**Summer Foundation**

**Annual Public Forum 2021**

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Captioned by: Carmel Downes

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PAUL CONROY: Good afternoon all and it is my great pleasure to welcome you all here today to Summer Foundation's 10th Annual Public Forum. My name is Paul Conroy, I am chairman of the Summer Foundation Board. Due to the continuing challenges of COVID-19 this year's forum is being held virtually from a studio here in Melbourne. The upside of this format of course is it makes it much easier for everyone else to participate from wherever they are.

I wish to acknowledge the traditional owners of the land on which our forum is being broadcast today. Where we are here is very close to the meeting of the lands of the Boon Wurrung and the Wurundjeri people of the Kulin Nation. I pay my respect to their elders past and present and to the Aboriginal elders of the many lands on which we are collectively gathered today.

Our theme for this year's forum is Reaching Towards Success: Closing the Door to Aged Care for Younger People. Today we will look forward to hearing what has been done and what still remains to be done to successfully resolve the issue of younger people with disabilities being forced to live in aged care. Our forum host today is Beverley O'Connor and 3 of our speakers have been able to meet us here in the studio while another 6 speakers will be joining us remotely.

Of course a lively discussion can raise as many questions as it does answers. So we have assembled a team of experts from the Department of Health, the National Disability Insurance Agency, the Department of Social Services and the Summer Foundation to help answer your questions. Please submit any questions you may have via the Zoom Q&A function during the course of the forum. We will keep taking questions up until around 1pm. At 1:20pm the Q&A session will commence whereupon your questions will be answered. Any questions that are not able to be addressed during the session will be answered following the event via the

Q&A resource that will be published on Summer Foundation's Annual Public Forum web page. A link to this document will also be circulated to attendees after the event. On that note I would like to hand it over to Beverley O'Connor to host the event.

BEVERLEY O'CONNOR: Paul, thank you so very much. Once again an enormous privilege to be with the Summer Foundation and with all of you today, even if it is remotely, we can't see you, but we know you are with us on this very important discussion, the pathway to a resolution of young people living in aged care. Such a critical one and one that the Federal Government now has firmly on the agenda. What a perfect way to start than with Paulene who is the most delightful young woman who lived in aged care for 6 years and thankfully moved out into her own apartment just over a year ago. Let's start at the beginning, Paulene, lovely to see you, welcome. How did you end up in aged care?

PAULENE BATES: Well, I had an incident at home and I didn't want to go back home so I was in the hospital for a while and I said to the transitioner, the nurse at the time, "Please find me other accommodation" and the 2 accommodation she could find was aged care. That was my only option was to enter into aged care. Not to my liking but, yeah.

BEVERLEY O'CONNOR: Was that quite a shock for you at the time that that was your only real option?

PAULENE BATES: It was, very much so. I thought, "Aged care? I'm going to die in aged care", so I was very shocked. Like I said, I had no option. I wasn't given any options. I was 44 and I thought, "Here I go in

aged care".

BEVERLEY O'CONNOR: At the time did you get the sense that that was it, that was where you were going to stay?

PAULENE BATES: Exactly. I just thought I'll end up dying in aged care and that was it.

BEVERLEY O'CONNOR: That's where your journey started, thankfully it didn't finish there but while you don't any longer live in aged care, thousands of young Australians still do. Let's hear from Andrew who currently lives in aged care in Tasmania:

(CAPTIONED VIDEO PLAYS)

BEVERLEY O'CONNOR: So some of the challenges that Andrew has raised just giving us an insight into what it means and what it feels like, as we heard from Paulene, to be living in aged care. As Andrew pointed out he is not yet 50. We are privileged to have with us the WA Senator, and Minister for the NDIS as we all know it, Linda Reynolds. Thank you so much for your time. I must say before we even start on this being a WA Senator, just a day after young Cleo Smith was found after such an extraordinary police operation, I imagine everyone is still sharing in that joy in WA?

LINDA REYNOLDS: Beverley, good morning and good morning to everybody who has joined this really important forum today. Yes, yesterday was an amazing day to be a West Australian. There were tears everywhere, I think, right across Western Australia. I don't think people

could quite believe that so many prayers had been answered and the police, who had done such a brilliant job, were successful. So a really, really good time to be here in Western Australia. Beverley can I start off by acknowledging the Whadjuk people of the Noongar nation from where I am coming to the seminar today in Western Australia. Can I also acknowledge all people who are participating today with the lived experience of a disability.

So it's very good to be with you here today. Thank you Beverley.

BEVERLEY O'CONNOR: Tell us a little about your connection to this issue of younger people living in aged care?

LINDA REYNOLDS: Firstly now as the minister for the NDIS I've got a responsibility for about 3,200 of the 3,900 people who are younger Australians living in aged care who currently are on the NDIS. But my connection to this came about in 2015, in fact through the Summer Foundation, as a Senator and the Summer Foundation came to visit me and explained to me the situation of younger Australians who are forced to live in aged care and I just simply could not believe it. Of course, as we all know, it is true. So I was - I thought, "Someone has to do something about it" and I thought, "Well, that's me, as a Senator". So I initiated my first parliamentary inquiry into this situation in 2015. And along the way I came to meet so many wonderful Australians who had no other choice but, as we have heard from Paulene and Andrew today, had no choice available to them. But I also met - in Geelong I met a wonderful young lady in 2015, Kirby, who was then in residential aged care and her amazing parents and I could see that despite the fact that she couldn't breathe on her own, she couldn't move, I could absolutely see this amazing personality and a great spirit and it just - she just

absolutely motivated me to make a difference. So here I am several years later, now as the Minister for the NDIS, and able to be responsible for maintaining the rage federally if you like, but also continuing the good work that has been done by so many for so long. Because ultimately this is not an issue that one person or one level of government on their own can fix. So, I will just leave you with this about how I came into this is I recently met another young woman in her 40s who due to surgery became a quadriplegic. She lives up in the Kimberley and she has no choice, absolutely no choice, about where she lives. I saw first-hand just how difficult it is the further you get away from capital cities in terms of getting the supports that you need, and in fact, she is funded for. I was determined before this, but I'm even more determined to really find a solution. Can I just say, Beverley, I think one of the really important things for us to discuss here today is that we all share a passion that no younger Australian should live in aged care but I also equally am convinced and determined that no younger Australian or no NDIS participant will be forced to do something that goes against their ability to have full choice and control over their lives. So something I think we are about to discuss but I think that is really important too.

BEVERLEY O'CONNOR: I think we will get to that during the course of the conversation. Your government has put it on the agenda but obviously with COVID and 2 very dramatic years in this country, do you feel it has lost momentum a little in terms of getting this moving forward?

LINDA REYNOLDS: I actually don't think it has. I think there is enough commitment in civil society, organisations like the Summer Foundation and others working in this sector. There is certainly no lack of focus from government, from DSS and also of course from the NDIA on this. Has

there been as much public attention on this? Probably not. But there is still a lot of work happening to tackle this issue.

BEVERLEY O'CONNOR: Let's bring in now - thanks, minister, we’ll be back with you in a little while - Dr Ben Gauntlett is the Australian Disability Discrimination Commissioner. Welcome to you Ben, thank you for your time. Give us your sense of how urgently this issue needs to be resolved and whether you feel it is moving at the pace it should be?

BEN GAUNTLETT: Thanks very much for having me today Beverley and to members of the audience, I acknowledge the traditional owners of the land upon which I am presenting, which is from Sydney, which is Gadigal Land of the Eora nation. I pay my respects to any Aboriginal and Torres Strait Islander members in the audience today and acknowledge that we are all presenting from different lands today and also listening to this presentation from different lands in Australia.

I think when we say is this policy area moving quick enough, the answer is there's no perfect answer because we need it to move as fast as possible. But to resolve the issue we need to combine several policy areas to enable people with disability to exercise choice and control throughout different parts of Australia at different times in their lives that may be wholly unexpected with different medical and health needs.

That requires in a particular geographic location there will be the availability of certain services at a particular time for a particular individual and unfortunately that model of support will take time to develop. And we need a combination of a better built environment, a better training of our allied health professionals to assess what needs people have and then to help people to leave hospital in circumstances where they do not enter aged care and for when people are in aged care,

we need there to be some way of helping them to move into better circumstances.

So we really do need the Australian disability strategy to engage with this area, with very much a zeal and intent to change the policy framework but we also need to understand that it is not just about the availability of a service, it is also the availability of a built environment, the availability of transport, but one of the good things that has occurred we are now openly collecting data on what is taking place, we are measuring success and we are hopefully moving to a situation where no people go into aged care - young people go into aged care in the future because it is a very serious human rights issue which Australia needs to resolve. The Committee on the Rights of Persons with Disabilities have been very clear about this and we need to see it for what it is, which is very significant human rights challenges.

BEVERLEY O'CONNOR: Thank you so much. Let's bring in now Jennifer Cullen, the adjunct associate professor and CEO of Synapse, an organisation that provides targeted research as well as specialist housing services for Australians impacted by brain injury and disability. For years the number of younger people in residential aged care was stuck at that 6,000 level, we are starting to see really good trends downwards, what are some of the key things you attribute this to?

JENNIFER CULLEN: Good morning Beverley and good morning everyone. Thank you for the opportunity to be here today and present. I am a very proud Wakka Wakka woman and I come to you from a very beautiful place in Queensland. I have been involved in young people in aged care movement for 20 years and if I sit back and reflect on some of the trends over that period of time and I go back and talk about the older days there was a public narrative. There was no overt discussion about younger people living in residential aged care.

What we have seen over the last really 2 decades is a very big movement that has focused on young people having a voice to speak about their rights. Like Ben was saying, their human rights not to live in residential aged care and we have seen over time that that has increased awareness across both the public and the private and government sectors. We've seen increasing in campaigning about why it isn't right for young people to be living there. Also there has been a change over the intersection between disability service system, between the health system, and also between the housing system. And to the Minister's point, what we have seen over that period of time has been an increase in government investment and an increase in state taking up and standing up for their responsibilities and also we've seen, overall, a reduction in that silo activity between the systems. I think what it has been really exciting has been seeing that younger people have also been involved in putting forward their voices of what appropriate and suitable housing would look like for them.

BEVERLEY O'CONNOR: Great to hear from you, Jennifer. We will be back with you during the course of the morning - the afternoon now in fact.

Deanne Davis, we know that a very large proportion of younger people who end up in nursing homes come via stay from hospital, as we heard from Paulene earlier. You work at Monash Health supporting people with a disability who are leaving hospital, what changes are you seeing at the coalface?

DEANNE DAVIS: It is great to be able to speak about some of the changes that we have seen over the last 3 years since the NDIS has rolled out in our regions and the change has really been a transformation of the options that are available for people who have housing and support

needs since the NDIS rollout. There has been a huge amount of resource put into capacity building within the health service so that the health service are very able to interface with the NDIS and support our patients who have a disability and end up in hospital to navigate the NDIS system to achieve the support outcomes and the housing outcomes that they need to leave hospital. There's also been systemic changes associated with the government targets and action plan and also the ACAS guidelines about how the systems work together and what processes support that action plan about people not entering aged care from hospital.

So that's been a privilege to be a part of actually and we've been on this journey with a lot of our patients through the hospital system and being able to support them to leave hospital with age-appropriate accommodation and supports that meet their complex disability support needs. And whilst it's not an easy journey, it's a very long journey and a long process, which is difficult for people - young people with a disability to live in hospital while that process occurs. The outcomes are actually life changing for people and it's a real privilege to see those outcomes at the end of that long journey for people. And whilst from a hospital sector it is easy to think of that as the end of the journey, as Paulene mentioned, it is actually the start of people's journey to a new future and opportunities to live life the way they want to live their life in the future.

BEVERLEY O'CONNOR: Thanks, Deanne. We are hearing lots of very positive developments and positive signs but of course there remain a lot of younger people still in nursing homes, still facing difficulties in exiting aged care. Let's hear again from Andrew:

(CAPTIONED VIDEO PLAYS)

BEVERLEY O'CONNOR: Wouldn't it indeed be lovely. So lots of challenges remaining for Andrew and his family. Let's come back to Paulene who is thankfully now out of aged care. But let's talk about what were the obstacles when you were trying to get out of aged care? What did you face?

PAULENE BATES: I had a coordinator at the time who gave me no option whatsoever so I got another coordinator, name was Nikki, and she sat down with me and said, "You know, I can get you into your own apartment, in Docklands where you want". My eyes just popped out of my head and I thought, "What? You can really do that?" She said, "Of course I can". So we just started and I persevered. Yes, there are - it is a lot of paperwork but like I said, I persevered and I...

BEVERLEY O'CONNOR: How easy was to it find a new coordinator, how did you manage to navigate that?

PAULENE BATES: It was easy.

BEVERLEY O'CONNOR: It was easy?

PAULENE BATES: It is easy, you've got a voice, use it.

BEVERLEY O'CONNOR: How did you find out you had that voice? Somebody was telling you there was no option.

PAULENE BATES: You have to ring - I rang Summer Housing. I spoke to Melody, she gave me an option, she said, "Okay, I've got a few

coordinators that would be willing to take you on". That's how it happened. I rang, spoke to someone, and that’s as easy as it was.

BEVERLEY O'CONNOR: So you found your way through have a voice within the system.

PAULENE BATES: As soon as I spoke to her she gave me the options. I was just overwhelmed. I just rang mum, sisters straight away and said, "I can move to my own apartment". And they were positive. No negativity. They’re positive people. You need positive people around you that is going to support you, "Go for it Paulene, you can do it."

BEVERLEY O'CONNOR: Thank you so much. Let's now go to Lauren Lovegrove, she is an NDIS support coordinator with MND NSW. Lauren, what barriers do you see for young people that find themselves stuck in aged care like we had with Paulene and Andrew who is still there?

LAUREN LOVEGROVE: I think similarly to what Paulene and Andrew has said, one of the barriers is not knowing the system and not knowing there are other options. If you don't have that support team behind you whether it is a coordinator or allied health team it is really hard to find out that information. So having that team is extremely important and then hopefully, as Paulene said, finding your voice and making your wishes known can also be difficult.

The other major issue, I think, is in regards to the process to apply for housing. It's very time consuming. It's difficult to navigate at times. It's not clear what process you're meant to follow, what information you are supposed to give. Again, you are relying on that team to hopefully be able to help you through that and if it is not there, then I don't know how

you would do that on your own. I think also just the options for living. Paulene was lucky enough to get an apartment on her own. That is what a lot of our clients would also like. I work with people with a neurodegenerative disease that can often be quite quickly changing and unfortunately does lead to death. During that time in what’s the last period of their life they really want to be on their own and be with their family and not living in a house with someone that they have never met before who has to almost share that journey of dying with them. That's very confronting for people and very difficult.

BEVERLEY O'CONNOR: Thank you, Lauren. Deanne, coming back to you, we are talking about wanting to get out of aged care but where you are, to your point, you are sometimes looking at them and trying to avoid people getting into aged care. How much of a problem is that?

DEANNE DAVIS: Over the past 3 years, I guess, since NDIS has created new options for people, but particularly since there's been much more clear guidelines and action plans around how to achieve that, I can only speak for our health service, but it really is only exceptional circumstances where residential aged care is considered for people now. There are a lot of NDIS-funded specialist disability accommodation options that are available for people with really high and complex support needs but there's also been a lot of housing - mainstream housing options and providers that are opening up broadly in the community where providers are willing to modify mainstream housing and people can live in mainstream housing with NDIS supports. So it really is the exceptional circumstances but there is still a problem for some of those people with really high and complex support needs, where there isn't appropriate disability accommodation or the appropriate level of funded support to

enable them to not enter aged care and those situations that we're seeing are usually for people where they might have a palliative - people with disabilities who might have a palliative condition and the time frames associated with navigating a disability housing solution for them, it's just too long. The time involved isn't reasonable for those people. Also, I guess, situations where younger people with disabilities develop early onset dementia or people who develop dementia as their primary disability, housing - appropriate housing for people with really advanced dementia, that is another space that we need to address.

BEVERLEY O'CONNOR: How much of an individual choice, back to what the Minister said right at the start, is it an individual choice or sometimes is that something that is a little bit trickier with somebody, for example, developing dementia?

DEANNE DAVIS: Definitely with the situations we have had where people have dementia, normally we are working with their families and their loved ones as well to come up with a solution that can meet their housing and support needs. The situations where people have less choice is when all of the disability options have been exhausted, they have really complex disability support needs and really complex health support needs as well and the interface between the 2 services is really tricky to navigate, particularly when people might need, people with bariatric support needs might need up to 4 people to be helping them move in bed and to transfer out of bed. So some of those really complex situations for people, we haven't quite got that tailored solution to address the very complex support needs for some of those individuals.

BEVERLEY O'CONNOR: The complexity is where sometimes it is a

lot trickier. Jennifer, are there system-wide changes that are needed or already in train that will help overcome some of the obstacles we have heard from Lauren and Deanne.

JENNIFER CULLEN: Absolutely Beverley and I certainly will come from a context in my reply around rural and regional remote Australia, Indigenous Australians and a brain injury perspective. What we see in those more isolated regional and remote communities that there is not the level of investment into the housing designs in those regions and obviously that is often because there is a presumption that there isn't a high volume of people. What we need to look at is a different response that housing often in those regions, particularly for Indigenous Australians, is from an intergenerational context. There are one or 2 examples in this country where architectural Indigenous-led designs and community responses have supported younger people to remain in their homes, on their country to live really deadly lives so that is something we need to look at. My response earlier talked about that separation between disability housing and also the health system. What we really need to see for those regional communities and remote communities is the link up between the National Indigenous Australians Agency, DSS, our Indigenous land councils, our Aboriginal benefits funds and for local communities to see how we can actually have a community-based response to those regions. I think one of the other points is in people we provide support and help either exit residential aged care often don't have high physical needs from a brain injury perspective, it is more about issues of impairment associated with executive functioning and I think we need to actually consider the housing side.

My last point is that we still have a mentality, build the house and a person will come. We need to flip that around and say to young people in

residential aged care what does a housing design look like for you?

My very last point going to both Andrew and Paulene is that we are still having a conversation about the bricks and mortar, we need to change that and say exactly what Andrew said, we need to look at building homes, not houses, being surrounded by family and lifting spirits. That is the next part of the conversation we have to have.

BEVERLEY O'CONNOR: Thank you so much. Just a reminder to all of you, at the end of our panel discussion here this morning we will be taking questions and we have another group that will come in, we will have an expert from the Department of Social Services, the Department of Health and of course also the Summer Foundation. So if you have any questions of your own please use the Zoom Q&A function to ask. We will collate those and then bring some of those issues up that you have raised during the course of this hour later on. I would like to now bring into the conversation John Koerber, he is the Summer Foundation Social Enterprise Lead. The Summer Foundation has been looking at this as an issue for many, many years now, probably a good 15 almost that we are coming up to. The Summer Foundation has taken the view there has to be an evidence-based approach. What are some of the research showing you?

JOHN KOERBER: Some of the key barriers have already been raised by some of the speakers earlier today, so a lack of available accommodation and support in the young person's area is something that does come up frequently and as other speakers have talked about can absolutely be the case in regional locations and more remote locations for particular styles of accommodation as well. We know there is not enough robust SDA accommodation being built in Australia at the moment and for certain

groups as has again been mentioned. For Aboriginal and Torres Strait Islander people for example there is not enough culturally appropriate accommodation and support available and being made available at the moment. But in other areas the data shows that the markets are building that supply and building that capacity. There is stock available in a lot of areas. There is supply available. There are vacancies as well. That one is as much a knowledge and a capacity issue of the people who are supporting people with disabilities as well. So part of the barrier is around the knowledge itself. Again, as we have already touched on, one of the other barriers or key drivers - one of the key pathways into aged care is through the hospital system and it is often that aged care can be seen as the most appropriate accommodation or support that is available where there is an urgent need so we are really talking about a difference in time frame for the health system and the NDIS processes are operating on at that stage and a shortage of age appropriate transitional care options as well.

I think the other - probably the third major barrier that is often being raised is younger people who are not eligible for NDIS as well, so that's particularly where it might be a psychosocial disability where it may be a little harder to prove that a disability is permanent and lifelong and therefore eligibility is not a straightforward process.

BEVERLEY O'CONNOR: Good, John, thank you very much. Let's go back to Minister Reynolds. We do appreciate you being with us. Just hearing some of these challenges I'm sure is very helpful for you moving forward. So what do you see is the greatest opportunity that there is for the NDIS to tackle these challenges?

LINDA REYNOLDS: Can I thank all the speakers who have provided input into some of the barriers. I think what it demonstrates is that none of

this is simple or easy, it is soluble but there is no silver bullet. We have had great success so far as we've heard but we still have 3,232 younger people in aged care and we need 3,232 separate solutions. A number of the barriers as we have heard include information barriers and historical reliance on more mainstream services who are not necessarily aware of the options or really understand the requirements, particularly as we have heard from Paulene and Andrew is there's a lack of transitional accommodation, particularly if people have been hospitalised. There's also a lack of social housing that is available - not just is available but is available to modify and there's also a lack of houses, as we heard clearly from Andrew, in the rental market because I know many people can rent, have the capacity to rent but they can't find a house where the owner will allow them to - us, the NDIA, to modify. So there are those barriers.

There are also barriers in accessing the workforce that's required for individuals, particularly the further out, as I said, of capital cities that you get. That is something we are looking at separately. So there's no one solution and there's no one level of government who can fix this. The NDIA has established a specialist YPIRAC team and they have expanded that team and they’ve got a task force that is working now at every individual case and look at them as individuals and really work out what is the best solution and how to achieve that for everybody who is currently in aged care. And having a talk to their families and their carers to work through those issues. They now do have a process to streamline and facilitate access who have not yet tested their access or eligibility for the NDIS. So we are going through and seeing whether we can't assist more in aged care to actually access the NDIA but again, as we know, that is not a silver bullet either because we are not responsible for all housing requirements. There seems to be an impression - an increasing impression, that NDIA is responsible for all housing but as I think - I think it was Jennifer said, it is

only for those who have really high need requirements and we can't be responsible for all social housing for people with disability but we can assist them on a plan to modify their home. As Andrew says, he wants his own home and he needs modifications for that. So over the next 12 months, sort of looking forwards, we will continue to work on policies and processes and really identify where are the things that we can continue to make a difference but again in a way that actually meets their choice.

One of the statistics that actually surprised me is that with the current records the NDIA has, over 50% of under 45s living in residential aged care actually don't have moving out of aged care as one of their goals and between 45 and 65 that goes up to 70%. So I think when we are talking about barriers, it is how do we work more closely in terms of what we are all doing to make sure that the participant's voice is heard and they understand what their options are and they can exercise true choice and control but to do that we also need to make sure that we have the right availability for a better option for them to choose to move out of residential aged care into as well. Again, it is not easy but we are making progress. Again, we still have a lot more work to do. Thank you Beverley.

BEVERLEY O'CONNOR: Faye Minty is CEO of Enliven Housing an organisation that builds and manages specialist disability accommodation or SDA. We know that SDA is designed specifically for people who have an extreme functional impairment or very high support needs. Of course, this has become a critical part of the puzzle of helping younger people move out of aged care. Faye in terms of supporting younger people out of aged care and into your properties, the properties that you are responsible for, what are some of the disconnects potentially?

FAYE MINTY: Thank you for that. Thank you first of all for inviting me to be part of the conversation. It is an interesting topic that is close to my heart. The biggest issue we have is that people will identify our properties as being somewhere they might like to go but the process from when they say, "Yes, that's where I want to live" to actually picking up the keys and moving in is a very slow and somewhat torturous route for many, many people. There are so many moving parts and it is not always clear. That’s the hardest part of it, there are no clear time frames and nothing you can plan around.

You are coordinating a lot of people's interests and it is obviously the person with disability who is in aged care or in hospital waiting to find their new housing solution. They’re sitting there waiting for an outcome and there is no timeline I can give somebody that says in 6 or in 8 weeks’ time we will have that solved and you will be in before this time.

We suggest timeframes but they don't work for anybody. I think the thing that causes me the most heartbreak is the sheer frustration of the person who is just in limbo and they don't know what to do. So then anybody who has worked with us knows we are a great organisation for facilitating meetings and we do that day in, day out. We talk to everybody and keep people in the loop. I'm sure everybody else is doing exactly the same thing. I am not saying we are unique in that space. We coordinate with the support coordinator, the support provider, we coordinate with the hospitals and we coordinate with the SDA application process and we just keep moving that process along and sometimes it is incredibly slow.

So I guess my top things for what are the, I guess, the barriers is the time frame, the lack of clarity where I can give people confidence and the impact that lack of knowledge, the ability to make informed decisions, has on the person with disability is just tremendous. It is horrific to watch and to be part of but knowing we are going to get there but I still can't say I am going to get there with any definite guarantee. I can't

guarantee they will get the SDA outcome they want. Their heartbreak when they get an SDA outcome that’s in shared housing and for a lot of our people with a newly acquired disability or have experienced one that has got significantly worse in recent times and requires a different housing solution, that - the idea of sharing is not something that sits easily with people and that causes a lot of unhappiness as well. But waiting to get your SDA determination is one thing, working out how is it all going to come together and that you will be adequately supported and knowing how long it is going to take, that is, I guess, the process we go through. But having provided all of that information about the barriers I do want to say being part of this system has been the most fabulous outcome when you see people move into their home, I don't care who provides that home, if that’s the right place for them, and that's where they want to be in the change in that person, the change in their outlook and the change in their attitude is just enormous and 6 months later when I go back to talk to people and do a visit, the outcomes are just enormous.

BEVERLEY O'CONNOR: Life changing indeed. I appreciate that. Ben, just to your point though, let's talk a little bit about the impact it has on individuals with the slowness of that process as Faye has just pointed out.

BEN GAUNTLETT: Thanks, Beverley. I think as Faye pointed out, one of the critical things we all need to remember in this process is we're dealing with people. People like you, like me, everyone in the audience, like Andrew. We need to understand in dealing with people they have family, support networks, emotions, they have feelings of angst, stress, they are not robots. We need to be dealing with - in dealing with people we need to understand very much. We need to ensure that people are supported appropriately to both make decisions and when they move into

accommodation. In Australia at present we need to look at universal design as a critical economic policy for the country. It is 22 times more expensive to retrofit accessibility considerations into a house than it is to build them up front. When we consider the arguments for keeping people out of aged care, we need to remember that in the Royal Commission Into Aged Care quality and safety it was found that 39.2% of people living in Australian aged care facilities had experienced violence, abuse, neglect and exploitation. There is an enormous safeguarding issue here as well.

We need to - appreciating we are dealing with people we need to support them but we also need to have a very clear policy imperative of universal design and one aspect of that is the adoption of the new mandatory accessibility considerations in the National Construction Code which unfortunately NSW, South Australia and Western Australia have not taken up. This jeopardises or can cause enormous problems for the long-term efficacy of the health care system, the aged care system and the disability support system because we need the built environment that is appropriate.

BEVERLEY O'CONNOR: As we pointed out at the start, thankfully Paulene is now in an apartment of her own. Let's take a look:

(VIDEO PLAYS)

BEVERLEY O'CONNOR: I should point out that not every apartment comes looking like that. We have a little interior designer aficionado to my right. She has adored decking out your apartment. I believe you have a parcel arriving every single day. You are the problem Australia Post is having with their deliveries! Paulene, tell us what has been really critical, other than the joy of decking out your apartment, what's made the difference for you?

PAULENE BATES: I know it sounds cliche but you can eat anything, do

anything how you want, when you want. There's no limit. When you are in aged care you are restricted. You've got to eat when they eat, go to sleep when they sleep. Now, you know, the world is your oyster so to speak. You can do everything you want.

BEVERLEY O'CONNOR: You have such a beautiful table.

PAULENE BATES: You are in the heart of the city. I am a social butterfly so you're always out shopping, entertaining. When people come over they're visiting you, not everyone in the nursing home. You've got your privacy. It's just - it's unbelievable really. So if I can do it, anyone can do it. So like listening to Andrew, I don't see why he can't do it. He can get a home and they can modify it to his liking. Why not? Speak up.

BEVERLEY O'CONNOR: Have the conversation.

PAULENE BATES: Speak up. If you don't speak no one's going to hear you.

BEVERLEY O'CONNOR: We hear you there Paulene and it just looks like a beautiful place that you have at the moment.

PAULENE BATES: Thank you.

BEVERLEY O'CONNOR: Let's talk about some of these conversations, the interface between the health services and the NDIS that are going to help young people avoid aged care.

JOHN KOERBER: Certainly having such clearly articulated government

targets has been essentially essential in galvanising resources and focus and I think over the last couple of years we have seen a lot of investment into new roles as well. We have things like health liaison officers, NDIA specialist planners and State and Territory funded clinical leads as well within some of the health services, NDIS champion networks as well, all of which are working very effectively but where we see the best results is where all of these specialist roles are working together with the person and their support coordinator in a collaborative and coherent framework where everybody's role and responsibility is clearly understood. So that's where the Summer Foundation's been doing a lot of work over the last couple of years as well through things like developing our collaborative discharge approach which was developed with a number of hospitals throughout Australia, which is really a best practice framework and tool kit for managing that interface between health and the NDIS and also our Housing Brokerage Service that we operate as well which works directly with people who have become stuck in hospital and their health and support teams to really embed that best practice collaborative approach and to show people what is possible and to bust some of those myths around what really is achievable for people as we have heard today.

BEVERLEY O'CONNOR: How do you break down some of those issues, you say there is stock but not necessarily the match. How can you work around the issues so the match up is there?

JOHN KOERBER: The process we take within the Housing Brokerage Service is starting with a conversation with the person and their support team around understanding what their housing needs and preferences are, what their support needs are, their functional needs are, where they want to live, who they want to live with, whether they want to live on their own or with other people as well which is

equally important and is one of the fundamental tenets of the NDIS is that everybody should be empowered to take reasonable risks in exercising choice in their own lives as well. That is really the heart of the process, understanding the needs and preferences of the individual and then undertaking that search to find accommodation that matches that.

BEVERLEY O'CONNOR: Minister, coming back to you, is there any merit in legislating against younger people going into aged care?

LINDA REYNOLDS: That is a good question and it has been raised with me. In short, my answer is no because when you think about all the barriers that have been raised here today I don't think legislation will fix a single one of them. What has worked so far is actually tackling the problem in the ways that we have discussed today and we need to keep working together person by person, so those who already have a goal to move out, how do we work with them? The NDIA is a solution for many but not all so if the NDIA is not the solution then what is for accommodation and other community-based supports and what role do organisations like the Summer Foundation and others have to play. So I think that legislation won't assist but keep doing what we are doing, keep reviewing what is working, doing more of what's working and as has been said, just keep wrapping services around together around individuals and provide them with the options for whether it's accommodation and SIL provided by the NDIA, whether it is helping them find their own rental property, whether it is helping them find States and Territories social housing and how do we do that to exercise their choice and control. I think the other thing that legislation won't help with is for those participants and non-participants in aged care who don't yet have moving out a goal and working with them to really understand why that is and how we can work with

them to either make it better for them where they currently are, make sure they are getting the support services they need but also work with them to present other options that might need their needs so they are then in a position to exercise true choice and control if we can provide them and they can see and believe they have an option that meets their needs in a better way. So I don't think legislation will deal with any of those issues. So, no...

BEVERLEY O'CONNOR: Thanks for that, Minister. Lauren, we heard Paulene say it was as simple as getting a new support coordinator to make that change for her. Every case is different. What skills and knowledge and resources do you think we need to make sure young people have?

LAUREN LOVEGROVE: I think we need to make sure they are aware of what the options are. You need people in the industry who are on top of that and can present that in a way that works for that person because each person is different, they take in information differently we need to be skilled in giving them that information in a way that works for them. Encourage them to be their own advocates where possible, for the family to advocate on their behalf where possible so they can find a new coordinator, they can find a new allied health team that can assist them linking them up with organisations like Summer Foundation who can also help point them in the right direction. I think knowledge is a big part of how we can improve things for people.

BEVERLEY O'CONNOR: Faye, you talked of some of the successes but you also talked about how slow the system can be sometimes. What do you see as your hopes? How do you see it reaching this connect of SDAs to the people who need these homes, how does it reach its full potential?

FAYE MINTY: I think support coordinators knowing what the options are and having the time to be educated on what the options are and getting adequate funding. Often it just becomes like it’s too hard and there is not enough time and there is a lot of pressure on people to help people move out of hospitals. Support coordinators like Lauren are the key to this entire experience, I assure you when they are good, like Lauren, it makes a huge difference. Knowing what is available and being able to support people to do it and having adequate time and funding to support people at their own pace to come to their own conclusion as to what is right for them.

BEVERLEY O'CONNOR: Minister, you have heard a lot from the coalface today. What does the NDIS have in train? What are your takeaways, do you think? What are you going to give your people to work on after today's discussion?

LINDA REYNOLDS: Well, Beverley, as I've said, they are already doing a lot but I think I'm even more convinced that they're on the right track in terms of working with states and territories, working with hospitals and working with organisations such as Summer Foundation and others to find solutions but I think having now an approach, person by person, and reviewing every single participant is, I think, a really important next step because that will then mean we will have a better idea of where the solutions do lie with the NDIA in terms of support and how we can speed that up or do something differently but I think it is also just as important so that we can identify sort of by state and by area who actually either wants to find their own home, rental home, or need a transition accommodation or need a State and Territory social housing option and that we can work with them to do that. So I think more of the same is

probably - well, more of the same but also more of what's working.

BEVERLEY O'CONNOR: Really understanding what is working and trying to translate. To your point about the numbers, they are quite surprising and it would seem that sometimes the conversation is maybe options aren't on the table for people?

LINDA REYNOLDS: I think you are right. That has certainly come out from this discussion today. I think we’ve got to be very careful. I’ve talked quite a lot about choice and control but I think we have to be very careful with our good intentions that we don't end up denying people choice and control and that we assume we know what's best for them but that we move at their pace. As you said, as a number of people said, it is talking to people, making sure that they've - we hear - their voice is heard, as Paulene has so powerfully said and we are not presuming we know what is best for them, that we can work out what they want and how we might go about providing that. Is that through the NDIS, is that through States and Territories, is that through community-based support, is that working with people who - the rental market and actually helping people with landlords, for example, and providing that stock and I think Commissioner Gauntlett makes an incredibly powerful point - several today but particularly on housing and building codes. So there is a lot of work happening between States and Territories on building codes but I don't think they've quite cracked it yet so that builders are required to, when they build something, make - as Andrew needs, he needs wider door, so it is much easier to adapt where necessary. So we've got a long way to go but we've come a long way too.

BEVERLEY O'CONNOR: Minister Reynolds we appreciate the time you

have given us and listening and taking on board so many of these points and to all of our speakers and contributors today it has been a really powerful conversation and really highlighted some of the key issues. We should leave the last word to where we started. Paulene, you are clearly living such a different life, what is your advice, what would you be saying to people, what are the key things to remember?

PAULENE BATES: You need the right support coordinator, that's number one. You must persevere, be persistent, speak up. Speak up because it can happen and it will happen. I'm living proof. If I can do it anyone can do it so you've got to speak up with the right people behind you, positive, no negative energy. Get the right support coordinator and things will go your way.

BEVERLEY O'CONNOR: Great advice. So lovely to have you with us. Thanks to our other guests in the studio as well. But just a reminder too, that we are going to be taking a short break but we have been receiving your questions and we will be coming back very shortly with the panel to put your questions to them and kind of wrap up some of the finer points. But for the moment, thank you so much for your company. Thanks so much to all our wonderful speakers who have contributed today. All the best. Thank you so much for your time. We will see you soon.

(BREAK)

(CAPTIONED VIDEO PLAYS)

BEVERLEY O'CONNOR: Lovely to be back with you for this final part of our Summer Foundation presentation with some questions for our expert panel. We have with us Luke Mansfield, who isDeputy Secretary, Disability and Carers at the Department of Social Services, Deb Connock, Branch Manager, Mainstream Interface and Royal Commissions at the NDIA, Eliza Strapp who’s the First Assistant Secretary Market and Workforce Division, Ageing and Aged Care Group at the federal Department of Health. Linda Hughes who is the UpSkill Lead at the Summer Foundation and Melody Carbans who is National Tenancy Matching Manager at the Summer Foundation. So thanks to all of you for being with us.

Let's start with Eliza, a topic on aged care. Is aged care seeing any changes in the number of characteristics of young people being referred to and entering aged care?

ELIZA STRAPP: Yes, thanks, great question. I think Minister Reynolds talked about earlier that we have seen, since the strategy began we have seen a 62% decrease in people entering residential aged care, which is great, but we still have got a way to go and we still have over 3,000 people in residential aged care. We are still - we are still seeing people enter every month. I think some of this is to do with people needing respite and not having tested their eligibility for the NDIS yet or not having had access to social housing and also needing a way to get out of hospital. We've just started a program where we've funded Ability First as system coordinators to work really closely with those people who might be in hospital or are at risk of entering residential aged care who are not NDIS or might need to test their NDIS eligibility to work with them around alternatives so we can keep them out of residential aged care. We know that once they go in it is really, really hard to get them out so our big focus is trying to prevent them from entering and we're hoping that this extra boost of support is going to make a big difference and also link really closely in with the work that the NDIA is doing.

BEVERLEY O'CONNOR: Let's go to Deb, a question on the NDIA. "I have found a large barrier to accessing SDA and therefore having to look at aged care are the health and nursing needs of people who require around the clock registered nursing support and provision of certain medications who have been told that they cannot access this through funded supports. What plans does the NDIA have in place to overcome this?”

DEB CONNOCK: That is a really complex question. I think we would all on this call understand that people have complex needs and some of those are very much disability related in terms of someone's functional capacity as a result of their disability and some people also have very complex medical support needs. So there is a - there are agreements in place between governments and the health system and the NDIS that sort of delineate some of those matters and, you know, disability support workers may not be qualified to administer certain medications because of the clinical governance arrangements that are required for all that. So in those instances there's certainly absolutely the opportunity for those support systems and supports to work collaboratively hand in hand so that there would be potentially some NDIS funding and some supports provided by the health system and I think to Minister Reynolds' point earlier, there's no one path for everyone, it is a combination of housing, health services, disability supports and all the other sort of parts of an ecosystem that better support someone. So it's never really either/or it generally is - needs to be a bit of everything and we all need to be working together to make sure that every individual, we fully understand the whole suite of their needs and each system then leans in to do the bit that they are responsible for, for the benefit.

BEVERLEY O'CONNOR: There is a good possibility though that there will definitely be people who fall through the cracks?

DEB CONNOCK: Oh well, one would hope not. I think that it is an evolution and we know that the complexities of people who perhaps acquire a disability, they have never had to deal with any of these sorts of systems before so some of the things that we have put in place with our colleagues in the Department of Social Services, Department of Health and with States and Territories by increasing the number of NDIS staff and to Eliza's point the system coordinators is to make sure we know who's there as early as possible and there are many avenues that we would hope that people would be able to - the pathways into each system so that we work across the top. So there shouldn't be people falling through the gap and we would want to know about it if that's the case.

BEVERLEY O'CONNOR: A question for you Melody on housing issues. We have heard of course some of the barriers during the course of this session. “What specific cohort of young people do you think are going to be the hardest to get out of aged care by 2025?”

MELODY CARBANS: I do think it is those with the most complex needs, so people with potentially complex behaviours, people with dementia, Parkinsons and require very high levels of support, so potentially 24/7 line of sight support. And the other group to consider are people that have a real lack of supporters around them, so people that don't have a lot of family, people that don't have guardians or you know, like distant guardians and really who aren't getting that constant provision of information provided to them to make informed decisions.

BEVERLEY O'CONNOR: Luke, let's come to you on a question that is really fascinating. We have had a fair bit of discussion around once people are injured they end up in hospital, why does the discussion around what sort of housing they are going to need start a lot sooner than necessarily just act as charged, which may become a bit complicated, what are your thoughts around that?

LUKE MANSFIELD: I think that is a really good question and I think that in terms of the work that we need to continue to do going forward, working with the States and Territories is to help educate hospitals around what they can do to intervene early with participants or people with disability in hospital to feed through that information through to the NDIA in particular but also to their own housing areas within States and Territory systems so there can be a better understanding earlier in the process what a person's individual needs are and so that can be explored because as everyone would appreciate, if there is a need for new housing or significant modifications of a home or for people to be waiting on social housing waiting lists, then that can take some time. So the earlier that that information does flow from the hospital through to other systems, housing systems, and the NDIA, the earlier that action can be put in place to make that transition smoother.

BEVERLEY O'CONNOR: Linda, a question to you on support coordinators. We heard a lot of discussion about support coordinators and particularly from Paulene who said that really made a huge difference. Participants seem to be - this question is under the mistaken belief that simply getting a support coordinator will simply solve their housing problems but many coordinators are not necessarily experienced in that area. What's been done to try to address that problem and equip all support coordinators

with that knowledge?

LINDA HUGHES: That's a really good question. I think that one of the things that we see is - you're right that there is a big variety in skills and experience that support coordinators have. We provide - at UpSkill we provide professional development for support coordinators really recognising that they play a really vital role in ensuring or supporting people to live well in the community, particularly people with complex support needs. We think that by having a look at our resources and having a look at what we offer would really help point people in the right direction as well as the Summer Foundation resources. We have also created a resource recently for participants on choosing a support coordinator and it really starts to unpack that question that you could ask a support coordinator before you engage them to see that they've got the right skill set that you are looking for. Support coordinators can have a variety of great skills in one area and perhaps in another area they don't have those skills so really choosing the right person. If you have a housing goal you need a support coordinator who has some runs on the board and has some experience and knows where to find information on supporting a person to leave hospital, leave RAC, who has experience in negotiating those mainstream interfaces that Deb talked about. This is complicated stuff and if you are asking another system to lean in and play their part you need to know which system to ask. So we would really recommend that you work with support coordinators who have that kind of knowledge to help address that complexity and those barriers that you might face leaving residential aged care or hospital.

BEVERLEY O'CONNOR: Thanks for that. Really getting the right match is what you are saying. Another question for Deb on NDIA. Many people

with disability have to share a house, and that came up again quite a few times. Other than the fact that people might want to share houses why does it have to happen that in some instances you do need to pair people up together?

DEB CONNOCK: It is a really good and complex question. I am not a delegate or a decision maker in terms of a plan funding but what I will do is I will give you sort of an overview. Essentially it comes down to an NDIS delegate or a planner is required to make what's called a reasonable and necessary decision under the NDIS Act. There are various matters that need to be considered in making that decision so obviously the person's needs and they will be informed by evidence often from occupational therapists and specialist and others and then there's other considerations that go to what is the best outcome and the other part for the scheme, as you will always also be aware that is scheme has to be sustainable. So with responsibility for the spending of taxpayers' funds we have to also make decisions, and it is outlined in the Act, that also have value for money components. We do know there are absolutely individuals who want to live alone, the same as I might choose to do or you might choose to do and there are also other people who - people without a disability who also share. So it is a fine balance of what the person's needs and wants are. Often it is determined by location of what is available in a certain area but a reasonable and necessary decision is made and that sometimes might mean that someone's found eligible - if they are eligible for SDA bearing in mind that that is actually a small number of NDIS participants and it might be they are found eligible for a particular swelling type, a particular design category and it also might be then that they have funding that allows - might be a 2 bedroom or a 3 bedroom, 2-person share. So then the person can go looking for an

opportunity for a dwelling - an available SDA dwelling that fits that design and funding category.

BEVERLEY O'CONNOR: Thanks, Deb. And a final question to Luke on advocacy. YPIRAC may be in need of advocacy support to ensure their access to support so that they can exit into more suitable housing. How can the government and the sector make sure that this group have the essential support needed?

LUKE MANSFIELD: I think there are a range of ways that people can get support to exercise their choice and control and to have their voice heard. Of course, in the context of YPIRAC, many unpaid carers, family members, others and support people in that process, also the system coordinators that Eliza referred to earlier that have been established by the Department of Health can help play a role in understanding the individual's needs and what their preferences might be and also the Australian Government and some State and Territory Governments fund independent advocacy services to help people with disability to exercise their choice and control. There are a number of different avenues that people can access and this is something that we'll continue to work with the disability community around as well as people who are supporting younger people in residential aged care about.

BEVERLEY O'CONNOR: Thanks to all our participants in this - taking some of these questions as we wrap up Summer Foundation Forum for the year. Just a note to let you know that the Summer Foundation team is keeping track of all questions that were asked during the forum and will get a comprehensive Q&A document up on their website as soon as humanly possible. Thanks again to all of you for joining us. It really has been a

terrific session and discussion and lots of work still yet to be done. It has been terrific once again to be with you. Time now just to hand back to Paul to wrap up.

PAUL CONROY: Thank you so much, Beverley. Once again you have coordinated, facilitated enthralling discussion. Thank you for your time. On behalf of Summer Foundation a sincere thanks to everyone who participated and joined us today. Special thanks to both our forum speakers and Q&A panellists for sharing their experience, insights and knowledge with us. We encourage everyone to keep the conversation going so we will have a video of today's forum on our website and a Q&A resource document up very shortly. In the meantime, please share your comments, feedback and suggestions via our social media channel, please use #YPIRAC. A quick reminder our website’s also a great place for useful resources for people with disability as well as health, disability and aged care professionals. That concludes the annual forum for this year. Thanks everyone for your interest and attendance and stay safe. Thank you.

(End of transcript)