be able to integrate those two together because the silos are separate?”. Think the experience from TAC is that bringing those two funding sources together through the TAC has enabled people to get better outcomes and fewer discharges into hospital; so I think a more-systemic way to fix the problem would be for the NDIS to provide the person's plan and, where they need clinical supports that might be the responsibility of the health system, that they are – that those supports are included in the person's

NDIS plan, delivered in an integrated way to the person, and in the back of house between Governments they work out the funding arrangements for those supports, rather than having a worker that's trying to bridge together a state-funded health support and an NDIS-funded disability support.

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MS HILL: Dr Morkham?

DR MORKHAM: With respect I think I have to disagree with Mr Bo'sher on some of the comments he's made. I hear what you're saying, Mr Bo'sher, about having a separate worker in each of the silos, but that's the point. The whole point is we need one person to make the silos work together, and we don't have that. And I think the TAC does have that person. I think we heard evidence from the three compensation schemes who appeared before the Commission, that they each have a worker who goes into the hospital at the very earliest opportunity and starts to bring those three programs together. The funding is – being a compensation scheme, obviously, as a single funder is advantageous to them, but nevertheless, each person's circumstances are unique and require a different solution. So having that key worker available at the very earliest opportunity enables those schemes to invest in that person's recovery from the very get-go and make sure that all the services and supports they need from those different areas are in place at hospital-discharge point.

So I do believe we need a key worker that can actively move across and within those systems to bring those integrated responses together, and I think we need that, because each person will be different and unique, and I don't think having a separate worker in each program will do it. I think we'll be back again to having arguments and argy-bargy, buck-passing about who pays for what.

One of the signature things I've heard this week, when we've had – the NDIS and senior government officials from Health and the department of social services do is constantly buck-pass about this. We've had the NDIS come along with great expectation about being a huge social reform, yet the conversation has deteriorated to the point of who pays for what, not how do we get the person's needs best met, who pays for it. "Is it Health that has to pay? Is it the NDIS? Is it someone else?" The person is in the middle of this – and it's the person who ultimately loses. So that has got to stop. And we do need someone; we do need an independent third-party intermediary to come in and provide that assistance, that expertise, that relationship-management, without which this will not happen.

MS HILL: Mr Jamieson, Youngcare has been involved in what's described in your statement as the north-metro pilot.

MR JAMIESON: Yes.

MS HILL: Could I ask you to explain to the Commission what that pilot has involved and how does it work?

45

MR JAMIESON: Okay; so around 12 months ago Youngcare and Metro North Health in Brisbane: we had an existing and formal relationship, but we – I suppose collectively we were dissatisfied with some of the outcomes that were happening for people, particularly those people that were stuck in the hospital system. And we
5 proposed to Metro North Health that we would fund a role for – initially it was a six-month period – to assist people with gaining their first plans that – for the NDIS that were stuck in hospital. And so we've funded a senior occupational therapist, and that role works across the metro-north system to – Metro North Health system to assist – initially to assist people to get their initial plans. Included in those were looking at
10 their assistive-technology needs, if they were to return home, home occupations. Do they need a specialist disability-accommodation outcome as part of their plan, or do they just require a supported independent living in their plan.

And so it's been able to assist people to get their plans, I suppose, fully developed first-up, and it saves time for people so that they're not receiving their first plan and then gaining the evidence to what they're going to need further on. It's – we've extended that role now for a further 12 months, and we've expanded on it as well, and so the role will work not just within the hospital system but also out in the
15 community, where we will try and reduce the number of re-admissions or new admissions into hospital, because we do understand that hospitals are a flashpoint for people, that if they go into hospital because of an exacerbation of a – of their disability or their condition, then there's every chance that they may not be able to return home. And because there is a lack of options out there, that's when people end up going into aged care. And that's one of the things that we, definitely, want to
20 stop.
25

We want to stop aged care being that first port of call that people look at when there's no other option. So this role has – is starting to get some really outstanding results. 90 per cent of people that have gone for SDA in their plan in the Metro
30 North Health system have received that, and more and more are getting it all the time, and, yes, it's proving to be really, really successful.

MS HILL: Let's look at those entries to residential aged care, and you just describe, Mr Jamieson, that hospital is often a flashpoint. Dr Morkham, we've heard your
35 description of there being a pipe-line referred to in evidence this week, and you referred to this earlier this morning. What is the pipe-line?

DR MORKHAM: The pipe-line is really an express route into aged care. So most of these young people enter residential aged care on discharge from hospital.
40 Unfortunately the fact that residential aged care can have a bed available is a very attractive opportunity for a hospital that doesn't provide accommodation, that is there to support sick people to get better and, when the person isn't sick any longer, does need to discharge. We, simply, haven't had the services and supports available to avoid that yet, and having that pipe-line straight into residential aged care has proved
45 irresistible, I think. It's also systematic – of a deep system inertia. There's been a complete reliance on aged care to the point where things are not even considered, other options are not even looked for. aged care is the default option now for

younger people looking to be discharged from aged care. We're seeing this more and more.

5 I think we've got – at least 10 people, we know, next week are going to be sent to residential aged care from hospital because there isn't anything else available to them, and I had an email at quarter past 9 last night from another young man we're working with in Sydney who's in hospital, who emailed me; he's being sent to an aged care on facility on Monday morning. So this is the pipe-line. The pipe-line is there, because there are no other options, number 1, number 2, because nobody is
10 looking for other options, and nobody is try to deliver those other options, develop and deliver them at all.

MS HILL: Using that young man in Sydney as an example – what role, in your view, Dr Morkham, does – do current assessment processes have in young people
15 entering residential aged care?

DR MORKHAM: So at the moment a younger person has to go through an aged care assessment team assessment. This is really the gate-keeper role. It's the gate-way into residential aged care for any person, regardless of their age. It doesn't
20 assess the competency of the residential-care facility to manage those needs. It really doesn't assess the level of need of the person. It ticks off a number of boxes and says, yes, under the Act you're eligible, because no other opportunity is available to you, if you're under 65. It's a very simple procedure to go through, simple as in not detailed enough. It doesn't ask the right questions of a younger person's – about a
25 younger person's needs or circumstances at all and, certainly, has no advice for the residential aged care facility who receives this person without any prior knowledge of them.

MS HILL: Do the new principles for ACAT assessors to apply under 6(1)(b) go far
30 enough?

DR MORKHAM: It's a very interesting question. I don't know that they do. I think again putting the emphasis back on the ACAT teams to make the decision is incorrect. Prior to the arrival of the NDIS, we'd managed to get a protocol in place
35 whereby every hospital looking to discharge someone to residential aged care had to go back to the state disability services people and ask "Was there anything available?". What could they do to help provide the services that person would need. If there was no other option than aged care, then the question became what will the state disability services do to support that person while in residential aged care.
40

With the arrival of the NDIS, that vanished. So now we have the ACAT team as the first port of call. That's got to stop, I think, and we need to go back to the hospital teams going straight to the NDIS and asking what are they going to do, what options do they have to help this person avoid residential aged care or make sure that their
45 time there is short and that they have the supports they need while they're in there. We also – if we're going to do that effectively, the NDIS has to smarten up its processes considerably. The time delays at the moment between getting approval for

anything – are, simply, unacceptable. So if we're going to make it work, the NDIS has to lift its game majorly.

5 COMMISSIONER BRIGGS: So are you saying, Dr Morkham, that the default to aged care has got worse since responsibility in this area has moved from the states to the Commonwealth?

DR MORKHAM: I am indeed, commissioner.

10 COMMISSIONER BRIGGS: Right.

MS HILL: Mr Bo'sher, Dr Morkham's evidence picks up on evidence that you've given earlier. Can I ask you: do ACAT assessors have the ability to consider 6(1)(b) of the new principles when it comes to young people entering residential aged care in such a way that young people – there is a limit to the amount of young people entering aged care?

MR BO'SHER: No. I don't think they do. I would agree with Dr Morkham, that they're not empowered with the systems or the processes or the training to be able to make that assessment well. But, importantly, they're also not empowered with the ability to fund any of those options. What they're empowered with is the ability to enable someone to access a funded aged care place. This week we've heard examples of ACAT assessments being approved in a matter of days, and we've heard what's a very common story about an SDA application taking six months to prepare. So we're talking – that's not even the approval process from NDIA; that's just the point of submitting a form to apply. And what we've got is a system where inappropriate placements can be funded in two or three days but an appropriate good practice solution will take six months to apply for and then a number of months for NDIA to make a decision and then a number of more months to transition into that place while it's stood up by a service provider.

And so what we've got are these time-lines that are incredibly inconsistent between – accessing a suboptimal option is very quick. It's very easy; accessing a good practice option, which Governments have funded – Governments have given NDIS the funding to make this happen, and Mr Lye talked about that in his evidence of, you know, the scheme has \$800 million to \$900 million to fund these places that's not being spent. The reason it's not being spent is the timeliness of NDIA decision-making is just glacially slow compared to the speed at which ACATs work. And in that sense, you know, we can look to some of the things that are working, you know, what's working well about the aged care gateway for young people, it's very fast, it's very simple to get out of hospital.

And no one wants to be in hospital. Hospitals, you know, don't want people to be there that don't need rehab because there's other people sitting in an acute bed that do need rehab. Younger people are not getting a good outcome by sitting in a rehab bed when they don't need to be there. Everyone wants to be back in the community, back with their family. NDIS has the funding to make that happen. The processes

don't support that. That's why we think that those decisions about entering aged care should be made by NDIA in the first instance and the obligation should be with NDIA and its funded supports to be able to find alternatives to aged care. And we think that's entirely possible and practicable to implement.

5

MS HILL: Does that mean it's too late once a young person has been assessed with an ACAT?

10 MR BO'SHER: That's right. What we heard from the TAC and what we know from all the work that we've done is that starting early with people in hospital is essential. But as soon as people are in hospital, and it's apparent that they're likely to be eligible for the scheme they should get into the NDIS and whether it's a support coordinator or a key worker should start working with them on day 1 of being admitted into the scheme and that would enable housing options to be explored. It would enable a lot of people to be able to return home who at the moment lose their home because they are stuck in hospital, are unclear whether they can get home modifications made, might lose their private rental, might have to sell their home.

20 You know, if we start early we can help more people return home but we can also line up specialist disability accommodation placements which are not possible to line up at the moment because the NDIS decision-making process is so slow to get that approved.

25 MS HILL: Let's turn then to the alternatives for young people in residential aged care. What are those alternatives, and I might start with you, Mr Jamieson?

30 MR JAMIESON: Yes. Returning home is one alternative but, again, the NDIS needs to come to the party and approve home modifications and assistive technology that would enable that. I think returning home should always be the first – the first option that's fully explored. There's, you know, there's supported independent living housing, and that – but more of that needs to be built. It's the same with SDA, more of it needs to be built. Aged care should – should not even be part of the options that we're looking at. And yet, you know, as we've been hearing more and more, it is the – it seems to be the default option. I think in assisting that, I suppose the example of the role that we have been piloting with Metro North, if more hospital boards had those dedicated roles, then people can be identified earlier so that they can work through those options right from – from the outset of getting a new diagnosis or – and that, so that that – that can be explored at the earliest possible – at the earliest possible time.

40

MS HILL: Dr Morkham, bearing in mind the time that the three of you have described that things are taking to happen, in your statement and your evidence earlier today you talked about a six month time limit. What's that six month time limit that you're referring to and how does that figure into alternatives to residential aged care in your thinking?

45

DR MORKHAM: So the six month time limit was referring to people who are already in residential aged care, and the provision of a key assistance wrangler, key worker person to be appointed to them to develop an exit strategy for that person; that should be activated at the end of six months or sooner if possible. We've

5 identified six months because we understand there's got to be – there are several actors who need to come to the party with this and sit down to work out the integrated response that's required. We've mentioned Health, Housing and the NDIS. We also have to sit down with that young person and their family, if they're

10 around, to find out what it is that they want. That isn't being done at all.

The SDA program at the moment is really embracing a build and they will come approach that is simply not good enough, and we're seeing large numbers of group homes built as a result, together with apartment developments which are great. Apartments are terrific; not everybody can live in an apartment. We want to see the

15 young person and their family asked from the very get-go what it is that they want, where do they want to live and how do they want to live. That consultation with them and their community should be the very starting point for any of these conversations. So six months is there because we're also aware that as well as getting those program actors to work collaboratively with one another and develop

20 the solutions they need to progress, we also need to look at the young person's capacity to transition successfully to the community again.

People – younger people who enter residential aged care commonly lose life skills. They decondition and become institutionalised very, very quickly which is why it is

25 so critical that we stop them going in in the first place. Rebuilding those life skills, the things that they've lost that they may need to depend on if they are to live successfully in the community can take time, it can take money and it can take a huge amount of effort. And that needs to be factored in. If that can all be put in place much earlier than six months that would be wonderful, but we put six months

30 there as a marker to make sure that that exit strategy is in place and active by the end of that time.

MS HILL: Dr Morkham, to return us to an earlier topic of data, can we be satisfied that we have the information that is needed – and you're shaking your head, Mr

35 Jamieson – to identify either young people who are presently in residential aged care or at risk of entering residential aged care?

DR MORKHAM: We know very little at all, Ms Hill, unfortunately. Again, I'm mindful of the evidence Ms Cairns provided and in discussions with her after she

40 provided her evidence, the TAC knows exactly where the 13 young people that are their members are, and they don't have a set-and-forget approach to them. They go back to them regularly and ask "Is this still where you want to be? Is there another option you want to pursue? What can we do about it?". They know the level of need that person has, they know their capacities and they work actively with them. They

45 don't walk away. So their case manager stays the course. They stay the course over years, not weeks or months as the NDIS with its support coordinators, but they are there for the long haul. That's what we need.

So no, we don't have the data at all. We don't know anything, in fact, the NDIS doesn't even know. The NDIS has no idea how many of the people it's funded in nursing homes have moved out. We put in a freedom of information to the NDIS and got that information back from them; they didn't know. They don't know what
5 the level of need these young people in nursing homes have. They haven't asked what it is they would like in terms of leaving aged care; they don't know where these young people would like to live and what circumstances they would like to live in. So we have very, very poor data, indeed. And again, I'd make the point, gathering data is critically important but we need to go back and ask these young
10 people and their families first and foremost about their preferences.

COMMISSIONER BRIGGS: Given the size of the task, there are about 5800 people, I think, in last estimates from DSS the other day; it doesn't seem beyond the capability of government agencies to do precisely what you're suggesting, Dr
15 Morkham.

DR MORKHAM: I agree, Commissioner, and I think we already have, through the NDIS, plan support coordinators who are with these young people who could be charged to ask for this information.
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COMMISSIONER BRIGGS: A good point. A very good point.

MS HILL: Mr Bo'sher, James Nutt, Kirby Littley, are both Summer Foundation advocates; how did you find Kirby and James?
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MR BO'SHER: The ability to connect with people with disability in the NDIS is extremely difficult. And I think that this is the fundamental problem that Dr Morkham is talking about, is that because the NDIS isn't involved in the admission process into aged care, many young people are going into aged care without the
30 NDIS even realising that they're going into aged care. And if the NDIS don't have any awareness of who's going in except for quarterly reports that are provided by the Department of Health there's clearly no opportunity for them to intervene. But those key questions that Dr Morkham talked about, what is the person's disability, what's their support needs, what are their housing needs and preferences, and what does a
35 good outcome look like for this person, that is just fundamental information that is needed in the housing market.

I know that specialist disability accommodation has come up quite a lot in the discussions this week and it is an enormously critical support. Our view is the
40 majority of young people in aged care will be eligible for specialist disability accommodation and yet the amount of specialist disability accommodation that's being built doesn't meet the needs of the group at the moment. So we need to think carefully about why that's the case and I would suggest that the single biggest reason that we're not seeing the amount of specialist disability accommodation being built is
45 that providers of housing are not confident that if they build that housing that young people will be able to move into that housing instead of moving into aged care.

So if we think about that situation at the moment, you know, right now, today, there are empty specialist disability accommodation places that young people in hospital at risk of aged care or in aged care, wishing to get out of, could move into. They could move into those places tomorrow. Those places exist, they're accessible places with
5 support that would meet these people's needs. The challenge is that those young people in aged care don't know where those vacancies are and those providers that have places that young people in aged care could move into can't connect with the young people in aged care. And so fixing this connection problem, understanding from the NDIA or an agency contracted by the NDIA to understand who all the
10 young people in aged care are, what their housing need is and to be able to proactively match them with the housing vacancies that meet their needs is a just a fundamental building block.

Our concern is that if we don't solve that, we could – you know, in three months' time we could bring online a thousand, two thousand new housing places; the vast majority of those will sit empty. You know, if government went out tomorrow and contracted 1000 new housing places for young people in aged care, and we did nothing else, if we just did that in isolation, I can tell you the vast majority of those
20 will be unfilled. They will sit there empty, and they will sit there empty because young people in aged care still don't have a way to find out about them.

They don't have the skilled support worker to help them explore those options and make that transition, and the NDIA doesn't have a systematic way to be able to tell the market who those people are and what their housing are. So I think there's a big
25 danger in rushing into government commissioning housing solutions if we don't know, as Dr Morkham said, what the needs and preferences are of this group. We need to understand that first and then that will spur significant development in the housing market, and where the market isn't responding then it's entirely appropriate and important for government to be able to come up with responses in those thinner
30 markets.

MS HILL: Mr Bo'sher, you're the CEO of the Summer Foundation but there's also Summer Housing who's a provider.

35 MR BO'SHER: Correct.

MS HILL: Could I ask you to explain what Summer Housing is and the relationship between the Summer Foundation and Summer Housing.

40 MR BO'SHER: Sure. So when I started talking about Summer Foundation today I mentioned that we run prototypes and the idea of that prototyping function is to fill a gap in the market that no one else is filling. And so quite a few years ago we identified a gap in the market being really accessible apartments for people with disability and we worked with TAC and Victoria to develop some apartments for
45 people with disability in Abbotsford and then in Newcastle in the Hunter. So they're apartments purchased in a bigger development, a mainstream private sale

apartment building where we would purchase 10 apartments off the plan from that developer, peppered throughout the building.

5 So we prototyped that. We saw that that got people like James Nutt out of living in a nursing home and into a really accessible apartment of his own. And we got to the point of thinking that that was something that was getting young people out of aged care, it was leading to great social and economic participation outcomes for people and that there was a role to scale that. We're an organisation that wants to prototype things; we don't want to be a provider, we don't want to work on scaling those things up. So we set up an independent organisation called Summer Housing that has its own board, its own management team, its own financials and is separate from us to scale that work.

15 So we handed over those assets that we had to Summer Housing and now our relationship with them is that we have a couple of our directors that sit on their board, and we undertake work for them on a contract basis to go around to aged care facilities and find young people who would be interested in moving into the apartments they're building. And that's a similar service that we provide to a range of other housing providers in the market to play that connecting role. And that's why I was reinforcing the importance of that connection process, because at the moment it relies on housing providers contracting an organisation like Summer Foundation to act as an intermediary but that's not a systems-based solution.

25 The kind of entrepreneurial approach to a gap in the market, if we're going to solve this problem at the scale that we're talking about in this Royal Commission, we need a systems-based solution, not a kind of entrepreneurial approach that might help some young people leave but is not going to be a comprehensive solution for this whole population.

30 MS HILL: Can I take you back, Mr Bo'sher, to the grassroots level. How did the Summer Foundation practically find James Nutt and Kirby Littley?

MR BO'SHER: So James had been living in a group home in the Hunter in New South Wales, and his support coordinator became aware of the work that Summer Foundation was doing, and it was largely by chance that his support coordinator found out about the work of the Summer Foundation. So that kind of speaks to, again, this lack of systematic approach to connecting people with housing. And to the Littleys, they're a family that we've supported – Kirby we've supported for a long time to help share her story about her experience in hospital, her experience in housing and it's been amazing, I think. This is an example of where the NDIS has been able to achieve great outcomes, is starting working with a family where someone was in a terrible situation that was not meeting their needs in any way, shape or form and then now being able to live in her own specialist disability accommodation property that she owns, that she has full choice and control of; I think they're the examples in the NDIS that we need to be able to build on and show where the NDIS is achieving success for people.

MS HILL: Dr Morkham, would you like to respond to what's been said, briefly?

DR MORKHAM: Look, I've got a couple of things I'd like to say, Ms Hill, thank you. First of all, these young people are Australian citizens and like any other citizen
5 they want the same opportunity to live in their own home with the supports they need, to be as independent as they can be and contributing members of their communities. At the moment, the SDA model the NDIS is supporting is predominantly leading to the development of more group homes. These are mini-institutions. These young people don't necessarily want to go and live in group
10 homes at all. So Mr Bo'sher has mentioned that some of these group homes are sitting vacant and that is correct.

We would get probably two or three calls a week from developers saying, "Look we've got this wonderful brand new group home; you must have some young people
15 living in a nursing home who would love to move in". Well, actually we don't. These young people are asked to move in after the fact. They've had no contribution, no involvement in the development of this service. We don't know what the model of care might be that they need to live there safely. Fundamentally, they don't want to live with others with a disability, though. And I still cannot
20 understand why we're seeking to develop group homes that have been the model for disability accommodation for the last 40 years. So that is the first thing I'd like to say.

The other thing; I think Mr Bo'sher mentioned the disconnect between the young
25 person and the developer, and finding vacancies that are out there. I want to turn that on its head and say that we need to connect the young person and the developer at the very outset, not after they've built the service and are looking for someone to fill it so they get a return on their investment. I want to see the developer sitting down with that young person from the get-go and asking that person what it is that they are
30 looking for, can that developer satisfy their need; if not, let's look for someone else. To do that, we think we need a housing clearing house where people can see what developers are active in a certain area, what they might want to offer. We can see where young people might be. The key worker could go to that clearing house, identify what developer is working in a particular locale, connect them with the
35 young person to start the conversation about what it is that young person is looking for in terms of housing and the services they need in the community.

So I think we need to remember that these are Australian citizens we're talking
40 about. They're not a problem to be solved, and they're certainly not a problem for people to be grateful when they're offered a group home opportunity when it isn't what they want. We also need to see nursing services; the model of care these young people need, wherever they live is fundamental to their health and wellbeing. Yet that isn't even on the agenda. So people are being asked to consider these opportunities sight unseen, and for most of these young people the system has failed
45 them many, many times; why should they trust in this.

We had an example of one of the people we've worked with who was offered an apartment in a development after it was completed. When she went to see the apartment, it was completely unsuitable to her needs. Too small, there was no way for the maxi taxi to let her out safely anywhere at the front door. She wasn't allowed to know who the other young people in the complex were going to be. She wasn't allowed to meet them. There was no opportunity for those young people to come together to negotiate with the SIL provider that was going to provide the services that they were having. So these young people and their families are being locked out of that conversation from the outset and we need to stop doing that. We need to be asking people what it is they want and working collaboratively with them and the services they need.

MS HILL: Mr Jamieson, you've been sitting there nodding your head at times. Youngcare builds houses for young people.

MR JAMIESON: Yes.

MS HILL: Does Youngcare have way of balancing the housing needs of people either in residential aged care or at risk of entering residential aged care with that model of care?

MR JAMIESON: Yes; we do, but I think, responding to Mr Bo'sher and Dr Morkham's comments as well as knowing where people want to be and what their needs are is a piece of the information that is, sadly, lacking for – I think, for everybody. We've got a very small window of opportunity to make this SDA opportunity work. It relies very heavily on investment from the investment sector and that, to enable us to build to scale to what it is, that we want to achieve for people. But right now we're doing it, and I think Dr Morkham said earlier "Build it, and they will come" kind of attitude, because – there are pieces of the puzzle that we're just not sure of. We know – the data that we have – we know where people are, but we don't know where they want to live and what is the housing model that they want to live in and what are the needs that they have around that, because we don't have all of that information. And so we're doing it – kind of sight-unseen, and that is a real risk when you're looking at the scale of what it is, that the sector want to achieve to get the best outcomes for people.

How Youngcare works is that we do – we try and identify people as early as possible and understand what their housing-needs are, and what it is, that they want to achieve in their housing environment, and if SDA is that, then we will work with them and their families to then work out the housing solution for them, and also we will support them to work with the SIL provider to, I suppose, negotiate the SIL needs that they will need within the house. And we will – as a provider, we will – we've got a very vested interest in making sure that it's the right outcome for them long-term, because we want them to get a great outcome that is going to be – that's going to support their needs, not just now but into the future and that; so it's important, that we do get it right. And I'm still not sure that we have all the information that we need across the sector to get it right. And as my colleagues have been saying, that

information can be got, if the NDIA did ask those right questions when they're engaging with people. So – we need it to be successful.

5 COMMISSIONER BRIGGS: Can I ask before you go on, Mr Jamieson, how long would it typically take, going through the sort of process that you've outlined, that you work with, to go through those discussions and then to get the appropriate accommodation in place and to have the person move in with the SIL supports they need?

10 MR JAMIESON: It's a very good question, Commissioner. Too long is – and that's not being flippant, but it does take time. We want to know what are your likes and dislikes, where do you want to live, what type of housing do you want, what supports are important, what do you want to do; we're building a house, but it's more than a house, that you need. You want that house to be functional and meet all
15 of your physical needs. But if you're going to share with somebody, then who is it, that you want to share with – and those things. So I would say "at least 12 months", because it – but longer in many cases, particularly at the start; so we're – Youngcare's built four places over 14 years. We'll build four places over the next 18 months, but it's also taking us an awful-long time through the planning-processes,
20 working out the finances to make sure that we've got sufficient funding – before we start – to complete the building. And so it is taking a long time. I think we will get better at it and quicker, and we need to get a whole lot better at it as a sector, because there's an awful lot of people that are waiting to move into housing. But as Mr Bo'sher said, if we go too fast at this stage, they're going to remain empty, because
25 we – we're not confident that we will have people achieve SDA for what it is, that we build right now. So - - -

COMMISSIONER BRIGGS: Yes. I think, as we heard the other day, many of these approaches – I think the NDIA said that we're learning as we go, and that does
30 take a while, but it, certainly, points to the urgency of government action to move quickly to get – collect the information that's necessary to provide the basis for this co-ordinated delivery of accommodation services and healthcare.

35 MS HILL: Mr Bo'sher, would you like to respond?

MR BO'SHER: Sure; maybe if I can add a couple of things – so over the next 12 months or so, we'll support a hundred people to move into newly-built specialist-disability-accommodation places, and similar to Mr Jamieson, our process would begin nine months before that dwelling is completed. It involves four months or so
40 of going out and finding people who might be interested and then three months of supporting that person to put together their documentation for the NDIA and then two months or so – on an optimistic time-frame – to get the NDIA to approve that and get the other supports in place, that they need.

45 Thinking about that nine-month time-frame – if we were able to understand who the young people are and connect directly with those young people in aged care and if they already had specialist disability accommodation approved, that nine-month

time-frame would cut right down to two months instead of nine months, because we would know who these people are, they would've already been asked about their housing-needs and preferences, and we could be much, much more targeted to be able to go out to people that had the funding as soon as the service was available to
5 move in. But that's not the case at the moment. We've got this very, very long lead-up time, because it involves a very inefficient process of going round nursing home by nursing home to find people and start a conversation that should've been started 12 months ago with them.

10 So I'd very much encourage the Commission to think about – if NDIA can get more than two per cent of people in aged care having SDA approved, instead of 98 per cent having no support funding to leave aged care, 98 per cent should have the funding to be leaving aged care. That statistic should be turned on its head. And if
15 that was the case and there was a structured way to engage with them, people could move out a lot faster.

I think – the other tension that's, I think, brought up in this discussion is that there are some people who will want to work very closely to design a property that really meets their very individual needs, and it's very customised for them. There are other
20 people that – that's not their preference; they just want to move into a high-quality dwelling that doesn't need to be highly customised around them. Like all Australians – some people want to be very involved in that process; some people just want to walk into something that's brand new. So people have different preferences. We should enable a system that can do that.

25 I think, regardless of whether people want to co-design that property or want to just move into something that's ready – what we know is this group of people have a very urgent housing-need. We've heard all week about the pressure of leaving hospital, and it's not likely, that housing-vacancies are going to line up perfectly with
30 when people need them. There are going to be these gaps, and those gaps are especially large, as the market's growing at the moment, and that brings into question the role of transitional housing, and I think that's really the glue in the system that's missing; the buffer that we need to be able to get good housing outcomes is people do need to have a housing option that is available next week or next month. And that
35 might not be where they're going to move into permanently, but it's a place that meets their needs, that should offer rehabilitation services so that they can continue their functional improvement, but that is a place they can be while they find the right long-term option.

40 And without that bridging housing, without that kind of buffer in between where people are in their long-term housing, we'll end up in the situation we're in, which is aged care plays that role. But as we've all talked about, when people go into aged care, their functioning declines, their mental health declines, and it's very, very hard to leave. So I think there's a big piece of work about building a transitional-housing
45 model in the NDIS that can give people a response next week or next month, even if it's then going to take time, to create that ideal long-term housing-option.

MS HILL: Mr Bo'sher, where does that leave those that don't fall within the NDIA, NDIS cohort? So – those young people that might be suffering from cancer, other life-limiting illnesses.

5 MR BO'SHER: Yes. The primary group that we're talking about, that aren't eligible for the NDIS are people where the palliative-care system is going to be the right service response. Our experience is those people that are getting knocked back on eligibility for the NDIS are, largely, people where – the NDIS is saying “You don't have a disability; you have a life-limiting health condition”. So for those
10 people what we should have is a palliative-care system that works effectively for people, that can provide in-home palliative-care services or palliative-care services that meet their needs.

15 Where there are people who are not approaching the end of their life, that have some other health condition that happens to not be classified by the NDIS as a disability, I think, we need to revisit that policy, and we need to think about why we have the scheme. We have the scheme, because – the idea is, regardless of how you acquired your disability, regardless of what that disability is, we're focussed on the functional impairment that's life-long. And if it happens, that there's some technicality, that
20 your particular condition has been decided to be a health condition rather than a disability – in our view, that's quite arbitrary. When we're thinking about the person and their lived experience – so I guess what I'm saying is I think we need a palliative-care system that works well for people that are approaching end of life, but we also need to revisit the question of people who might not be eligible for the NDIS
25 because of an arbitrarily defined health condition.

MS HILL: Dr Morkham.

30 DR MORKHAM: Couple of thoughts come to mind, Ms Hill. First of all I think we're beholden to old thinking about disability at the moment across the broad spectrum of this discussion, particularly in the way the NDIS approaches it and sees people with a disability as a problem to be solved, this housing that people need is a problem and people should be grateful to be offered an opportunity to move into something, as I said before. And the person I mentioned earlier – who was offered
35 an opportunity to move into an apartment and didn't – the response from the scheme was “Goodness me, why not? Surely you want to move out of the nursing-home”. Well, yes, the person did, but not into something that wasn't appropriate either. That's the first thing. We've got to stop assuming people with disability should be grateful for anything that's offered to them.

40 The second thing is that the delays and problems in delivering a supported accommodation – certainly, there are major delays and problems with that, but that shouldn't stop us. Government can act to solve those, and we need government to do so. We need government at all levels to start to act collaboratively, work together to
45 do so. One of the things that we need is a building-code that mandates accessible, visible and adaptable building that are new; new buildings to be that. We don't have that at the moment; so all the apartment towers we see going up around the country:

none of them are built to be accessible. Everything has to be retrofitted at great cost. Very, very simple change in the rule there would stop that happening, and we'd open up a market immediately. With regard - - -

5 COMMISSIONER BRIGGS: Are you serious? Can I just hear that again? So modern apartment buildings which are being built everywhere to house many people in cities don't have mandatory disability access.

DR MORKHAM: No. They - - -

10

COMMISSIONER BRIGGS: Well, that's extraordinary.

DR MORKHAM: Sorry, Commissioner; they may have mandatory access to the building that is accessible, but the apartments themselves are not.

15

COMMISSIONER BRIGGS: Okay. I hear what you're saying. That's a different kettle of fish.

DR MORKHAM: Yes. We've had discussions with developers and asked. Would they consider doing that. And they've said "no", because they can fit more apartments on one level but don't have the circulation space that people need – with a disability. So there's a cost.

20

COMMISSIONER BRIGGS: Yes; because they can get more apartments on a floor and make more returns.

25

DR MORKHAM: Yes. Indeed.

COMMISSIONER BRIGGS: I understand; sorry about that.

30

DR MORKHAM: No. Not at all. The other comment is about the market itself. Relying on the market to do this without any direction from the NDIS is doomed to fail, and we're seeing this already in rural and remote areas. So the market needs to be directed by the NDIS about where it should look, not just "Build, and they will come", not just assume people are going to be grateful for anything that they're offered, but directed to look at the model of care that needs to accompany the development of that housing. That's absent at the moment. So the NDIS needs to take a much heavier hand with managing the market and the providers that respond to that.

35

40

I think my colleague Mr Bo'sher has mentioned interim housing; we see that as fundamental for stopping the entry of younger people into residential aged care. We want the Government, Federal Government, if need be, to establish a dedicated interim-housing funding stream to do just that. We can't afford to wait. If we're serious about stopping this, we need that dedicated funding right now, and we would call on the Federal Government to make that available as a priority.

45

The other comment I'd like to make is about people who are not in the NDIS but are in residential aged care, not members of the scheme. When the NDIS first began, everybody in a residential aged care facility was presumed to be moving into the NDIS. That was the scheme's position. It subsequently changed that and started to
5 cut people out – who weren't, in the scheme's estimation, eligible for their services. Every disability, in my view, is the result of a health event. Health and disability are intertwined. These adverse health events cause the disability, cause the loss of function that the NDIS is there to respond to. So to say to someone, simply because you have a terminal illness and that – we consider that a health event and we're not
10 going to help you is, simply, unacceptable. Anybody in a nursing home by the mere fact that they've been considered eligible to go there should be under the NDIS's aegis. Thank you.

MS HILL: Dr Morkham, you touched on young people in rural and regional areas, and we've heard evidence this week from Jessie Spicer, experience of living in a
15 country town, and we've heard from Mr Amato and his experience of being in residential aged care in a regional area, and they're two very different experiences. We've got Ms Spicer's experience, where it works really well, and Mr Amato, who wanted to get out of there. Reflecting on your observation that we're talking about
20 young people, we're talking about Australian citizens – how can we accommodate, how can we understand and represent the needs of all young people, all Australians to live where they want to live, where they're at risk of entering residential aged care or currently in residential aged care?

DR MORKHAM: I think the very simple answer to that, Ms Hill, is to ask that
25 young person and their family and their community. For some of these young people, particularly for Aboriginal and Torres Strait Islander people, the community involvement is fundamental to successful responses. We need to, simply, ask and work with the young person and their family to develop and deliver whatever it is,
30 that, they think, is needed. Australia is not a third-world country; we're a very wealthy first-world nation, and the fact we're not doing this is a national disgrace. So my answer to that is the responses will be as varied as the number of young people we have in nursing homes and the needs they have. We need many, many different options on the spectrum to solve this problem, but first and foremost we
35 need to consult with those young people and their families and communities first.

MS HILL: Mr Jamieson, in your evidence today you've described that Youngcare tries to get in and identify those young people at risk really early on. How does
40 Youngcare do that? How does Youngcare know who they need to be identifying in the circumstances?

MR JAMIESON: I suppose a lot of the time that will come through our Youngcare Connect line, or we will receive a grant application from somebody. And - - -

45 MS HILL: So that's a telephone service - - -

MR JAMIESON: Telephone and – yes, and so we’ll – and quite often the presenting issue is not really the whole issue, and so we take time to understand where people are and what their situation is and then start building those relationships. We have marketing campaigns; we go out on social media. We have
5 our website and that, and so we engage with people in whatever way that we possibly can. And we have a dedicated role that manages that.

I also wanted to touch on what Dr Morkham said about remote and regional services. We – Youngcare was very fortunate to be hosted on Groote Island in the Northern
10 Territory by the MJD foundation up there that – it’s an organisation that works with, predominantly, Indigenous people in the Northern Territory who have this condition, Machado-Joseph disease, and it’s a life-limiting condition. And the concentration of people in the Northern Territory with this condition is the highest concentration in the world. So we got to see first-hand the challenges that this group of people have,
15 and the thing with them is that they got together with the local council in 1999, and they built and designed a dual-purpose facility. It’s 12-bed aged care and disability centre, and now and for the last few years, it’s used as a day service. But these people that live on this island end up having to go to Darwin for long periods of time, and quite often they go to Darwin and die. And so they don’t get the opportunity to
20 live and die in their own community.

And that is – the complexity of what their needs are is absolutely huge. But it’s something that needs to be considered when you look at all the recommendations about how the – we can improve the services that we offer people throughout
25 Australia. Just because somebody is born in a remote part of Australia doesn’t mean that they should have lesser opportunities to live and die well as the rest of the country.

MS HILL: Mr Bo’sher, is it reasonable, to leave SDA to the marketplace, when
30 we’ve got examples of young people in regional and remote areas that aren’t able to live where they want to live and you’ve described the fact of having empty SDA properties?

MR BO’SHER: So what the NDIS has designed in specialist disability
35 accommodation is to give people a portable subsidy that attaches to the person and that they can use to shop around in the market, and that is a real innovation, and that really comes from the NDIS’s focus on choice and control. It’s almost – it’s hard, to think of any other Government housing program where we’ve given people so much ability to drive how the market is developing. So, conceptually, in theory, the NDIS
40 approach of – give people a housing-subsidy that – they can shop around. They can use that for a five-bedroom group home, if they want to do that. They can use it for a one-bedroom apartment. They can live in any location that works for them. This is giving people a huge – they can own their own property. This is a huge amount of autonomy and choice and control for people. And so you’ve got that, which, we
45 think, is very – a very fundamental part of the scheme, choice and control over where you live and who you live with.

The other thing that specialist disability is – created is that the cost of building this housing is very significant. So 6000 young people in aged care, average capital cost of about \$400,000 per person – we’re talking about \$2.5 billion worth of housing-stock that needs to be built. Government has to make choices about how it
5 approaches these things. It’s decided not to fund the upfront capital cost of that housing but instead to rely on private finance to be able to do that. It – there’s no doubt in my mind that there is sufficient private finance to do that. We work extensively with large retail banks and superannuation funds. There is more than enough capital that would like to be investing in building this housing for people
10 with disability, especially from industry super funds and retail banks.

There is, literally – there is hundreds and hundreds of millions of dollars that those superannuation funds would commit tomorrow, if they were confident, that the housing that got built was going to be occupied by a person with disability. But right
15 now they don’t have that confidence. So what I’m trying to outline is that we’ve got a choice-based market, which is a great thing. We’ve got capital-providers who are very eager to invest in that housing and make long-term investments with superannuation-fund members’ money; what we don’t have is a way to connect those two things together. And so what we need to be able to do is explain what the
20 demand is – for housing – and have a way that confidently connects together people that need housing with housing-providers, and whether they’re – “Build, and they’ll come” approach, whether they’re co-designing with people with disability is a question that we can leave till later, but what’s needed is that connection process, because until we have that, we can’t have the conversation with co-designing or
25 moving into something that’s already built.

So having said all of that – there are markets where this is not going to work. There are some young people in aged care or at risk where this market-based approach is not going to deliver an outcome for them. And that’s especially the case in the
30 regional – very regional and remote areas. It’s also the case for some young people in aged care that are very difficult to house for whatever reason from a housing-provider’s perspective, whether that’s because of behaviours, whether that’s because of other reasons; there are a group of people where a market-based solution isn’t going to work.

35 But what we have now is a market that can’t even get going because of the lack of connection process. So if we had a way to document all the housing-needs and preferences and provide that subsidy in people’s plans, the market would respond to, in my view, more than 90 per cent of that group. We’re left with the remaining 10
40 per cent group that are, largely, going to be in remote and regional areas and some that have very-difficult-to-house issues. And for those groups Government needs to think about a different approach. And it should start with working with those people to understand what they need and then have a conversation with the not-for-profit housing-sector and with state Governments about how to create solutions for that
45 group where the market isn’t working.

MS HILL: Dr Morkham, do you agree? The solution is more than bricks and mortar in that respect?

5 DR MORKHAM: Bricks and mortar are an important part of the solution, but the focus has been only there. So I think Mr Bo'sher's identified there are groups of these young people who won't fit into the normal housing-profile. That doesn't mean to say we don't work with them and their families, communities to deliver whatever it is, they needed. Mr Jamieson has mentioned a community who made a decision to go down a more-congregate care model because it suited their needs and their community requirements. We need to be respectful of all of these things, but I don't think the reliance of the market as it is currently configured is adequate at all and, certainly, not focussing on bricks and mortar, just – "Build more housing, and we fix the problem". It isn't so in any way at all.

15 Again we have to have the joined-up services that people need. We need health services for example, who, generally, stop at the hospital door, to provide a continuum of care that comes into the community with that person and remains in place. We've already heard that these young people come along with a complex health-and-disability-entwined need; to deliver the services those people need to live safely and with confidence in the community, we need health services there with them. We need a well-trained workforce, not just certificate III and IV in disability that is currently the case, but highly skilled workers with the capacity to meet the needs these people have so they can have confidence they're going to be okay.

20 So the market approach at the moment is, in my view, very poor and inadequate. It needs a greater sense of direction, and it's been established on this notion, this old-fashioned notion that these people with a disability are a problem to be solved, not citizens whose needs and preferences must be respected.

25 MS HILL: Mr Jamieson, would you like to respond?

MR JAMIESON: I think my colleagues have explained that incredibly well, and I don't think I've got anything more to offer to it, because - - -

30 MS HILL: I'll let you off the hook, then.

MR JAMIESON: Yes; they've explained that incredibly well, and I agree.

35 MS HILL: Dr Morkham, you've talked about the need for there to be transitional arrangements, and indeed, all three of you have. Could I ask for you to consider the need for transitional care arrangements for young people at risk of entering residential aged care, how presently the system isn't able to accommodate the need for transitional care arrangements.

40 DR MORKHAM: So at the moment, at the point of discharge, because the entry of the NDIS is late in the piece, they come in very late, they don't come in early in the person's presence in the hospital environment, there's no great preparation, there's

no chance to build the relationships to start to work together to build the services the person needs. So an interim housing-option would enable the person to be discharged to another place where those services and supports could be developed and built and put in place so the person could then move on to wherever it is, that they want to live in the community. So that, I think, is the importance of having interim housing.

At the moment it doesn't happen because of the pressure hospitals face – to discharge – and the lack of options available; as we said before, aged care is all there is, all that is considered. If there is an available option, it's usually the – a family home that needs modification. So moving to an interim housing-option would allow that modification to be undertaken and completed; it would enable the other services to be built. So I'm not sure if I've answered your question as precisely, but I think it's fundamentally important, that we have that stream in place.

15

MS HILL: Would you like to respond, Mr Bo'sher?

MR BO'SHER: I couldn't agree more. I think we, absolutely, need transitional housing, and in terms of what that looks like – I think some of the characteristics of that transitional housing are that it needs to be immediately available when people need it. There can't be long delays; otherwise it defeats the purpose of having transitional housing. So the place and the support model need to be available in a very short period of time. NDIA need to be able to approve it in a very short period of time, and the place itself needs to have a strong focus on rehabilitation and on building people's capacity, because what we don't want is to create alternative versions of aged care where we're just housing people and calling it transitional housing and calling it a disability service when, in fact, it has all the characteristics of aged care, that it's a large congregate model with no focus on capacity building.

So I think what's really important is that there is a clear model for transitional housing that's developed with those kind of characteristics about fast access from the NDIS, immediately available supply, a focus on rehabilitation and skills building and that will give people a place to stay while they either wait for an option for SDA that they've already selected to get built, or work with a provider to be able to co-design something that works for them or wait for home modifications to their own property.

And I think that would really transform the experience for so many people that at the moment are on the precipice of entering aged care and there's nothing else available and even if there was, you know, hospitals often don't think that NDIS approval is a viable discharge option, so hospitals will often say, "If you need to wait on the NDIS to approve something, that doesn't count as a viable discharge option from our perspective because we have no confidence that that's going to be approved in a timely way". So that NDIS approval is a really critical component to make transitional housing work.

45

MS HILL: Dr Morkham, do you consider it feasible to remove residential aged care as an option for young people right now without there being a transitional housing model in play?

5 DR MORKHAM: Unless we have transitional housing in place, and when I talk
about transitional housing I don't mean we're building that, we can take advantage of
opportunities that already exist. As we heard the compensation schemes describe,
they have arrangements with other partners that have accessible accommodation that
10 they make use of in an interim way. Without that interim option, it means people
will live in hospital and hospitals are dangerous places. If you're healthy and well,
they're dangerous places to be. You can acquire dreadful infections that are
untreatable. It's not good. You can become deconditioned and institutionalised if
you live for a long time in a hospital.

15 And I'm sure we've all had experience of people who've lived for months and years
in hospital and found it very, very difficult to transition them anywhere else because
of that, quite apart from the massive cost to the health system that represents. So
unless we get that housing stream in place, it means – and we cut aged care off,
20 which we should be doing, we are really going to condemn people to living in
hospitals.

MS HILL: Mr Bo'sher.

25 MR BO'SHER: That's where I think the question for the government is there are so
many dependencies here, getting the NDIS processes right, getting a long-term
housing market working, getting interim housing and transitional housing options set
up. There are many pieces to this puzzle but I think it's realistic to think that in a not
very long period of time, you know, 18 months, 24 months it's reasonable to think
30 that any person that's at risk of going into aged care has the NDIS funding that they
need to purchase an alternative service. If we fix the NDIS piece of this puzzle to be
able to get the funding into people's plans, and we can fix that in a space of 18 to 24
months then the only remaining issues will be market constraints, and they will be
market constraints about the availability of housing supply or the availability of
workforce.

35 But we need to be able to take the piece of the puzzle off the table where service
providers that want to be able to offer a service can't even offer that service now
because people don't have the funding that they need. So when we're thinking about
targets and when we're thinking about when is it reasonable to stop young people
40 going into aged care I think we can perhaps break that target in two of over a period
of, say, 24 months that the only reason that people are going into aged care after that
point is because of a lack of market response, a workforce issue, a housing supply
issue, but the reason they're going into aged care is not because they don't have an
NDIS plan in place and they don't have the funding from the NDIS.

45 We should be able to take that piece of the problem off the table in a very short
period of time and then it will shine a very strong light on where the market is not

working and government should be thinking about alternative commissioning models where the market isn't working. At the moment it's so tangled up in people aren't in the scheme or they don't have the funding or the market is not responding, but if we can take the NDIS piece of that puzzle off the table very quickly, then that will leave
5 a very strong light on the remaining market constraint issue.

COMMISSIONER BRIGGS: So for that to work you would clearly need the NDIS to establish good relationships with the States and the major hospitals to stem that flow. The second point is that already there should be – the NDIS should know
10 already, for those people who are living in aged care, who they are and be having the conversations with them. So there's two points of interaction. We haven't heard much from the NDIS about their links with the health system. Nor do we know, I might add, whether the young people with the very serious levels and complexity of
15 disability are in the major teaching hospitals or whether they're spread across the country. Do you know that?

DR MORKHAM: Sorry, Commissioner?

COMMISSIONER BRIGGS: Are the young people who are, dare I say it, on this
20 track into aged care, do they typically come out of the major city hospitals because of the very, very serious natures of their disability, or are there some in the country areas as well?

DR MORKHAM: Predominantly out of the major hospitals in the cities because of
25 catastrophic injury or exacerbation of disease. Yes.

COMMISSIONER BRIGGS: Okay. So the task is not inconceivably hard.

DR MORKHAM: Not at all. Not at all. If I could add one comment, Ms Hill, and
30 support Mr Bo'sher's comments. I think the only other thing I'd want to add is the need to bring health services into play very directly and very early on. If we miss that part of the puzzle we miss a fundamental part of the solution. We have to have health services involved because they are going to be needed in the community. We don't have the health services we need there at the moment. Where we've had, since
35 the arrival of the NDIS we've had community-based nursing services start to charge full fee for service for any nursing responses which the NDIS won't reimburse for.

So we've got people now living with the need for catheter changes, tracheostomy
40 care, PEG feed management who are having to turn up to hospital emergency departments where they sit and wait for a catheter change, which could have been done in their own homes previously. So as well as the things that Mr Bo'sher has mentioned, we've got to have health services involved from the get-go and they have to start turning their minds to how they can support these young people in the
45 community as well.

MS HILL: Dr Morkham, we know that the 2015 Senate Committee recommended a national framework for rehabilitation. What's happened with that?

DR MORKHAM: Absolutely nothing. Absolutely nothing. And it's a fundamental failure. These young people need rehabilitation quite considerably to not only recover from catastrophic injury but from episodes of disease exacerbation, and the NDIS in its wisdom has decided that it will only provide allied health supports to
5 maintain a person's function, not to improve them. It sees this improvement of function as the responsibility of the health system. Now, that's a very nice position to take except the health system doesn't have the capacity to do that either. We don't have a national rehabilitation strategy in this country, amazingly so.

10 Nothing has been done to progress that recommendation. In Victoria we had a tremendous community-based based acquired brain injury slow stream rehabilitation model that was the envy of other States. That has ceased to exist with the arrival of the NDIS purely because in a – for a reason nobody is quite sure about it ended up
15 being funded out of disability services and when the NDIS came, the funding for that from disability services was folded into the State's commitment to the scheme. We've tried very hard to hang on to that. It's not facility based, it's highly effective, very cost effective as well and achieves tremendous results.

It actually shows that if you invest early on you can reduce the care needs of the
20 person over time so there's benefit in that investment. But that program has now ceased and we're being told that the one rehabilitation facility in the State will pick up the slack. We've worked with that facility and they do discharge to nursing homes from that facility. People weren't discharged from slow to recover to nursing
25 homes, so we're quite appalled that this wonderful program that was in place, that was very cost effective and efficient and effective for the people using it has now gone.

MS HILL: Mr Bo'sher, would you like to respond on the topic of slow stream
30 rehabilitation?

MR BO'SHER: Sure. I think we've heard from witnesses throughout the week like the Littleys about the importance of rehabilitation services and the importance of that
35 dignity in regaining your functioning, whether that's communication or whether it's other – other capacities; that's clearly important. It's clearly relevant to the NDIS social service objective about reducing lifetime cost. So I think it is really fundamental. I guess it does come back to a tension that we talked about earlier in the hearing today over what services should sit within the NDISs remit versus what should be coordinated between the NDIS and the health system.

40 And I think this is another one of those services that is has fallen between the gaps because it is in had a grey zone, that this question clearly the health system has an obligation to provide some rehabilitation to anyone that acquires a disability, but at the same time the NDIS is going to bear the consequence of the success of that
45 rehabilitation and the NDIS is also going to provide ongoing allied health support as Dr Morkham talked about to maintain that functioning. But in between where the health system stops and where the NDIS begins we've got this big gap where the NDIS is thinking about maintaining functioning; the health system is thinking about

immediate post-injury recovery, but that period in between, that slow to recover period, is what's really missing in the scheme at the moment.

5 And I guess, thinking about it, you know, I think in all these discussions we should be trying to put the person with disability at the centre of this. What does that person's experience need to look like. The evidence that Kirby Littley and her family gave was that she needed a place to live but rehabilitation was also provided. I think that place to live when people are ready to be discharged from hospital, clearly the NDISs responsibility. Should the NDIS or State governments pay for rehabilitation; in some ways it doesn't matter as long as one of them do. It's very intricately tied to the place that the person is living, so in my view, and Summer Foundation's view, it should be funded through the person's NDIS package and delivered in an integrated way with the day to day supports and the housing that they need to bring together that integrated transitional housing and rehabilitation package.

15 That might be one element of a much bigger national strategy on rehabilitation and that would be a really good thing but I do think we need to make sure that whatever is delivered in the rehabilitation side is also well connected with housing and other supports that people need. I think the NDIS – through the NDIS vehicle of NDIS plans is a great way to be able to make that integrated funding work.

20 DR MORKHAM: I think that the Alliance's view is that the NDIS should fund rehabilitation. There are clear fiscal benefits in doing so and if we go back and look at the reports that have been done on the Victorian on the Slow to Recover program, there's a very clear evidence base to say if you invest early, you cut down lifetime care costs over the course of the life of that person considerably. We have evidence about this and you would think it would be in the NDISs benefit to fund this type of rehabilitation for the person. I support Mr Bo'sher's comments about we know from evidence also in the medical field that rehabilitation achieves best outcomes when it's delivered in the surroundings that are familiar to the person.

30 So if that is promoted and delivered in the person's home they will get the best outcome from that. We really do believe the NDIS should fund this immediately and stop delivering these young people the lack of care and the lack of opportunity to recover that they currently face.

35 MS HILL: Now, I set the three of you some homework. You've all had the opportunity to watch to varying extents and follow along in the Commission in the course of this week; is that right?

40 DR MORKHAM: It is. It certainly is.

45 MS HILL: And I asked the three of you to consider overnight whether there was one thing that had struck you since this hearing commenced on Monday. And I might start with you, Mr Bo'sher.

MR BO'SHER: Sure. What has struck me is a consistent theme throughout the week this week is how every single person that's appeared at this inquiry has said that aged care is not appropriate for young people, whether that was people that had a direct experience themselves, family members, the NDIA, DSS, the Department of Health; I've been struck by the fact that everyone, including the Human Rights Commission, have been so forthright in saying that this is not the right option and yet it persists. I think it's very striking how we've had a dialogue this week about how inappropriate this is and yet it continues. I think when we think about who are the people that are expressing those comments, you know, I think Liz Cairns from the TAC summed it up very well yesterday when she talked about – on Wednesday, sorry, when she talked about the way that hospital staff face pressures because they've got a whole bunch of people sitting in an acute setting who they know will benefit from rehabilitation.

15 And so when someone is sitting in a rehabilitation bed, the need to move that person on isn't just – it's not just health systems being nefarious; it's because they know that there are other people that need that service. And so I think what we see in the system is a whole bunch of people are trying to do their best; ACAT assessors are trying to do their best. Hospital staff are trying to do their best. Support coordinators are trying to do their best. But the system is not set up to enable people, who are in this line of work because they care, they're in it because they want to achieve good outcomes for people, but the way the system is designed ends up with those professionals not being able to do their best for someone and that person ending up with a bad outcome.

25 And so what gives me a lot of hope from the Royal Commission this week is that we know that the money is there through the NDIS to solve this problem and that's a very hard part of the puzzle to fix, but we've already fixed it; we've got the money sitting there in the NDIS. Now what we need to do is fix the couple of funding gaps we've got around transitional housing, around acute supports, around clinical supports, and around rehab. And if we can fix those small funding gaps and get the right system processes in there, this is an entirely solvable problem that everybody has been motivated to fix. And so that's what has really struck me this week is that consistent theme that everyone wants to fix this problem. They're trying to do their best but they're trying to do their best in a system that's not set up to enable them to succeed.

MS HILL: Thank you, Mr Bo'sher. Mr Jamieson.

40 MR JAMIESON: Yes, what struck me this week is hearing some of the incredible powerful stories from some of the witnesses that have been so brave to retell their story in such a public forum. And the – that is going to assist in making change in this country, and it's vital that we make that change. For far too long aged care has been considered the – the provider of last resort. But it's become the provider of practice because that's the go-to option and that's not good enough. I think more than anything attitudes need to change, attitudes systemically need to change to – to getting it right, to – to consider that a person that has an exacerbation in their health –

health needs or has a new diagnosis, it should not be considered that aged care is appropriate for somebody under the age of 65 at all.

And so if this Commission does anything it's vital that it changes those attitudes.
5 And I agree with Mr Bo'sher, the funding, it's there. We've solved such a big part of that puzzle. But there's still a ways to go and I'm really looking forward to what the outcomes are going to be.

10 MS HILL: Mr Jamieson, you work with young people in your working week every day of the week.

MR JAMIESON: Every day.

15 MS HILL: How has it felt to you watching the evidence of these young people, these families share their stories, their experiences?

MR JAMIESON: Even though I work with people in very similar situations to the people that have provided evidence this week, every day, it really hit home that, wow, you know, it's vital that this information, it gets out and it was – it was quite emotional, I suppose, watching and listening to – to the evidence that's been given.
20 And people's lives can change in an instant and it's up – it's up to us, it's up to government, it's up to the sector to – when that does happen, that we provide the best opportunity to get the best outcomes long term for people.

25 MS HILL: Thank you, Mr Jamieson. Dr Morkham, what struck you, sitting here since Monday?

DR MORKHAM: Several things struck me, Ms Hill. The first of all, I think, was the revelation that we have a Clayton's action plan in place for these young people.
30 We've got an action plan you have when you don't have a plan at all, really. We have an action plan that has no funding, no measurement, no real targets, nothing in there to say there's any desire to do anything immediately whatsoever. We already have heard that there were no – some of the key stakeholders were absent from the reference group. So I think the action plan has been revealed to be not fit for purpose
35 whatsoever and if we're going to continue down that path we need to completely rethink what we're doing and how we're going to do it.

One of the other observations I had was the almost complete reliance on the market to solve this problem when the market doesn't have an understanding at all about the nature of the problem and what's needed. It's still very segmented and I think if we
40 continue to rely on the market we're doomed to fail. I think it was gratifying in one sense to hear senior government officials admit that they have manifestly failed to deal with this problem over many, many years yet, as I said earlier, we're being asked to trust them again through the action plan to do something now, when we
45 have the same set of circumstances in that action plan that we had 14 years ago that failed then, so gratifying to hear them say they had manifestly failed but no great indication of how we might take that forward.

Lastly, I think my observation was that there is a complete lack of will to do anything at all from those government officials. I didn't hear any clear indication of what they think we need to do or how we might approach it, how they're going to involve these young people and their families and their communities in solving the problem and I
5 didn't hear anything about a desire to start right now. So I was very, very disappointed in that but interested to hear that. I guess those four areas would be my thoughts on this week.

10 MS HILL: Thank you, Dr Morkham. Mr Jamieson, what do you say the Aged Care Royal Commission can do about this; is it a matter of tweaking the action plan or is it something else?

15 MR JAMIESON: Definitely tweaking the action plan. Dr Morkham summed it up really well; the will to get it right has to be there from a government level. I certainly know that the will from the sector is there and it's been there consistently for as long as I've worked – worked in it. We don't turn up not to try and get the best outcome and that we're willing to get it right. I think from a policy level, it needs to be – it needs to be sorted.

20 MS HILL: Mr Bo'sher, what is the right approach, reflecting on the evidence that you've heard this week and evidence from your colleagues in the witness box there?

25 MR BO'SHER: Yes, sure. Perhaps if I can take a few minutes to talk about that and kind of zoom out and think about, we've had a lot of detailed evidence about very detailed problems with ACAT assessment, with NDIS funding, if we take some steps back and think about what are the fundamental areas that the Royal
30 Commission needs to be able to solve in order for this issue to be resolved. There's nine things that have – that we've reflected on during the week that we think need to be dealt with by the Royal Commission and those nine things cover off kind of three different areas. So one area is about getting the systems and policy and framework right. The second area is around making sure that the funding gaps and service gaps that exist at the moment are filled, and the third area is making sure that we have the right data and evidence base to be able to move forward on this problem. So those
35 are nine recommendations.

40 So the first thing that we think the Royal Commission needs to be able to do to solve this issue is to allocate responsibility for young people going into aged care clearly to the NDIA. The diffuse and fragmented responsibilities we have now clearly have not created the right incentives to solve this issue, and so we think the NDIA should be responsible. They've got the funding levers and they've got the mechanisms to be
45 able to fund alternatives. The second is our reflection this week is that the target timeframe is not ambitious enough in generating urgent action from government. We think that timeframe should be brought forward, that the target to halve and fully reduce entries into aged care needs to be brought significantly forward to create a sense of urgent action from government.

Seeing only 66 of the four and a half thousand young people in aged care have the funding to leave is evidence that six months after launching the action plan there's not enough urgent progress. And the third thing at that policy system level is getting the hospital/NDIS interface working. I think the TACs evidence of starting early and
5 having the hospital and disability system working together to achieve outcomes is a great example of how it could move forward. The four things we heard that this week of funding gaps and service gaps for people, we've heard a lot about the funding and service gap of navigating complex systems, that that sense of being lost, not having a key worker that's on your side, not having advocacy support, having a
10 fully skilled support coordination workforce, those things need to be addressed. We need to invest in the support to navigate the system.

The fifth thing that we need to invest in is investing in transitional housing. We've spoken a lot about that in this session, where we can get an ACAT assessment and
15 move into aged care in the space of days but getting SDA takes months and months. So we think that transitional housing funding piece is critical. We also need to invest in both community rehabilitation and we also need to invest in the clinical supports that people need when they've got complex health needs, and I think Kirby's story spoke really well to that this week. In that third domain of having the data and the
20 evidence base to work from, we know that we need to identify who all these young people are and understand their housing needs and preferences, and we need a way to aggregate those together so that we can generate responses.

And if we're able to do that I have no doubt that it will unlock thousands and
25 thousands of new SDA places that will be invested in if we can solve that connection piece. And the ninth area that the Royal Commission, in our view, should look at is how we evaluate where people move to after they leave aged care and how, as governments, they can promote good practice in where people move to. So that recommendation is also a word of caution because there is a danger that by putting a
30 huge timing pressure on government to solve this issue and get young people out of aged care we risk just recreating aged care settings in the community by another name. So it's vital, we think, that any effort to get young people out of aged care tracks those people's outcomes and makes sure that people are achieving good independence outcomes but also achieving very good social and community
35 participation outcomes because that's the whole point of this.

It's about getting young people out of isolated institutional settings into the community where they're living a good life, and we need to be able to track that otherwise we won't – we risk people moving out into even more institutionalised
40 settings in the community. So they're the nine areas that we think the Royal Commission should look at.

MS HILL: Dr Morkham, I asked you at the beginning of this evidence how we learn from past mistakes. I want to ask you a final question which is: how do we
45 capture the outrage that we have heard in this hearing room, outside of this hearing room, in those circumstances that this is a long-running problem – or not a problem,

a long-running issue that we don't have an answer to? How do we capture that here and now so that there is a meaningful outcome for those young people?

DR MORKHAM: How do we capture the essence of the issue?

5

MS HILL: Yes.

DR MORKHAM: I think we have to return to speaking to young people and their families again. They are the ones at the very centre of this maelstrom, and we need to refer to them constantly to seek their advice, their feelings, their views, their aspirations, their needs. The NDIS always talks first about goals and aspirations but it's very hard to consider that until your needs are met. And if your needs aren't met it's very hard to think about where to from here. So we need to make sure people's needs are met, I think, fundamentally. Capturing that is very important, and I think this Royal Commission has been a great opportunity to forensically examine this issue in the way that it has.

We hope the Royal Commission will encourage governments to work together, might I say, direct governments to act decisively, to act immediately and to deliver the resources and the commitment, the will to do something that we've got to have if we're going to stop this. We've waited too long already. You know, we've had too many failed attempts in the past and that has been discussed over the last three or four days of hearings. We want the Royal Commission to charge governments to do something right now, stop young people going into nursing homes, or no more enter by 2022. Commissioner – the Disability Discrimination Commissioner has already drawn the line in the sand saying we don't want any young person in aged care by 2025, and we support that absolutely.

Governments can make this so right now if they have the will and they're willing to commit the resources to do so. So having lengthy targets, I don't think is appropriate. We want the Commission to give these young people and their families hope, hope that they don't have to go into aged care, hope that if they are in aged care they can relocate to the community if they want. Hope that they will get the supports and services they need as they desire.

35

Finally, we want this Royal Commission to stop history repeating itself. We've been here far too many times, we don't need to go back and do it again. We need a fresh round of thinking, we need governments to work collaboratively with one another, we need the programs to work with one another to fund the solutions that we know are there. Finally I'd like to read, if I may, an email from a young man I mentioned earlier who emailed me at quarter past 9 last night. Without mentioning his name, this is what he said:

40

On Monday morning I found myself in the same boat as 6000 young Australians residing in nursing homes. It's not an event to be proud of.

45

He describes the name and the place of the nursing home he has been moved to from hospital and says:

5 *I wish to thank the NDIA for refusing my request for 24 hour care at home in my own flat over the road from the Woolworths where my friend works –*

in his community, in other words.

10 *I hope the NDIA can sleep well at night. And I hope the NDIA can be very proud of the effort, sarcasm intended. In reality it's a national tragedy and a day of shame. It's nothing to be proud of when I joined the 6000 people residing in nursing homes on Monday morning on September 16, 2019. I'm sorry to have to tell you this.*

15 MS HILL: Commissioner, that concludes my examination.

COMMISSIONER BRIGGS: Thank you very much. This morning's evidence has been quite striking in the picture that the three of you have been able to paint of what the issues are and how to fix this system. I think they build on the evidence that
20 we've heard this week about how hit and miss it is about whether or not a young person with disability will ever be contacted by anyone in order to get out of aged care. I find that particularly distressing in this day and age. But your evidence has shown us that the NDIS really has the capability through its support worker system to at least initially make those contacts so we can, or the government can collect the
25 vital information it needs to know about the wants and needs of young people with disabilities.

You've then taken that discussion further to start to talk about what needs to happen when these young people are in hospital in order to stop the flow. I fully appreciate
30 the challenge of working through how you then coordinate a series of health rehabilitation, social support, housing options to make that happen and I appreciate the fact that you were prepared to discuss the differences between you. That's very useful for us. We touched – you touched for a little while on the circumstances of younger people with disabilities who are in Aboriginal and Torres Strait Islander
35 communities, and mentioned the importance of working with their community around solutions, but also working with other indigenous service provision, which I think is something we're very interested in.

The fact that the market hasn't worked to date is not a reason why it mightn't work,
40 but I was kind of entertained by the evidence from the NDIS the other day about all the ways they had to modify this market solution to deliver services in rural and remote Australia as far as housing went, which said there are some clear issue that need to be addressed on the housing front. I took note of your comment, Mr Bo'sher, about the connectivity needed and I certainly took note of your comment, Dr
45 Morkham, about the need for a service wrangler. It's the best word I've heard so far, because fundamentally in this system as in the aged care system there really does need to be someone active on your side, working with you and those who love you to

deliver a life for you. So I want to say thank you very much and you'll be pleased to hear that I'm excusing Dr Morkham, Mr Bo'sher and Mr Jamieson from giving further evidence to us today. So thank you very much.

5 DR MORKHAM: Thank you.

<THE WITNESSES WITHDREW [11.42 am]

10

MS HILL: As the Commission pleases. I believe we now have a short break, Commissioner.

15 COMMISSIONER BRIGGS: Yes, it's definitely time for a cup of tea. We might resume around 5 to 12, or should we go for 10 to 12? 5 to 12.

MS HILL: As the Commissioner pleases.

20 **ADJOURNED** [11.43 am]

RESUMED [11.57 am]

25

COMMISSIONER BRIGGS: Mr Knowles.

MR KNOWLES: Commissioner. I call Kym Peake.

30

<KYM LEE-ANNE PEAKE, AFFIRMED [11.58 am]

<EXAMINATION BY MR KNOWLES

35

MR KNOWLES: Ms Peake, can you tell the Royal Commission your full name.

MS PEAKE: It's Kym Lee-Anne Peake.

40

MR KNOWLES: What is your present position?

MS PEAKE: I'm the secretary of the Victorian Department of Health and Human Services.

45

MR KNOWLES: And how long have you occupied that position for?

MS PEAKE: I've been in that position since November 2015.

MR KNOWLES: And what prior experience did you have for that?

5 MS PEAKE: Prior to that I was the deputy secretary of public sector reform at –
sorry, immediately prior to that I was the deputy secretary of governance, policy and
coordination at the Victorian Department of Premier and Cabinet. Prior to that I was
the lead deputy secretary of strategy and planning at the Department of Economic
10 secretary, higher education and skills group at the Department of Education and
Training in Victoria.

MR KNOWLES: Thank you. Now, you've prepared a statement for the Royal
Commission dated 29 August 2019. That's document WIT.0420.0001.0001. Do you
15 have a copy of your statement there with you in the witness box?

MS PEAKE: I do.

MR KNOWLES: There's a copy of it on the screen beside you as well. Have you
20 read your statement lately?

MS PEAKE: I have. Thank you.

MR KNOWLES: Thank you. Now, are there any changes you wish to make to
25 your statement?

MS PEAKE: Yes. Just a couple, and I apologise for this. Just a couple of typos in
that bio. So the – my role as - - -

30 MR KNOWLES: Where is that bio, just for the record, Ms Peake?

MS PEAKE: Under professional background, paragraph 5.

MR KNOWLES: Thank you.
35

MS PEAKE: So at 5.2, that should say that I was the deputy secretary of higher
education and skills group between January 2010 and November 2014, rather than
2015. And then at 5.4, it should show that I was the deputy secretary at Premier and
40 Cabinet from March 2015 to November 2015.

MR KNOWLES: Thank you. Now, subject of those changes, are the contents of
the statement true and correct to the best of your knowledge and belief?

MS PEAKE: They are.
45

MR KNOWLES: Thank you. I seek to tender the statement of Kym Lee-Anne
Peake dated 29 August 2019.

COMMISSIONER BRIGGS: The witness statement as amended of Kym Lee-Anne Peake dated 29 August 2019 will be exhibit 9-22.

5 **EXHIBIT #9-22 WITNESS STATEMENT AS AMENDED OF KYM LEE-ANNE PEAKE DATED 29/08/2019 (WIT.0420.0001.0001)**

10 MR KNOWLES: Now, Ms Peake, across this hearing this week, as you will most probably be aware, there's been a range of evidence given from a range of people that residential aged care is not appropriate for younger people. I'll take it you've heard some of that evidence at various times, or at least been aware of it.

15 MS PEAKE: I am, yes.

MR KNOWLES: Yes. Thank you. And is it the Victorian Government's position also that residential aged care is not an appropriate option for younger people in general?

20 MS PEAKE: It is, and if I may, I do want to acknowledge the stories and experiences of people who've appeared before the Royal Commission and the impact that being in residential aged care has had on their lives.

25 MR KNOWLES: Now, despite that position of the Victorian Government, like elsewhere in Victoria, the numbers, to use an expression that's been employed earlier this week, have been stubbornly high, haven't they?

MS PEAKE: They have not moved. That's correct.

30 MR KNOWLES: Yes. And what are those numbers over the past six or so years?

35 MS PEAKE: Certainly. As I've outlined in my statement, the most recent data that we have shows that over the last six years there's been about 1500 residents in residential aged care services. Of those, around 252 in public sector residential aged care at our last count.

MR KNOWLES: Now, in terms of that data going to the numbers, what's the source of that for the Victorian Government?

40 MS PEAKE: We largely rely on Commonwealth data, but we have also had snapshot data that we have taken from our hospital discharge data.

45 MR KNOWLES: And does that snapshot data go to the types of people that end up as younger people in residential aged care.

MS PEAKE: It does, both in terms of their – the presenting conditions for them in health services and then the predominant reason, that they are entering residential aged care.

5 MR KNOWLES: And is it shared with the Commonwealth, that Victorian Government data?

MS PEAKE: It is. And they also have access to that sort of data through their own data collections as well.

10

MR KNOWLES: Just, though, in terms of the reasons for people entering residential aged care or the conditions that lead to them entering residential aged care on discharge from hospitals, is that hospital discharge data shared with the Commonwealth by the Victorian Government?

15

MS PEAKE: My understanding is that there is certainly, through the ACAS teams, information that is provided back through the Commonwealth, but I'm happy to take the specific question on notice about the extent to which our collections are available to the Commonwealth.

20

MR KNOWLES: You're referring to the Aged Care Assessment Service teams; is that right?

MS PEAKE: Yes. That's right.

25

MR KNOWLES: Thank you. I say that because they're called in Victoria a different name to the rest of the country which is Aged Care Assessment Team assessors, but – and that's where the data sources is collected in that regard?

30

MS PEAKE: That's right.

MR KNOWLES: Okay. Now, in paragraph 15 of your statement, if I could just take you to you that, there's a reference to Victorian hospital discharge data showing that younger people discharged from health services into residential aged care, 42 per cent of discharges over 10 years are most likely to be aged between 60 to 64 and have high and complex support needs. Am I to understand from that that 42 per cent of the overall numbers discharged over a 10 year period are aged 60 to 64?

35

MS PEAKE: So to be clearer and clarify that statement, 42 per cent of people who are discharged for the first time into aged care – residential aged care are between – are aged – that's what the 42 per cent is referring to, and I can give you precise numbers.

40

MR KNOWLES: Yes.

45

MS PEAKE: So over the 10 year period there were 8952 inpatients under 65 discharged to an aged care residential facility for the first time, of whom 3736 were aged between 60 to 64.

5 MR KNOWLES: What is that 10 year period; is it relatively recent?

MS PEAKE: It is; It's through to – my understanding is it's through to 2016.

10 MR KNOWLES: That's based on hospital discharge data. Are you able to say what proportion of people entering aged care, at least in terms of Victoria, are from a hospital setting and those that are not?

MS PEAKE: Yes. So the majority - - -

15 MR KNOWLES: In terms of younger people I'm talking about, of course.

MS PEAKE: Younger people, yes, come through from – actually from inpatient services and I think in my statement we have provided the precise figures but my recollection is that it was in the order of around 80 per cent are coming from
20 inpatient services; a much smaller portion coming from our rehabilitation services.

MR KNOWLES: But that rehabilitation service, is that connected to a hospital or a health service setting?

25 MS PEAKE: That's right, yes.

MR KNOWLES: Is there any data that you have in relation to numbers of people or proportion of younger people entering into residential aged care in Victoria not via that hospital or health service setting?
30

MS PEAKE: So coming through – sorry, coming through rehabilitation services?

MR KNOWLES: Through other pathways than the hospital discharge pathway?

35 MS PEAKE: I don't have detailed data with me. I'm very happy to take that away but some of the other pathways come through some of our palliative care – community palliative care services, for example, and a much smaller proportion would come through for the younger age group would come from – directly from the community where there's families, for example, who find it difficult to continue to
40 care for a loved one who – a person who has a condition that is deteriorating, more difficult behaviours, that sort of thing.

MR KNOWLES: And just picking up on something you say there in relation to community palliative care, would that be where somebody is being looked after in their home in - - -
45

MS PEAKE: That's right. That's right.

MR KNOWLES: - - - the end of life stage?

MS PEAKE: That's correct. So as a State we fund a community palliative care service that is available not only to people who are discharged from health services
5 but more generally to members of the community.

MR KNOWLES: And so a person may end up not being able to be looked after in their home via that program and you think that's also a pathway into residential aged care.
10

MS PEAKE: That's right.

MR KNOWLES: In Victoria.

15 MS PEAKE: That's right.

COMMISSIONER BRIGGS: Can I ask you, why is it that they're not on a hospice pathway for palliative care?

20 MS PEAKE: And that is another pathway, so there definitely would be – there is a lot of people who would come from a community palliative care service into an inpatient palliative care service, and there are some limits to the availability of those services in regional Victoria.

25 COMMISSIONER BRIGGS: Okay. That makes sense.

MR KNOWLES: Yes, I think in your statement you've said that in terms of public palliative care – and this is at paragraph 63, there are designated inpatient hospital services on the one hand.
30

MS PEAKE: Yes.

MR KNOWLES: And they are such that there are 257 designated beds across the State and then otherwise there are day hospices.
35

MS PEAKE: Correct.

MR KNOWLES: But I take it, like the actual inpatient hospital services, they're quite limited in the number of spaces that they have available for people?
40

MS PEAKE: So certainly we have had growing investment into palliative care and community-based palliative care services in recent years, and – but it is an area that is always under pressure in the context of an ageing population.

45 MR KNOWLES: And is that the reason why, perhaps, given that there is that pressure, that residential aged care is perhaps an option that is taken up at times, rather than people going there?

MS PEAKE: Yes, but it is a much, much less frequent pathway than pathways through either our admitted services so our inpatient services, or through our rehabilitation services which are lesser again, so I wouldn't want to overestimate or overstate that pathway.

5

MR KNOWLES: Yes, and in that paragraph I took you to a moment ago, I think it was paragraph 15 of your statement, there are the figures there that you have that 80 per cent of people – younger people are discharged from an inpatient acute service.

10 MS PEAKE: Yes.

MR KNOWLES: With only around eight per cent discharge from a rehabilitation service.

15 MS PEAKE: Yes.

MR KNOWLES: And palliative care needs account for some smaller proportion in the remaining 12 per cent; is that what you say?

20 MS PEAKE: That's correct. That's right.

MR KNOWLES: Thank you. Now, what proportion of younger people in residential aged care are in public sector residential aged care services in Victoria?

25 MS PEAKE: Yes, so it's about 20 per cent of younger people in residential aged care that are in our public sector services.

MR KNOWLES: And does that represent a larger proportion than the number of – the proportion of overall residential aged care services provided by the public sector?

30

MS PEAKE: Sorry, I might just ask you to - - -

MR KNOWLES: I might rephrase that, pardon me. What's the proportion overall of residential aged care services in Victoria that are provided by the public sector?

35

MS PEAKE: So our public sector residential aged care services represent about 11 per cent of the total residential aged care sector.

MR KNOWLES: So there is arguably an over-representation in public sector residential aged care services of younger people?

40

MS PEAKE: What we see in our public sector residential aged care services is a population which has much higher support needs. They tend to have more comorbidities and, certainly, the younger population that we see in our public sector residential aged care services similarly are people with much higher support needs.

45

MR KNOWLES: Can I take you to paragraph 23 of your statement and you've there referred to an analysis of some data in respect of the reasons why younger people end up being discharged into residential aged care services for the first time and you've given those four reasons.

5

MS PEAKE: Yes.

MR KNOWLES: How was that dataset actually collected?

10 MS PEAKE: So really this is analysis going back to your earlier question from our Victorian admitted episode dataset and looking at the characteristics of people who have been referred into public sector residential aged care.

MR KNOWLES: Right.

15

MS PEAKE: And, in fact, into residential aged care, generally.

MR KNOWLES: Yes, so it's collected at the point of discharge - - -

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MS PEAKE: Correct.

MR KNOWLES: - - - from a hospital, essentially.

MS PEAKE: That's right.

25

MR KNOWLES: Yes. And is that also data that's shared with other governments and in particular the Commonwealth?

30 MS PEAKE: So really, consistent with my earlier response, my understanding is that this data is available by virtue of the Commonwealth-funded service that is undertaking the assessments of - of patients being discharged into residential aged care but I'm very happy to go back and look more specifically at the sharing of this dataset.

35 MR KNOWLES: If you could, that would be appreciated, Ms Peake. In that regard, you're again referring to the ACAS.

MS PEAKE: Correct.

40

MR KNOWLES: The Aged Care Assessment Service.

MS PEAKE: Yes.

45 MR KNOWLES: Yes, I see. Now, obviously hospitals or health services are, you've indicated, 80 per cent of people going into residential aged care in Victoria come from the acute inpatient setting in a hospital.

MS PEAKE: Yes.

MR KNOWLES: Of those that are discharged from hospital. In terms of those discharges from hospital, what are the reasons why people have to leave hospital?

5

MS PEAKE: Well - - -

MR KNOWLES: When they do - - -

10 MS PEAKE: Yes. I mean - - -

MR KNOWLES: - - - into residential aged care, what are the drivers that meant that they have to leave the hospital at that time?

15 MS PEAKE: So really, there are – there are three predominant drivers. The first is that an acute setting is not an appropriate setting for people to spend extended periods of time, unless there is no alternative option for them. It is very much like residential aged care; it's an environment where there aren't opportunities for social engagement, where there is a risk of further loss of functioning and where, in addition, there is a risk of acquired infection. So that really is the first reason that it is not an ideal setting, it is not an appropriate setting for people to spend extended periods of time beyond their clinical needs.

20

The second reason is that there is – and the main reason that there is a discharge then into a residential aged care setting is generally due to the lack of an appropriate alternative accommodation. And the third reason tends to be that there isn't an alternative care option that provides the level of support that someone may need.

25

MR KNOWLES: When you say that, the alternative being the care that one thinks might be available in a residential aged care facility.

30

MS PEAKE: So the – or the alternative of what could be provided to someone, if they had very, very high needs, including behavioural-support needs 24/7, that where they – that there aren't other alternatives that can provide that type of intensive support.

35

MR KNOWLES: And in terms of those shortages in accommodation that you've just referred to – that, from the evidence that we've heard this week, would appear to be a longstanding issue.

40

MS PEAKE: It is.

MR KNOWLES: Can you say why you perceive that to be the case in terms of at least Victoria?

45

MS PEAKE: Yes. So I think there are really three reasons. The first reason is that this isn't an area where the market has naturally stepped in to provide products that

are appropriate to the needs of people, particularly people with physical disabilities and people with significant behavioural-support needs. And that is – the second reason really is that’s particularly acute, the market gaps, in regional locations, and I think the third reason is that there have not been the – in any of the planning that’s
5 really been done or the previous strategies a sufficient approach to bring together the accommodation model with the care model, because – the accommodation is critical, but it isn’t sufficient to provide the support and quality of life that people deserve and need.

10 MR KNOWLES: And what role do you see that the Victorian Government might play in respect of interim accommodation or even long-term accommodation in terms of that shortage that you’ve just described?

MS PEAKE: Yes; so I would distinguish here particularly between people who are
15 able to access an NDIS package and those who are not.

MR KNOWLES: Yes.

MS PEAKE: For people who are able to access a – an NDIS package – I do think
20 that our aspiration, our goal for the NDIS should be that there is a stimulation of interim accommodation as well as long-term accommodation that is supported through packages. I think that the Royal Commission has heard evidence about the TAC rapid-interim-housing model. I think that is really interesting as a way of providing people with much more appropriate interim arrangements. For people who
25 are not eligible for the NDIA, we continue to work on both specialist services that can provide support to them, if there is a period of rehabilitation that is required to restore a level of functioning that enables a return home – and we can talk a little bit more about some of the specialist services that we have, that provide that sort of support, and we also continue to work through our housing-program to look at both
30 social housing as well as supports for private rental that can provide other options for people as well.

MR KNOWLES: You’ve said – you mentioned the NDIS there. You’ve said in
35 your statement at paragraph 37 that the early stages of implementation of the NDIS has not yet made a significant difference in connection with these gaps that are leading to younger people still entering into residential aged care in the first place. Why do you see that not having made a significant difference at this stage?

MS PEAKE: Yes. That’s a very big question. When it comes to the questions
40 around interim and long-term accommodation, I do think that there is a need for the National Disability Insurance Agency to play a much stronger stewardship role in how to activate the market, in how to work with the development industry to really look at providing them with the sort of information that they need to stimulate new types of products but also to provide incentives for the development of different
45 types of accommodation for regional locations where the markets will be thinner, as well as for those particular cohorts that I mentioned earlier. So in the

accommodation space I think that the market is not just going to appear by itself. When we talk about, then, the services – sorry.

5 MR KNOWLES: Yes. No. Do I also understand, when you refer to location and type of people having to live in the particular accommodation, that there are some matters that are – undue reliance on the market may not work, it may not work, to rely on the market in that way?

10 MS PEAKE: By itself, I don't think so.

MR KNOWLES: Yes. And what do you see as adding to that and needing to be used in addition to simple reliance on the market?

15 MS PEAKE: Yes. So as I indicated, I think that there does need to be a really active steward role exercised by the National Disability Insurance Agency as the logical authority to really work with the developers to stimulate different types of product, and that will only happen, I think, if the information incentives are right, and there is also an opportunity for, I think, there to be thought given to what might be some practical changes to NDIA rules that would also facilitate different types of
20 arrangements. Generally speaking I absolutely believe in the principles of choice and control and providing individual homes for people, but there may well be groups where a more core-and-cluster model would be more appropriate to enable there to be the right sorts of supports wrapped around. So thinking about how the rules enable the development of different types of housing-products, I think, is really
25 important, as well as making sure that the level of funding, the level of subsidy is going to meet the sort of construction needs for different types of cohorts.

30 MR KNOWLES: Yes. You've said in your statement that – you've referred to the previous national action on younger people in residential aged care; you've referred to the initiative from 2006 to 2011.

MS PEAKE: Yes.

35 MR KNOWLES: Now, I don't think there's any dispute; that was largely unsuccessful in effecting any significant or lasting change. At paragraph 47 of your statement, you actually say, in connection with this initiative:

40 *This was in part due to the positioning of the initiative as a disability reform rather than as a truly multidisciplinary collaboration.*

MS PEAKE: Yes.

45 MR KNOWLES: Now, are you familiar with the terms of the current younger-people-in-residential-aged care action plan?

MS PEAKE: I am.

MR KNOWLES: Yes. And before I go further, I should ask, to your knowledge; was the Victorian Government consulted about the formulation of that plan?

MS PEAKE: We were not.

5

MR KNOWLES: And that's despite, obviously, the fact that the hospital system is integral to how that plan will play out?

MS PEAKE: That's correct.

10

MR KNOWLES: And to your knowledge, does the Victorian Government have any involvement in administering the action plan?

MS PEAKE: So it's, certainly, been presented to us as co-governors if you like, the disability-reform council and oversight of the National Disability-Insurance Scheme, and it's presented to us, given our complementary responsibilities for health, but it's really been presented as a fait accompli rather than a discussion about governance of implementation of the plan.

MR KNOWLES: That presentation of a fait accompli: do you regard that as appropriate in all the circumstances?

MS PEAKE: I, certainly, think it's a missed opportunity, and I do think that there is a risk that this plan, like the previous initiative, is too narrowcast as a disability initiative – rather than taking the opportunity to take – to really have a multidisciplinary approach to planning, to governance and to support.

MR KNOWLES: Well, that was – you've anticipated my next question, Ms Peake; that's what I was going to ask you. The previous initiative, you've said, in your opinion was unsuccessful, at least in part due to the way in which it was focussed purely on disability.

MS PEAKE: That's correct.

MR KNOWLES: Do you have reservations about this action plan for the same reason?

MS PEAKE: I do.

MR KNOWLES: Now, you may not be aware of this, but there – accept from me for the moment that no additional funding has been specifically allocated to implementing the action plan. You're a very experienced public servant. From your extensive public-service experience – does that bode well for its success?

MS PEAKE: Look; there are always opportunities to redesign existing resources to get better value from them. So I wouldn't want to be saying that there is no prospects for success without additional funding. Obviously, given the needs of this

group, ensuring that there is sufficient funding for the development of accommodation and for new service models will be essential to the success of the plan.

5 MR KNOWLES: Now, you've described some of the Victorian service initiatives that exist for people with high and complex support needs, and that appears at paragraph 48 and following of your statement. One of the first that you mention – and this is in paragraph 49 – is the Slow to Recover program.

10 MS PEAKE: Yes.

MR KNOWLES: What did that do?

15 MS PEAKE: Yes; so the Slow to Recover program was a program within our disability program to support planning and rehabilitation for people who particularly had significant acquired brain injury to really enable them a longer period of support to gain functioning so that they could live a fulfilling life.

20 MR KNOWLES: And how successful was that, providing people with that more-prolonged period at an early stage to recover and rehabilitate?

25 MS PEAKE: It really was important, and one of the things, I think, was effective about the approach – and it is the approach we take in our health-rehabilitation programs as well – was that it wasn't about time. It was about setting of goals and then supporting people for as long as it was required, to achieve those goals.

MR KNOWLES: And where was it provided? What was the environment in which it was provided, and how was it provided, by whom?

30 MS PEAKE: So it was predominantly provided in home and community settings. It brought together multidisciplinary supports. So – allied health as well as disability support, planning-type support to really make sure that you had that integrated approach between the goal setting and support for people about their rehabilitation, fitting into the work that was happening in the rest of their life.

35

MR KNOWLES: And you mentioned time not being the emphasis. How long could a people – a person remain on the Slow to Recover program?

40 MS PEAKE: So – look; it really – predominantly it was still a shorter period, and I'm very happy to take that away and get precise detail for you. So three to six months is my understanding, but there weren't then hard dead lines, and it was a program that could be recommenced so that it could be re-introduced to people throughout their life so that there would be episodes of support that – were often the case for people.

45

MR KNOWLES: Yes. But you estimate that, typically, it was around six – three to six months, the program would run.

MS PEAKE: Let me take that away and get you more precise information.

MR KNOWLES: All right. Well, I might ask you to do that as well, Ms Peake.
Thank you. When that program concluded – you said that it was often delivered in
5 the home with a view, I take it, to people being sufficiently re-enabled to be able to
live at home perhaps with or without supports.

MS PEAKE: Yes. That's right.

10 MR KNOWLES: And so for many they would end up going home. What happens,
if they didn't have a home or didn't have a place where they could go? What were
the options for them?

MS PEAKE: Yes. So again there – in the disability context there were a lot of
15 people who were then residents of our supported accommodation. So – our
disability-supported-accommodation services, and that was always seen as preferable
to a residential aged care service being their home.

MR KNOWLES: So what's happened to that program now, the Slow to Recover
20 program?

MS PEAKE: Yes. So the participants in that program: they were – they have been
transitioned to the National Disability Insurance Scheme with their plans, and so the
support for that rehabilitation work has transitioned with them to the NDIA, and we
25 have been working with the NDIA and with the support of the Young-People-In-
Nursing-Home Alliance to really encourage the embedding of the principles of that
program continuing into the delivery of therapy and the delivery of plans through the
NDIS.

30 MR KNOWLES: Did you hear Ms – Dr Morkham's evidence from this morning,
that she was of the understanding that the rehabilitation facility that was now being
used in that regard was discharging people to residential aged care?

MS PEAKE: I did.
35

MR KNOWLES: Yes. And do you have anything to say in response to that as to
why that might have occurred, if it has occurred?

MS PEAKE: Look. I think the conclusion of that is that the sort of principles and
40 focus of the program have become more diffuse as they've been implemented by
planners that have varied interpretations of the plans that they were putting in place
and varying capabilities to really provide the sort of support for people's plans, and
so it's, absolutely, an area that there needs to be continued really – investment in
building the capability of planners to adopt those principles and make sure that
45 residential aged care is not becoming a default home for people.

MR KNOWLES: The advent of the NDIS in that instance, arguably, if people ended up in residential aged care, has actually been detrimental.

5 MS PEAKE: And – that’s right, and so it’s something, as the NDIS matures, that is, I think, very, very important, that that doesn’t get lost and that there is a renewed focus on the purpose of re-enablement and the support that people need for re-enablement.

10 MR KNOWLES: Yes. You’ve also, in terms of disability services for people with high and complex support needs, referred in your statement to specialist services for people with significant acquired disability.

MS PEAKE: Yes.

15 MR KNOWLES: Can you just explain to the Royal Commission what those services are and how they operate?

MS PEAKE: Certainly. So there are two services that Victoria has established, co-
20 incidentally coinciding with the beginning of the NDIS but not because of the beginning of the NDIS. They were really services that were developed, recognising the gaps that existed in service models. The first is the Alfred Health Acquired Brain Injury Rehabilitation Centre. This is a service that provides both inpatients, admitted residential rehabilitation services, as well as connection back home. So –
25 community-based rehabilitation support, as well as secondary consultation to other rehabilitation services, and it is, obviously, focussed on people of all ages with severe and catastrophic ABI. The service commenced in 2014, and it’s – it comprises a 46-bed unit, although at any given time it – there’s only 32 beds that are operated, to make sure that it is safe. It is a mix of those beds being funded by the department and by TAC. So TAC also uses this service.

30 There’s also a four-bed step-down facility for that transitional living-service as I described, as well as the community-based rehabilitation that occurs in 12-week blocks and – again very much goal-oriented, not time-limited. That community rehabilitation in particular for many patients is a life-long service, and the patients
35 who are admitted to the inpatient unit, usually, spend between – about six to 12 months. The second unit is the Austin’s – Austin Health spinal unit. It includes acute management, rehabilitation, outpatient clinics, a community-integration-and-spinal-outreach service and community-spinal-liaison nurses who support people for up to two years after discharge from rehabilitation. And for that service again
40 patients are, generally, admitted for around three to six months.

MR KNOWLES: Right. Now, you’ve said in your statement at sub-paragraph 53.1 that, since commencement of the Alfred Health Acquired Brain Injury Rehabilitation Centre – that the Centre had looked after 46 clients in residential aged care. And
45 that’s about 16 per cent of overall numbers. How has that come to pass, that these people have ended up in residential aged care, that 16 per cent? Were they there

previously? I assume not. And if so, why have they ended up in residential aged care?

5 MS PEAKE: Yes. So – look. It really is very unusual, for people from our two specialist services to be discharged into residential aged care, and if I just give you some other data from – of the 784 patients since 2016/2017, only 12 have been discharged into residential aged care. So in more-recent times the numbers have continued to improve as we have built up the capacity or the health services have built up the capacity of those community services. So the reasons really to have gone in the past and continue in small numbers to – go to the ability to provide sufficient support at home, trying to wrap around as much as we can to ensure that that is possible, as much as we can. Austin Health spinal unit is – almost never that someone is discharged to residential aged care.

15 MR KNOWLES: So are you saying that the bulk of the 46 people that are referred to there are more at the earlier stages - - -

MS PEAKE: Correct.

20 MR KNOWLES: - - - of this program and there are fewer now?

MS PEAKE: That's correct.

25 MR KNOWLES: What's been done to reduce that?

MS PEAKE: It really is about embedding the community support. So for people with spinal injuries, it's the spinal liaison nurses who work up to two years from discharge and for the ABI patients, again, it is the outreach, the community-based rehabilitation and importantly also the secondary consultation for other services if they're more regionally – other rehabilitation services if they're more regionally located.

MR KNOWLES: Now - - -

35 MS PEAKE: Sorry, one other thing I should add is that in line with that focus of really not wanting to discharge anyone into a residential aged care service, I am aware that the Austin Health have had two people who have been with them for two and a half years. So they really are very committed. So whilst generally it's three to six months, they have had a couple of patients who have been there for a much longer time awaiting resolution of alternative specialist accommodation.

MR KNOWLES: I see. Now, you've also referred to the nature of palliative care provided in Victoria, and this is at paragraphs 62 and following.

45 MS PEAKE: Yes.

MR KNOWLES: You talk about, in the heading at least, expansion of palliative care. Can you just tell the Royal Commission something about the extent of expansion over recent years in terms of palliative care provision services in Victoria.

5 MS PEAKE: Yes. So I can certainly get you the dollar amounts of the expansion, but in 2016 we released an end of life care framework which really focused on how we make sure that palliative care is person-centred, so it's really tailored to the individual needs of – of people who are requiring palliative care that there are different approaches that if someone is having a – is living with a condition where
10 they are going to need palliative care over a longer period of time, and we've increased the investment into community palliative care as a result of that.

MR KNOWLES: I take it, obviously it's a matter of choice as you say, it's person-centred but - - -

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MS PEAKE: That's right.

MR KNOWLES: - - - is that something that reflects people's desire if they can, to end their lives in their homes; is that what you're saying?

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MS PEAKE: That's right. As well – and there is – there are – as per my statement, we have inpatient palliative care and for some people that level of support, that level of clinical care is really, really important. But wherever possible, we do try and support palliation services being delivered to people at home.

25

MR KNOWLES: You will have heard that one of the ways in which younger people end up in residential aged care is because they have cancer.

MS PEAKE: Yes.

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MR KNOWLES: And they are not able to access palliative care services. How is that something that is avoided, or attempted to be avoided in Victoria; what do you do to try and avoid that?

35 MS PEAKE: Yes, so we have very well developed cancer networks that really look at every aspect of care for someone living with cancer, including at the end of life, and they do a lot of work at looking at the models of care and the research being translated into practice to improve models of care for people. We have a lot of services that are about providing outreach, not only palliative care but other forms of
40 nursing and support for people as part of our cancer programs. And – and I would, you know, I would emphasise that palliative care is made available wherever people are living under the State programs. So whether that's inpatient, at home, in a – in supported – disability supported accommodation or in residential aged care.

45 MR KNOWLES: So am I right in thinking that in terms of the – if it's a younger person, there are networks in government to identify who they are through cancer wards in hospitals and the like - - -

MS PEAKE: Yes.

5 MR KNOWLES: - - - to ensure that wherever possible they do not go into residential aged care; is that what - - -

10 MS PEAKE: Yes, so we have specifically hospital palliative care consultancy teams who work, whether it's cancer or whether it's another of the wards, work very closely across the health services to make sure that there's good planning while someone is an admitted patient and that there is good continuity of that planning back out into community settings so good referrals and warm handovers to our community palliative care services that are often delivered by non-government organisations.

15 MR KNOWLES: Now, you've referred in your statement to various opportunities for further reform. Perhaps before I come to that, one of the things that has recently been the subject of implementation, as I understand it, is hospital liaison officer roles that are proposed in Victoria.

20 MS PEAKE: Yes.

MR KNOWLES: Those roles are in collaboration with the NDIA; is that right?

25 MS PEAKE: That's right, so that the NDIA is actually recruiting to those roles so they are doing that at the moment. My understanding is the five roles that will be rolled out in Victoria, they're into the sort of shortlisting process with an expectation that the roles will be in place by October.

30 MR KNOWLES: This year?

MS PEAKE: Correct.

MR KNOWLES: Where would those five people be located?

35 MS PEAKE: We are still in discussions with the NDIA about what's the best spread of those positions. They won't only support one single hospital, they'll support sort of clusters of hospitals. Obviously, with only five positions they will need to work between hospitals so we're just finalising the logistics of that.

40 MR KNOWLES: And what will those hospital liaison officers actually do?

45 MS PEAKE: Yes. It's a very important question. I did hear some of the evidence in the previous panel about how to – what is necessary to really improve planning in health services. So the intention of these positions is not to be that one-stop person to do all of the planning but it is to be a point of really escalating where someone is being delayed in a plan being developed or the implementation of that plan. And to

help bring together, sort of at a systemic level, the health resources so the people who are doing discharge planning, help connect them better to NDIA planners.

5 MR KNOWLES: So is this role somewhat different to what, I think, Ms Cairns from - - -

MS PEAKE: That's right.

10 MR KNOWLES: - - - the TAC referred to in terms of these dedicated planners and they might have only 25 people at any given time that they deal with. This is a different role.

15 MS PEAKE: This is more of an escalation point and facilitating systems working together rather than a service delivery role, and so I definitely think that in addition to having this escalation point, the work that we're looking at through the hospital discharge plan that has been also endorsed by the Disability Reform Council developed in conjunction with the Health Ministers' Advisory Council is really, really critical to really go to what should those models look like in the future of how

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MR KNOWLES: So what are the – you said delays in planning, what are the sorts of things that might be escalated to a hospital liaison officer and what would they do about them?

25 MS PEAKE: Yes. So at the moment our latest survey of the health services would indicate that there's about 72 patients in health services who have been in a health service for about over 100 days, about 101 days beyond their clinical need, and these are positions that would really help to fast-track, making sure that there is resolution of the accommodation needs or the activation of somebody's plan around care needs

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MR KNOWLES: And yes, in terms of resolution of accommodation needs, obviously if they can return home that is good, but what do you understand the hospital liaison officers will do to prevent that resolution of accommodation needs ending up being entry into residential aged care for younger people?

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MS PEAKE: Yes, and this is where I do think that they need to be supplemented. They by themselves will not be able to resolve that. They will need to work with other parts of the health system as well as the aged care system as well as the

40 disability system, and the housing system to make sure that they've got the – the other resources to have those options made available. In other words, it will be other players that will need to come up with those solutions. This will be simply a role that is belling the cat, that here is a person who is still waiting for that solution to be found, including escalating to me, for me to escalate to the NDIA to really try and

45 find those creative solutions.

COMMISSIONER BRIGGS: So the question is, why aren't the support officers engaged with finding those creative solutions?

MS PEAKE: Yes. So you mean the support coordinators?

5

COMMISSIONER BRIGGS: Yes.

MS PEAKE: I think that they're – the evidence that the Royal Commission has heard about the capabilities and variability of capabilities is a critical issue.

10

COMMISSIONER BRIGGS: Thank you, Ms Peake.

MR KNOWLES: And just in terms of that hospital liaison officer role, is there any dedicated part of it which would be to prevent entry into residential aged care for younger people as such?

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MS PEAKE: Look, again, it's really – it will be a focus of ensuring that the bits of the system are working together, the different service systems are working together but they won't have a dedicated KPI or a dedicated responsibility for working out what those alternative solutions are. They will rely on other parts of the puzzle to do that.

20

MR KNOWLES: So there's no specific requirement of a hospital liaison officer to ensure that younger people don't enter into residential aged care?

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MS PEAKE: No, I think it's definitely something that we will be looking to embed through their work and to be asking the questions, but it's not their specific responsibility, no.

30

MR KNOWLES: And in that context, whose specific responsibility will it be?

MS PEAKE: That's an excellent question and I think that the conversation that the panel had this morning about there needing to be a very different systems approach to this is absolutely correct, that it would – I'd be very attracted to the idea that was raised this morning about there being a single position that could be created but, equally, I think that the commentary this morning from – I think it was Mr Bo'sher that having someone who has that skillset of having a knowledge about each of the systems at a depth that would be required in sufficient supply is pretty unlikely, at least in the short term, and so the alternative to having a single position being accountable, I think is going to have to be that the NDIA has responsibility.

35

40

So the service coordinator has ultimate accountability but they rely on a care team model where there are people from the health system, there are people from our housing services where that is relevant, and there are people from, where it is relevant, aged care who are all working together to look at what are those pathways to provide better options for people.

45

MR KNOWLES: And in terms of the department's role in all of that - - -

MS PEAKE: Yes.

5 MR KNOWLES: - - - what did the department do to facilitate those better linkages with the NDIA?

MS PEAKE: Yes, so as a member of both the Health Ministerial Advisory Council and as a member of supporting the Minister on the Disability Reform Council we
10 really have a very important stewardship role in working with the NDIA to look at what those practical governance models can look like, as well as a role in helping to upskill the health workforce to make sure they can actively participate in more integrated care models.

15 MR KNOWLES: And what are the practical governance models, what would they best look like to ensure that one doesn't have younger people going into residential aged care?

MS PEAKE: Yes, yes. So there are lots of examples that we have of clinical
20 panels. For example, we have had a clinical panel that has looked at what the pathway for someone with an acquired brain injury is, and that is – with the TAC, and that is a model that we are talking to the NDIA about replicating for people who are not connected to the TAC, and I think that sort of model about how you have multidisciplinary clinical panels that can work on – work together with disability
25 coordinators, the specialist coordinators, to really work out what those creative options, that my overarching view would be that they do have to be formalised. They do have to be structured in terms of mechanisms to bring the right players together to be jointly planning and jointly making decisions, sharing assessments and ensuring that the range of supports are going to be put in place.

30 So, for example, if there was an interim accommodation similar to the rapid housing option that the TAC has developed, you would want to make sure that the community outreach for rehabilitation services was lined up to come in at the right time. And that that was being supplemented where it was necessary with other sorts
35 of community health or allied health support. So it's not only about the initial assessment about what an option would be, it's the activating the services coming together in a way that's going to work for an individual.

40 And the last thing that I would say is that all of that just can't be done to someone, it's really important that they're – that a patient in this case is a partner in those decisions and that increasingly I think we are recognising that it's not only the consumer but their families as well that need to be brought into those planning processes.

45 MR KNOWLES: You mentioned assessments and we've already referred to aged care assessments. Obviously they're directed to people ordinarily who are going to be seeking access to aged care.

MS PEAKE: Yes.

MR KNOWLES: And ordinarily those people are older people.

5 MS PEAKE: Yes.

MR KNOWLES: And so would you see them as really having a default setting geared to aged care and in particular, if one is needing alternative accommodation, residential aged care?

10

MS PEAKE: Yes. So obviously they do have requirements under the guidelines for their work to – that residential aged care should sort of be the last resort. They're not quite the words but all other alternative options should be examined. But I don't think they have the specialist expertise to understand what those range of options should be, and to your earlier question about therefore who should be the lead in a more integrated model, I think it has to be the disability planner working with health services and housing services, rather than it being the Aged Care Assessment Team as the coordinating point.

15

20 MR KNOWLES: So if you're a younger person and you've got to the point of being subject to an ACAS assessment would you agree that, not in all cases, but you've suddenly got a bias towards being tipped into residential aged care as an alternative accommodation option?

25 MS PEAKE: I certainly think that is the system they will know best.

MR KNOWLES: So is that a yes?

30 MS PEAKE: I can't speak for a workforce. I know that they do – they do work incredibly hard to try and make the connections with other services that they do have care teams that they engage with, so it would be a generalisation for me to say every one of them has a bias towards aged care but I think the data would indicate that overall, that aged care is the service that they know best and if it's reached the point where they are doing an assessment, that it is – that the option that is more likely if there isn't an easy alternative or a very evident alternative option is more likely to be the option that – that they will turn to.

35

40 MR KNOWLES: Now, we've heard evidence earlier, as you also alluded to, from Ms Cairns from the TAC that 13 out of approximately two and a half thousand active participants in that scheme are in residential aged care. Do you have any views yourself as to why the numbers of people there in residential aged – this is younger people, I should say – younger people in residential aged care are so low?

45 MS PEAKE: Sorry, would you mind just repeating the first bit of the question?

MR KNOWLES: We've heard from Ms Cairns that the numbers of younger people in residential aged care under 65 in the TAC scheme out of two and a half thousand active participants is about 13.

5 MS PEAKE: Yes.

MR KNOWLES: Do you have any view yourself as to how that's been achieved and why it is so low?

10 MS PEAKE: I do. And I mean, I think this comes through from TAC evidence as well that it's a combination of having an expectation that there will be other alternatives found, backed up by very intensive dedicated workforce to find those solutions and then backed up with the sort of funding support to enable those solutions. I think it's those three. It's cultural, it's expertise and dedicated effort and
15 then it's having the sufficient funding support to make it happen.

MR KNOWLES: In paragraph 93 of your statement, you've said:

We do not assume –

20

this is in relation to specialist disability accommodation and similar types of accommodation. You say:

*We do not assume that the best models of care and accommodation will simply
25 emerge from a market responding to individual care plans and funding packages.*

25

Can you explain why you say that with a particular emphasis on the heavy reliance, it would seem, by the Commonwealth on market forces to generate sufficient SDA?

30

MS PEAKE: Yes. And it really goes back to our earlier conversation that I think the development market needs better information about the likely volume, about the sort of returns that they could expect and around the sort of geographic spread that is required, and I don't think that they are going to just get that information from
35 individual care planners reaching out to look at something for an individual. There needs to be a more grouped up approach to market development. And secondly, I think that there is, for some cohorts, there is a very specific set of needs – specifications and the sort of product – housing product that is going to be needed is going to need to be customised and again, I don't see that that being driven by simply
40 individual demand.

40

It does need there to be purposeful engagement about what does that model look like and where is it needed, who is it needed for, and what is going to be the way by which there's going to be sufficient occupancy to make it work.

45

MR KNOWLES: In terms of SDA, are you familiar – and it's been the subject of evidence this week – with the Productivity Commission's report in 2011 that

considered that there would be a shortfall – estimated shortfall at full scheme of about 12 and a half thousand – for about 12 and a half thousand participants in the scheme.

5 MS PEAKE: Yes.

MR KNOWLES: That's eight years out from the date of full scheme. Do you have any views yourself as to why, and we still have the shortfall, there's no doubting that, do you have any views as to why that hasn't been addressed at some earlier stage
10 yourself?

MS PEAKE: In terms of the accommodation availability specifically?

MR KNOWLES: Yes.
15

MS PEAKE: I think it just goes back to that there hasn't been that sufficient oversight and leadership around driving the monitoring of supply and the engagement with the development market, and financiers to really ensure there's the investment and the models that are coming through.
20

MR KNOWLES: Now, at paragraph 87 of your statement, and this is the last thing I want to ask you about, Ms Peake, you've referred to transitions out of aged care for younger people remaining a critical area of need for the foreseeable future.

25 MS PEAKE: Yes.

MR KNOWLES: And that there are – there's going to need to be resources, special knowledge and experience.

30 MS PEAKE: Yes.

MR KNOWLES:

35 *And the costs and resources required for transition separate from the cost of future care need consideration in NDIS funding arrangements.*

Can you just explain what you mean by that, and how that might work?

MS PEAKE: And look, it's really the corollary to preventing young people coming
40 into residential aged care at the moment requiring that dedicated focus expertise and then tailored investment. There's a – right now we've got a group of people who are in public sector or general residential aged care who need all of those ingredients as well, and we're not going to be able to just move to a time where we're not having some more people coming into residential aged care whilst we're putting all of those
45 other things in place, including sufficient supply of alternative accommodation.

So I think it is absolutely our responsibility to make sure in the meantime that people who are in residential aged care or entering residential aged care, in smaller numbers hopefully, receive that intensive focus and support on what is their exit pathway.

5 MR KNOWLES: Yes. I don't have any further questions for Ms Peake, Commissioner.

10 COMMISSIONER BRIGGS: Okay. Ms Peake, I found your evidence very helpful today. I really thought it gave us a good understanding of the richness of the State knowledge and experience in this area that is just waiting to be drawn upon as part of the broader directions that might be taken in this area. I also really like the way you took us around the question of what is needed in terms of coordination, service wrangling, what the roles and responsibilities of different bodies are, and I appreciated what you said about there needing to be an expectation about where this will go because I think that is of fundamental importance to stopping the flow of young people with disabilities into residential aged care.

15 But then you supplemented that by saying it needed to be followed up by a dedicated workforce who knows what the options are, and funding support to make it happen and that's a really, really helpful intervention to this Royal Commission. So thank you.

MS PEAKE: My pleasure.

25 COMMISSIONER BRIGGS: And you'll be pleased to hear that you're formally excused from giving further evidence to us.

MS PEAKE: Thank you.

30 <THE WITNESS WITHDREW [1.00 pm]

35 COMMISSIONER BRIGGS: Okay. I think we are now going to break for lunch, and I'm looking for us to coming back at 1.45, please.

MR KNOWLES: If it pleases the Commissioner.

40 **ADJOURNED** [1.01 pm]

RESUMED [1.47 pm]

45 COMMISSIONER BRIGGS: Mr Knowles.

MR KNOWLES: Commissioner. Commissioner, for too long the experiences of younger people in residential aged care have been out of sight and out of mind. This hearing has brought the experiences of younger people in residential aged care into the light. We've heard evidence from those who are in residential aged care, those
5 who've left it and from loved ones and supporters. We've heard the emotion behind Ms Lisa Corcoran's number 1 goal in life, which was in her words "to get the fuck out of the nursing home". We've heard Mr Neale Radley's references to his room as cell 14. We've heard Mr James Nutt refer to his time in aged care as a prison sentence.

10

Each of these witnesses have spent, and in the case of Ms Corcoran and Mr Radley, continue to spend years of their lives in residential aged care. Ms Jessica Dodds, Ms Kate Roche and Mr Mario Amato and the Littlely family told us of their frustrations and despair, their ongoing efforts to find alternatives and, for a lucky few, their joy at
15 finding solutions that have brought about real improvements to their lives and health. The story of Ms Robyn Spicer and her daughter, Jessie, was a welcome positive but it is an exception. Younger people should not have to live in residential aged care. Many witnesses told us residential aged care was their only option, that it was a last resort in the absence of other more appropriate solutions, such as alternative
20 community housing options, specialist disability accommodation, high level community supports, appropriate palliative services or the availability of home modifications.

25

Residential aged care has become the solution for gaps in other systems. But residential aged care is inappropriate for younger people. It's designed for older people at a different stage in their lives with different interests and different aspirations. Living in residential aged care deskills and disempowers younger people. Aged care fails to meet their care needs, leads to isolation and physical and psychological deterioration and in some cases results in neglect and unsafe care. Mr
30 Nutt, Mr Radley, Mr Amato and Ms Corcoran have suffered as the people they made friendships with in residential aged care have died. Mr Radley spoke about his loss of control and isolation. He said he feels like a prisoner with no freedom to get out.

35

Ms Corcoran reflected that she had lost that respect that all people crave. She said that she was a human being like everybody else. Ms Roche and Mr Radley gave evidence about the lack of appropriate care and rehabilitation and how this led to deconditioning. Ms Roche spoke about her extensive efforts to keep her husband, Michael Burge, out of an aged care facility. When she couldn't locate a suitable
40 alternative, he moved into an aged care facility where staff treated him as if he had dementia when he did not. He was socially isolated, uninterested in the activities targeted to older residents and for some time was unable to access rehabilitation services unless Ms Roche purchased them for him.

45

This highlights the difficulty in accessing rehabilitation across the residential aged care landscape. It is not a core focus of residential aged care and illustrates one of the fundamental deficits for younger people who need rehabilitation support. Ms Roche took leave from her employment to be her husband's advocate. She made a

point that others echoed across the whole of this week, without a committed and informed advocate a younger person will have much more difficulty in getting what they need to avoid entry into aged care or what they need to exit from it.

5 The navigation of fragmented health, aged care and disability programs has proved difficult for the majority of these witnesses. This emphasises the importance of independent key workers, or system wranglers as they've been called and, as has been suggested by the Disability Discrimination Commissioner, Dr Ben Gauntlett, as well as by Dr Bronwyn Morkham of the Younger People in Nursing Homes National
10 Alliance, younger people need independent supports, intensive planning and individual advocacy, including at the transition points between these particular programs.

15 Commissioner, it's clear that exiting aged care with appropriate care services and accommodation can make a profound difference to younger people's lives. The evidence of Ms Kirby Littley and her parents, Carol and Kevin, illustrates this. After significant dedication Kirby, then aged 29, made her way out of residential aged care and was able to move back home with her mum and dad and then subsequently into tailored disability accommodation. Ms Littley said she now enjoys independence,
20 choice, a social life and increased optimism. She has goals to one day drive a car and ultimately to return to work.

Mr Nutt left aged care after spending most of his 20s there, and then completed a certificate II in community services with a view to helping others. He describes his
25 current life in specialist disability accommodation or SDA as being about choice, control and independence. Commissioner, you also heard from Mr Amato who has made a remarkable journey from a residential aged care facility to life in the community with his partner. He continues to gain independence. He now works part-time as a tax practitioner and is looking forward to travelling overseas. He said
30 his life in aged care was depressing; his life now is positive and engaging.

This striking dichotomy between the life of a younger people in aged care facility and their life in the community shows why, save for very limited exceptions, residential aged care should not be used to provide care to younger people. Of
35 course, I want to acknowledge that there are aspects of the evidence this week that describe care that is not fit for any person, older or younger, for example, isolation, disrespect and neglect. This hearing is about the inherent unsuitability of aged care for younger people. But those issues of substandard aged care more generally remain a key focus of the Royal Commission's broader inquiry.

40
What drives younger people into residential aged care? Who are those people? What are their care needs? Why are they unable to leave? There is an obvious and concerning lack of information held by the Commonwealth to answer these questions. Without this baseline information, initiatives such as the
45 Commonwealth's March 2019 Younger People in Residential Aged Care action plan cannot be appropriately targeted and will not achieve its goals as limited as they are. Commissioner, you will recall that a recommendation to improve data collection and

the establishment of a database of younger people in aged care was made by a Senate Committee in 2015. It is yet to be actioned. In 2019, much about the population of younger people in residential aged care remains unknown. This demonstrates that government has failed to prioritise younger people in aged care, despite policy rhetoric that it will do so.

The Australian Institute of Health and Welfare's recent report on younger people in residential aged care revealed that 12 and a half per cent of them have cancer as their primary health condition. This is second only to dementia. Of the people who enter aged care due to cancer, around 80 per cent die within the first year of their stay. In effect, residential aged care has become a wrong door alternative to palliative care for too many younger people. The evidence of Ms Jessica Dodds about the death of her husband, Tony, revealed one of the tragic personal stories behind these statistics. When his care needs as a cancer patient became too high to be met at home Mr Dodds was placed in a residential aged care facility.

Ms Dodds' evidence highlighted how unsuitable this solution was in meeting her husband's end of life care needs. Ms Dodds' evidence indicated a lack of integration between the NDIS, hospital, palliative care and Aged Care Assessment Team processes. She feels the system failed her and her husband, Tony. The Younger People in Residential Aged Care action plan doesn't engage at all with the needs of cancer patients who are moved to residential aged care. It's focused on people with a disability who are eligible for the National Disability Insurance Scheme. Ms Vicki Rundle, acting CEO of the NDIA, the National Disability Insurance Agency, acknowledged in her evidence that cancer patients may well not be eligible for the NDIS.

And it's also wrong to assume that people like Mr Dodds and Mr Radley can only have their care needs met in residential aged care. The convenient assumption is that residential aged care facilities provide 24 hour care that is comparable to complex nursing level care. But that's not the case. The Australian Government has reported that registered nurses account for less than 15 per cent of the direct care workforce in residential aged care, while personal care attendants constitute 72 per cent of that workforce. Mr Radley highlighted this make-up in that three occasions when he was – there were three occasions when he was urgently transported to hospital from his aged care home. He says each of those hospital visits resulted from a lack of skill in caring for someone with needs such as his.

Across the health sector and the community the mistaken belief that aged care provides constant support, whether it be directed to palliative care or rehabilitative care or any other care persists. This misunderstanding must be addressed. The level of care a person can expect to receive in a residential aged care facility also doesn't compare favourably with the level of care a person can receive if they qualify for the NDIS and secure SDA housing with supported independent living and other supports. In that regard, one might consider Ms Littley's evidence. She now lives in a modified unit with 24 hour supports. These supports include carers during the day

to assist as needed, ongoing rehabilitation and access to a supported independent living support worker from 6 pm to 8 am each night.

5 Commissioner, I now turn to the evidence of the Commonwealth Government witnesses. That evidence suggests that there has been a distinct lack of leadership on this issue, despite the Commonwealth having clear ownership of the policy and funding mechanisms that underpin it. First, you heard from Dr Nicholas Hartland, first assistant secretary of the Department of Health. Dr Hartland acknowledged the persistent and unacceptable numbers of younger people in residential aged care and the shuffling of responsibilities between State and Territory and Commonwealth Governments. These responsibilities include the policy settings for and funding of the aged care assessment process.

15 Dr Hartland gave evidence about the policy behind ACAT assessments, including the method by which ACAT assessors are expected to test whether there is no other more appropriate accommodation to meet a person's needs than residential aged care. Dr Hartland's evidence demonstrated a lack of accountability for ACAT decisions approving access to aged care. ACAT documents considered by him in the course of giving his evidence failed to show compliance with the obligation to fully examine other care and support options before a younger person enters into residential aged care. Mr Michael Lye, Deputy Secretary of the Department of Social Services, gave evidence to describe that Agency's overarching policy responsibility for the action plan as well as for the NDIS. He conceded, Commissioner, that Government has manifestly failed to make inroads to address the issue of younger people in residential aged care. He acknowledged that the current system defaults to aged care and that that default setting must be disrupted. Both Dr Hartland and Mr Lye conceded the need for fresh thinking. In this light, the lack of concrete targets and mile-stones associated with the action plan is, simply, startling.

30 Ms Vicki Rundle of the NDIA acknowledged that, in preventing younger people entering residential aged care or getting them out of aged care, the NDIS is only part of the solution. Some younger people will not even be eligible for NDIS support. Her evidence highlighted that there is still much to do to ensure that younger people in residential aged care are enjoying their rights under article 19 of the United Nations convention on the rights of persons with disabilities. The Disability Discrimination Commissioner, Dr Ben Gauntlett, elaborated on this issue, and I will return to it shortly.

40 Commissioner, at the end of this hearing, we remain none the wiser as to why, in response to previous inquiries and reports, the Commonwealth has failed to comprehensively and methodically identify the cohort of younger people who are in or are at risk of entering into residential aged care. Time and again, there have been calls for better data and better understanding. It is only in the last few weeks, that data has become available – about the extent to which younger people with palliative-stage cancer are entering aged care. There are still startling and significant gaps in understanding the causes and conditions that are leading younger people into

residential aged care. There also remain very many opportunities for process integration between the Commonwealth, the states and the territories.

5 The action plan is relatively recent, but it appears to have been completed without proper consultation with all interested parties and without a full understanding of exactly who is in the target group. State Governments, as we've heard, were, evidently, not consulted. Much has been made of specialist disability accommodation as the solution to this situation; however, to date, the market has not been motivated to take up the opportunity to build SDA. In 2011, the productivity
10 Commission estimated that at full scheme around 28,000 NDIS participants would require SDA. At that time, it was estimated, that there would be a shortfall of some, approximately, 12,500 participants. Even now, taking into account SDA which is currently under development and for which construction has not yet been completed, there's still estimated to be a shortfall of over 9000 places.

15 Despite all of that, there nonetheless continues to be a distinct lack of clarity about exactly how much additional SDA housing is required and where and what housing is required. Ms Rundle conceded that there are no projections into the future, about supply or demand for SDA. Ultimately it remains unclear, how the SDA shortfall
20 will be met without a fundamental change in approach. If SDA is going to ensure that younger people can leave or avoid entering residential aged care, clearly, much more must be done, than waiting for the market to respond.

Commissioner, I note also that in terms of the evidence of Commonwealth witnesses
25 – questions have been asked of them across this week, and where questions were asked of them, that they were unable to answer, those answers will be sought following the conclusion of this hearing, and information in respect of those answers is expected to relate to, among other things availability of data, endorsed minutes of meetings, projections and modelling.

30 I now turn to the younger-people-in-residential-aged care action plan. A panel of Government witnesses from the action-plan-project board gave evidence to the Royal Commission this week. Despite their testimony, as well as other evidence given during this hearing, about the action plan, we are still left to ponder how the action
35 plan will achieve its goals without clear and measurable targets. We're also left with the distinct impression that those goals are too vague and way too modest or both. The action plan cobbles together a number of disparate projects with limited connection to the root causes of younger people being admitted to aged care.

40 The action plan relies on the co-operation of the states and territories, and yet, as we've heard, the Commonwealth did not consult with the states and territories before announcing it. The action plan's stake-holder reference group lacks members from the states and territories. Commissioner, Ms Kym Peake of the Victorian Department of Health and Human Services gave evidence today and gave evidence
45 to that very effect. Her evidence also demonstrates the centrality of the states and territories when it comes to diverting younger people away from residential aged care.

The states and territories have to manage the tension of someone being in hospital, no longer requiring acute care but being unable, also, to return home safely due to their care needs. The states and territories deliver the ACAT assessments, and therefore they determine if there are no more-appropriate care facilities or services under the approval of care-recipients principles, 2014. The states and territories provide community palliation and hospices. They offer community mental-health services. They deliver rehabilitation services. They oversee public housing. They must be at the table. They should've been at the table, and yet they're still not.

10 There are other issues with the action plan. It places great weight on the success of new SDA accommodation, but as we've heard, the market has been slow to respond to the call for this type of development. There's a significant shortfall in the availability of SDA and a lack of information about the amount of SDA likely to be available in the future or its location. There is a reliance on the market for provision of SDA, not only the right type of SDA but also the right SDA in the right place, even in thin markets.

Another limitation of the action plan is that it focuses only on those who are active NDIS participants. As at 30 June 2019, 4721 younger people living in residential aged care had an active NDIS plan. That's a figure such that there is still over a thousand people who do not have an active NDIS plan. So, clearly, there is a sizeable portion of younger people in residential aged care who are not covered by the NDIS. Even of those that do, only 66 of them have SDA approved as part of their plan, 66. And, obviously, in respect of those 66 – they're still remaining in residential aged care at the present time. It's entirely unclear to us, how the action plan will address the plight of younger people in residential aged care who are not eligible for NDIS supports such as – for instance, those younger people in residential aged care with cancer but with no disability that is capable of being addressed by the NDIS. On its face, the action plan, simply, won't help those people.

30 An alternative vision was presented this week by the panel of state-insurance-scheme witnesses from New South Wales, Victoria and South Australia. These schemes engage with health and rehabilitation processes for a participant at an early stage; they provide client liaison and discharge-planning supports and remain in contact with the participant to ensure their needs are met. Unlike the NDIS, there is a focus on rehabilitation. Although these schemes work with clients with high and complex care needs, admission of younger people to residential aged care is very rare indeed.

Of course, there are some key differences between these schemes and the NDIS. Nonetheless, specific lessons can still be learned from them. Most important perhaps is the early and meaningful collaboration with the health sector and sharing of information with that sector and others to best meet the needs of participants and potential participants in the schemes. The state-insurance-scheme witnesses agreed, that a skilled and dedicated workforce is essential to plan and implement packages of care that meet the needs and goals of those requiring long-term care, and we've heard evidence today, commissioner, how that level of skill and dedication may, in some instances, be lacking in terms of the NDIS. They – the scheme witnesses also

identified the importance of early and strong links to hospital and rehabilitation services used by their scheme participants. They highlighted the importance of longer-term rehabilitation.

5 Now – I now come, commissioner, to the evidence that we heard earlier today from witnesses from three advocacy bodies. That evidence was powerful. It showed leadership in this area. And might I say that the people who gave that evidence, from the Summer foundation, the Young People in Nursing-homes national alliance and Youngcare, are not only well informed and have deep insights into what needs to be
10 done to divert younger people away from residential aged care and into appropriate accommodation and supports; they're also a panel of witnesses with decades of experience in this area. They're eminently qualified to give evidence about it, and, certainly, it's submitted, that their evidence should be given great weight.

15 These witnesses noted a lack of urgency associated with the action plan. It was brought in in March of 2019, but even in the six months or so since then, they couldn't refer to any discernible progress in respect of the action plan. We heard that the current situation is the result of a complete lack of will by Government and that there is a real risk of history repeating itself in the nature of the 2006 initiative, which
20 did very little, if anything, to resolve this issue.

For them, the solution requires engagement with state and territory health, housing and disability portfolios. It also requires engagement with the aged care sector. To date, this engagement that has the potential to tackle some of the root causes of the
25 issue has not meaningfully occurred between the states and the Commonwealth. These advocacy bodies urgently demanded improved processes and pathways of hospital discharge to close what they term the direct pipeline to aged care and improve data collection.

30 We heard also that people get lost; like Mr Nutt and Mr Amato, when they are found, they're often found, simply, by chance. This prompts the consideration of the importance of independent key worker-advocates or, as they've been described today, system-wranglers. The need for greater integration of all systems with the NDIS, in conjunction with faster and easier decision-making on the part of the NDIS
35 that delivers all necessary supports, was another common theme of their evidence. One thing that came out today, obviously, was the ease with which an ACAT decision could be made such that it would occur – within two days a person would be within a residential aged care facility, but SDA would take months and months and months, just for a decision to be made, and even when the decision was made, it may
40 be a long time before the accommodation itself would become available.

The witnesses today on the advocacy panel made it clear that, while the SDA market is critical, the issue is not just about the bricks and mortar. A younger person must also have full access to necessary clinical supports such as nursing and care services.
45 The panel also identified the importance of a dedicated federal funding stream for interim accommodation and support, with access to extended rehabilitation, while

home modifications or assistive technology are sourced. These are common-sense solutions, we say with respect.

5 Commissioner, the evidence this week leaves us in absolutely no doubt about the question of younger people in residential aged care being fundamentally one of human rights. Article 19 of the United Nations convention on the rights of persons with disabilities makes clear that people with disabilities have the right to choose their place of residence and where and with whom they live on an equal basis with others. They are not obliged to live in a particular living-arrangement. People with 10 disabilities have the right to access to services, to supported living and inclusion into the community to prevent isolation.

The action plan in this regard has come to the attention of the Australian Human-Rights Commission. In its July 2019 submission to the United Nations on 15 Australia's compliance with the convention, the Australian Human-Rights Commission recommended that the action plan be amended to provide that no person aged under 65 years should live in residential aged care by 2025. The Australian Human-Rights Commission also recommended that the action plan put more emphasis on dedicated and well-funded advocacy for all people with disabilities 20 living in or at risk of entering aged care facilities. It was also recommended, that the action plan be amended to include those who are ineligible for the NDIS. All of those recommendations, we say, are entirely appropriate, and we urge them on the Royal Commission, to make recommendations of the same nature. As presently framed, the third goal of the action plan accepts that, as at 2025, 1000 younger 25 people will still enter residential aged care every year. That is, simply, not acceptable.

The Disability Discrimination Commissioner, Dr Gauntlett, gave evidence that the action plan's goals were inadequate. He, evidently, agreed with the submission that 30 we make to you, Commissioner, today. He made clear that the implicit assumption that there is a place for young people in aged care is misguided, and yet he was unsurprised, that Ms Rundle had conceded in her evidence to the Royal Commission that younger people in residential aged care are not enjoying their rights under article 19 of the UN Convention. Dr Gauntlett noted the fundamental lack of appropriate 35 accommodation for people with disability and warned that it is dangerous, to rely upon, purely, market models to meet this shortfall. He also stressed the importance of independent advocacy to enable younger people at risk of entry into aged care to have their rights protected.

40 Commissioner, this hearing concerns the plight, as has been said before, of a hidden part of our community. We have this week wanted to, as Dr Gauntlett put it, shine the brightest light into the darkest places. Dr Gauntlett's evidence was clear and compassionate and right. As he said, by 2025, we should have no younger people with disabilities in Australia living in aged care institutions. Indeed, no younger 45 people with or without a disability should have to enter or live in residential aged care. It is shocking to learn that someone as young as Mr Nutt could find himself in a residential aged care facility designed for people 60 years his senior. Perhaps even

more shocking is the fact that, even now, around 40 people under the age of 65 are being admitted – on average – into residential aged care each week. And that figure has not substantially changed over the last decade and even earlier. So since this hearing began on Monday, around 30 younger people will have entered residential aged care.

Ms Corcoran and Mr Radley should not have to continue to endure in an environment that does not meet their social or care needs. Mr Amato, Ms Littley and Mr Nutt should not have to wait as long as they did to leave aged care. Indeed, none of them should have had to enter aged care in the first place. Ms Spicer should've had a realistic choice about where she lives. We thank those witnesses for their deeply personal accounts.

The circumstances in which Mr Dodd and Mr Burge died and other younger people in residential aged care have lost all hope have been shocking. It, simply, cannot go on. Our thoughts turn to those younger people currently in aged care. While they wait for the opportunity to leave, they must be given equity of funding compared to those in the community with similar care needs. They must have access to ongoing rehabilitation to enhance their opportunities to succeed in the community. And they must have choice and control over their funding and who provides services to them.

The current action plan does not do enough soon enough and will only reach those who are NDIS-eligible. It is not separately funded, and it is not integrated with the states and territories. It appears unlikely to reach its goals, and those goals are themselves overly modest, or not measurable, or both. Despite the action plan, there continues to be a lack of information and understanding about the factors that need to be addressed for younger people to move out of aged care or to avoid entering it. We can understand in those circumstances why Dr Morkham referred to it as a Claytons' action plan. We strongly support her demand that no younger people should be entering aged care by 2022 and Dr Gauntlett's position that no younger person should be in aged care at all by 2025.

While specialist disability accommodation is one solution, it doesn't work alone. SDA must be accompanied by all necessary supports, such as nursing-care and supported independent living. The NDIS must be quickly accessible and able to adapt plans quickly when people's needs change. There is a clear message. Residential aged care is not designed or appropriate for the vast majority of younger people. Aged care should no longer be the Band-Aid solution for the gaps or failures in other systems. Mr Amato summed it up. Younger people shouldn't be in aged care.

There are lessons from state-insurance schemes which provide a joined-up response to prioritise keeping participants in the community. We've also heard from advocacy groups who've told us about innovative ways to stimulate the provision of more appropriate accommodation and care in the community. This shouldn't be a complicated problem. It should not wait for the progressive rollout of the NDIS or for the market to provide enough SDA to accommodate people whose conditions

have deteriorated while they were waiting. This problem should not be left to be discussed over the next five or 10 years but should be addressed now as a national priority. There are urgent policy and service gaps that must be addressed, appropriate palliative-care options, improved access to slow-stream rehabilitation, better social housing and more-accountable planning and decision-making. They're all critical.

This is an issue which must be shared, but strongly led. Health, Disability, Housing, aged care and social services all have a role to play. This requires a committed effort from state, territory and Commonwealth Governments. It requires information-collecting, sharing and analysis. It requires fresh thinking, dedicated resources and strong will. It requires an end to decades of empty rhetoric and blame-shifting. Thank you, Commissioner.

COMMISSIONER BRIGGS: Thank you. Thank you, counsel, for that very eloquent summary of this sorry story that we have heard this week. People with disabilities and young people with disabilities living in aged care should be given the opportunity to have a life and to live in the community. The Royal Commission has heard evidence from young people with disabilities, their families, their carers, government experts in the field, and we heard the system has manifestly failed. There does need to be speedy action, and my fellow Royal Commissioner and I, Commissioner Tracey, are very committed to making strong recommendations in this area.

That brings the week of hearings to an end. I'd like to thank the County Court for making this court available to us. It was very generous of us – of them, and they've been very generous in their support. I especially want to thank Sam Thorpe, who's helped me in the first week of me presiding over a hearing, and he's done so wonderfully well. I want to make tribute to you, to Mr Rozen, Ms Hill and Ms Bergin for the great job they've done, but I especially want to thank Dan, Matt, Rodger and Roger, who've dedicated some of their – a great deal of their time to preparing for this hearing this week. It's been terrific of them. For those of you responsible for setting up the hearing in Melbourne this week on our team – thank you for that as well. The service, as ever, has been superb.

It now gives me pleasure, to say that this is the end of this hearing. We're going to adjourn until the 7th of October 2019, where we will be having a hearing on access and equity issues in aged care at the Commonwealth law courts in Melbourne. And that hearing will commence at 9.30 am.

MATTER ADJOURNED at 2.24 pm UNTIL MONDAY, 7 OCTOBER 2019

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