**Summer Foundation Annual Public Forum “How Long Is Too Long?  
  
Di Winkler:** Good morning to all of you. Welcome to the Summer Foundation’s annual public forum. My name is Di Winkler; I’m the founder of the Summer Foundation and recently returned to the role of CEO.

Our forum today is being held on the land of the Wurundjeri people of the Kulin Nation.

I wish to acknowledge them, the traditional owners and pay my respect to their owners, past and present.

I also pay my respects to Aboriginal elders of other communities who may be here today.

Our theme for this year’s forum is “How Long Is Too Long?”

We’ll be exploring just what it will take to stop younger people going in to aged care for good.

Everyone here today along with those who are joining us live online via Facebook is eager to hear from our expert panelists as we discuss what is being done to solve this wicked problem and how long it may take.

We encourage you to contribute your thoughts both during and after the forum via social media on Facebook, you’re welcome to interact with our live stream and on Twitter, please use the hash tag “how long?”

A couple of quick housekeeping issues before we begin, the toilets are located just outside the glass doors to my left, all the parts of this building are non smoking, and in the unlikely event if emergency, please follow the directions of the Summer Foundation staff and NAB’s fire wardens.

So let’s get started. I’d like to introduce the host of today’s forum, Beverley O’Connor. Beverley is the presenter of ABC News 24’s The World program and it’s Beverley’s fourth consecutive year hosting our biannual forum and we are very grateful. Thank you so much, Beverley for your ongoing commitment and a very warm welcome.

**Beverley O’Connor:** Thank you Di, so much and I must say it’s been an absolute joy and privilege to be part of this journey with you and it’s very exciting to see the stage we are now at and the conversation we’re going to have today which is such a critical one and one as we all know came up so importantly during the recent royal commission.  
It’s lovely to see so many of you again for this forum, as Di pointed out, we’re here to discuss today what it’s going to take to stop younger people going in to aged care for good and so critical to this issue is how long is too long to solve this issue?

Let’s take a look.

**Video plays**

Well, we’re very lucky to have with us Helen Burt.

Helen is a younger woman who currently lives in an aged care facility in eastern Melbourne, let’s look at her story.

**Video plays**

I think many of you would find that quite heartbreaking.

Helen, it’s one thing to sit here and talk sit here and talk about this timeframe, two years, five years, 10 years, it’s an academic question for many people, I guess, but for you, it’s much more than that, isn’t it?

**Helen:** Yes, I suppose that for me, there really needs to be a sense of urgency because like the person who said in the earlier clip, it’s just so wrong, it’s so wrong, how can anyone think it’s okay? Every day that you’re in a nursing home, you’re going backwards, you’re not living your life, it’s I started off thinking when I was thinking about how I’d answer that my life’s been on hold for six and a half years, but it hasn’t, it means it’s been going backwards, you go backwards physically, you go backwards socially and spiritually in every way and without an enormous effort by yourself or by the people around you, and I’m lucky I do have people around me who are willing to put in that effort, you just, you just there in a room and it’s not a way to spend any part of your life..

**Beverley:** And when you talk about putting in an enormous effort, I imagine the system’s just not geared to assist you to do much more than what you’re doing at the moment.

**Helen:** Well, no, and it’s, you have to fit in to rigid timetables, I go to bed at seven o’clock at night because that’s a staffing issue and often, I’m not out of bed till eleven o’clock, well, not out of bed and dressed until eleven o’clock the next day, there’s so little of my day left to do anything and luckily, I have friends and family and they keep me connected to life outside, but if I didn’t have that, I can’t imagine where I’d be and also, physically, you’re not allowed to do anything. You’re not allowed to make a cup of tea, you’re not allowed to even attempt to cook or that sort of thing, it’s, again, it’s, you just forget, the muscle memory goes on all of those things.

**Beverley:** You paint a very, very evocative picture.  
Dr. George Taleporos is the policy manager at the Summer Foundation, he rather cheekily told me he’s been watching me on television for so long, he thinks I must be 95. George, I’ll forgive you because that means you’re getting older, too. George, this really isn’t a conversation about whether aged care is suitable for younger people, is it, or whether it could be made suitable.

**George:** Well, I don’t think there’s anyone in this room who wants to have that conversation. I think that the reference to the Royal Commission, we were a bit concerned that maybe there’d be a focus on how to make aged care better for young people, but thankfully, that wasn’t the focus. The focus was squarely on how to get young people out and how to stop them from going in the first place and we know, as Helen said, that when people go in, it could be a death sentence and it’s important that we get people out as soon as possible.

**Beverley:** George, as you’re talking, I understand we’ve got some statistics that really illustrate what you’re saying in terms of young people going in to aged care and how detrimental it can be can be, let’s take a look.

**George:** So you can see, that there young people every day and they rarely or never visit their friends and these statistics show how bad it is and they speak for themselves, so it’s important that we do everything we can to stop them from going in and to get them out.

**Beverley:** Scott McNaughton, good morning to you. We’re very delighted that you could be with us, you’re the acting deputy CEO for the government communications and stakeholder engagement at the National Disability Insurance Agency, we need to work on that title to get it down, I think.

Vicki Rundle was due to be with us, but unfortunately, she’s had a bit of a change of plan, she did speak to the Royal Commission on behalf of the NDIA, take us through what you think are some of the key issues that were raised at the royal commission.

**Scott:** Yeah, thanks, Beverley and thanks so much to the Summer Foundation for inviting the NDIA here today and apologies from Vicki. Vicki and I both presented at the Royal Commission and we certainly welcomed that opportunity because it does put the spotlight on this really critical issue for governance and sector to work through and as George and Helen’s story demonstrates, at the agency, we think it’s a really inappropriate place for young people with a disability to be living in residential aged care, it’s disempowering, it’s isolating as Helen so powerfully mentioned. We come from the lens that the NDIS creates a really good disruptor here, that the NDIS now looks at and as George mentioned, not only has there been around about 5800 or 6000 young people today in this country living in aged care under the age of 65, almost, I think as George said, close to 2000 people a year enter aged care, so we have to do two things, we have to find ways and work with participants in aged care to find better alternate accommodation and to disrupt the flow, so we need to work through all of those service systems and to make sure that aged care isn’t that default pathway for people, we need to change that, we need to disrupt it and that’s going to take an effort from us at the NDIA, but it also means the housing sector, accommodation providers, state and territory governments, we’ve all got a part to play because we know today out there, there is not enough specialist disability accommodation built ready to go. We can help with funding for that, that’s absolutely true, but we need the providers to come along for the journey as well, so we’re here and really wanting to support this, absolutely is a key area of focus for us, it’s a key area of focus for our minister and working with Summer Foundation and others to work our way through this.

**Beverley:** So explain to me a little bit more about how you could do that disruption and how you could be that constant sort of fly in the ointment in a way to get this sorted.

**Scott:** So one of the key areas of focus and what the research tells us that quite often, the pathway for young people in to nursing homes is through hospital system and quite often, that’s through an aged care assessment and what we’re looking at doing is how do we disrupt that? How do we disrupt that becomes the standard flow in and in fact, Allanah and the TAC do this really well already. So Allanah we are going to plagiarise and learn from them quite a bit, but how do we have our staff in the hospital settings and when we hear that someone is likely to require a specialist accommodation setting, it’s not aged care and that we look for alternative opportunities, even if it’s transitional until we can get the home modifications done or until we can get the right specialist disability accommodation setting ready, we need to do those things and that’s for us a big disruptor.

**Beverley:** Which brings us beautifully to Iain Edwards, thanks so much, Scott.  
Iain is the operations director of community health at Peninsula Health, so lovely to have with us, Iain, the majority of younger people of course who do end up in aged care come directly as we heard from Scott from a health setting. Can you explain some of the key considerations from a hospital perspective when a person whose support needs have recently increased in terms of the discharge process and facing discharge.

**Iain:** So the health service, one of the challenges in our core business is the delivery of health care and there’s a culture within the organisation that patients come in and we provide a level of health services to meet their health related needs, but there are, there needs to be a different sort of approach or change in around having a more holistic approach in working with people with a disability, we do have a range of people who access our health services with a newly acquired disability, they may have had a stroke or something that results in their care needs being increased or changed or they may have an already existing disability and for whatever reason, whether it’s a progressive condition like motor neurone disease or multiple sclerosis, where their care needs have changed, the hospital is about treating health needs and health care and the hospital again is not dissimilar to an aged care facility, but it’s not the best spot for people to be sitting in a bed for any length or period of time while trying to identify how we can best meet the needs for an appropriate discharge. One of the things of consideration around discharge, it does need to ensure the safety of that person, so a safe discharge does occur and that we’re not putting discharging an individual in to any level of risk. The challenges I guess with the health services is at the time of a newly acquired disability and again, it depends whether they’ve got good family or carer support or whether they’ve got very limited support, so we’re looking at whether the family can take them home, at the moment, it’s quite a long process for organising the home modification through the assessment processes and equipment provision, that can take some time, so often, we’re looking at some sort of transitional housing or care requirements to meet the support needs of that individual or for someone who doesn’t have good family or carer support, that’s again a different situation and we’re looking at more long-term requirements where we are looking for more secure specialist disability accommodation and that can be very challenging often in a timely responsive way.

**Beverley:** So to Scott’s point, the lack of suitable accommodation is the big stumbling block.

**Iain:** So on the peninsula, we do have quite a thin, as far as specialist disability accommodation, but it is not just the lack of accommodation, it’s the process to get in to one, so with a housing option package provided where that individual support needs are identified and then try and identify a facility that can best provide those supports and is set up to provide those supports, it can take some time around that assessment process.

**Beverley:** All right, thank you so much, Iain. Well, earlier this year, the Summer Foundation supported around one hundred people to make individual submissions to the aged care royal commission and of course, findings are going to be coming out a little later today. Let’s take a look at the wonderful wisdom these people had to share. Now all of them have a personal connection to the issue of young people in aged care.

**Video plays**

**Beverley:** Very strong, again, very powerful messages there. Helen, let’s come back to you. We’ve heard both Scott and Iain talk about some of the barriers, from your point of view, how, what are some of the issues you faced when you’ve tried to find other accommodation?

**Helen:** I guess for the first year, I desperately tried to find other things and I just couldn’t, there didn’t seem to be anything, even though when I had my ACAS assessment, they ticked a box to say that there was no other accommodation available, age appropriate accommodation, of course, that was just a phone call when someone looked at a database and said, we haven’t got anything, but I tried through my own contacts and got nowhere in the first year and I suppose I just bunkered down and became accepting of my lot, I just thought, this is never going to change, this is where I’ll probably die, and you make the best of what you can, it’s, you can’t live being angry and looking for something and being disappointed over and over.

**Beverley:** So let’s go over a little bit, when you said you said down and they said, no, nothing available, was that it? Was that where the conversation stopped? There wasn’t another opportunity to say, look, can we have another look?

**Helen:** No, I was off the DHHS system and as far as I was concerned, I was fine, I was in a nursing home and they worried about other people, and I know they’ve got a big job to do and enormous waiting lists and that sort of thing, but it’s, that’s just negligence that they could so easily write you off as not needing a different option just because you were in a nursing home.

**Beverley**: Yep, and they sort of felt that they’d drawn the line the sand.

**Helen:** Yeah.

**Beverley:** You’ve been there for some time now, give us a sense of the impact it’s had the longer it’s gone on for you.

**Helen:** Yeah, six and a half years, it’s a very long time, it’s, I’ve tried my hardest not to, I’ve kept up with physio and all that sort of thing, I’ve tried to keep a bit of positivity about life, but it is just a battle every day and yet you can’t commit to anything, you just feel like I’m in a nursing home, I don’t know, it’s very hard to explain, yeah, so I just went along and made what I could and to give them their dues, the staff in the nursing home were fantastic, most of them, and they could see how isolated I was and they enjoyed having someone to talk to, someone more their age, yeah, so time just went and as I said, I just accepted it, and I had other things, I hadn’t heard about the SDA, supported disability accommodation and the NDIS until I got an email from Gina from the Summer Foundation and she said there’s a session on two days later, would you be interested, you might be interested. I was there in a flash, all my receptors just went, if there’s something else that would suit me, I’m going.

**Beverley:** Fantastic, so again, a bit of a spark of hope. We’ll come to some of that down the track during this conversation. George, let’s come back to you, we’ve heard about the length of time in aged care complicating a person’s transition to suitable housing, how do you think that impacts the Summer Foundation’s thinking about targets about trying to really stop young people getting in to that situation in the first place?

**George:** I think that’s a really good question because it puts our focus on that question that we are here to discuss and that is how long is too long and what we want to see is that if people are in aged care now, that the NDIS steps up and does everything it can to find people suitable housing and support because as we’ve heard from Helen, the longer you are in aged care, the harder it is, you will lose your skills, you’ll lose your independence and you’ll also sometimes unfortunately lose the ability to see yourself leaving aged care and this is why we want all the young people out of aged care by 2025 and we want to stop them from going in by 2022.

**Beverley:** And that’s such a key point that you make because so often, it’s characterised as just a transitional situation, that younger people are only going in a transitional period, but what we’re hearing from Helen is that transitional period goes on and on and on, so what’s the Summer Foundation’s view on that?

**George:** Well, it’s nursing homes are not the appropriate place for an option for the same reasons that we’ve heard because people deteriorate and people lose hope. We need transitional options where people can access the community, where they can maintain those sorts of connections and also where they can access rehabilitation and that’s not in aged care.

**Beverley:** Scott, I’d like to come back to you, what are your thoughts, you talked about being the disruptor, what are your thoughts on the role of interim or transitional housing solution, so places where people can live rather than going in to aged care while you are still trying to work for their final solution?

**Scott:** It’s a really good point and it’s one of those, because we are going to try and divert participants from going in to aged care. There’s a number of ways that we can actually do that we can do that and for some people, it’s actually, we can work on modifying their own house and putting the right supports and care in their own place, but to do that can take time because you might have go to through council permits and get quotes and do those things that are required, so it might take three to six months or maybe even longer. We try and truncate that process as much as we can, but it can take time, but if there is a goal for that person to get back in to their own home with the right care and support, what is the option? We don’t want the person staying in the hospital systems and we don’t really want the person going in to aged care even as a transition and this is one of the areas that we do butt up against some challenges, what are the most appropriate transitional accommodation options? There isn’t a really good robust ubiquitous market out there just yet for that, there are some places, there are some times that aged care is used as a transitional approach, but we make sure we’re putting in the right supports for the person’s plan as well, but we really do need to keep working with the accommodation market to see that transitional options because it’s a really important pivotal point because sometimes we’re waiting for a new SDA specialist disability accommodation property being built and bricks and mortar take time as well and even though Summer and a whole range of providers are doing great things out there in terms of building properties, we know they take time and at the moment, we’ve got much more demand of people wanting to access that than we’ve got for the accommodation sector in terms of supply, so there are two issues to the accommodation market, one is the long-term SDA supply and we see it increase gradually, but the transitional market is really important for us and we’re working more with providers in that space. As I said, there may be some cases where aged care as a transitional temporary arrangement could be appropriate as long as it’s ring fenced and capped whilst we’re doing a better long term solution, so these are the sorts of things that we’re trying to work with Summer on and the accommodation providers to make sure that there is not only plenty of supply of SDA properties, but also transitional.

**Beverley:** And do you think the NDIA should be funding?

**Scott:** So the NDIS funds, obviously, specialist disability accommodation which is new in this approach, we also fund short-term accommodation in a participant’s plan and we’re making some adjustments to that at the moment to make sure that there is a good policy setting that here is an appropriate funding source for someone to access transitional accommodation that they may need, so the NDIS can provide that support for them.

**Beverley:** Terrific, thanks, Scott. Mary-Lou Devlin, where are you? At the back, thank you. You’re a senior social worker at Monash Health, now your team regularly works with people who are at risk of entering aged care, what are some of the key challenges that you’re facing to try and stop them slipping in to that system?

**Mary-Lou:** Yeah, I think they’ve been touched on already, so I think time is a massive factor when working with these patients, the NDIS process trying to find the right housing option, it all takes a lot of time and a lot of planning and once we go through those stages with our patients, there often isn’t those resources at the end to give them an immediate option, so we explore the things like short-term accommodation and often, that’s not an option for people with complex needs and then we’re looking to try and get those SDAs or the complex home mods, but in a hospital setting, we’re really, really trapped by that time element, so that’s a major issue for us, we’re trying our best to provide the evidence and set patients and participants up with their first plan to make sure that they have all the supports built in for the long term.

**Beverley:** And in terms of, we heard from Iain talking about the lack of supply, it sounds like you run out of options quite quickly.

**Mary-Lou:** Yeah, so the Housing Hub, the stock on there has increased over time, over the last year or so, but even still accessing shared supported accom, that’s a lengthy process, it’s not quick, people have very, very complex needs, so having multiple planning meetings with the NDIA to make sure that they have the right supports built in to that and then the service providers going off and getting the SIL quotes approved, they’re not just quick processes and sometimes we might go through all of that and then they’re still not fit for that house, so we’re back to square one.

**Beverley:** So it sounds, Iain coming back to you, it sounds like some of the issues are quite systemic and bureaucratic.

**Iain:** There are some systemic and process issues, I think there are also capability issues within an organisations because some of those specialist assessments identify may not necessarily sit in the health system, they might sit more in the ambulatory space, but the process as far as eligibility to access and the planning, that all takes time and then the planning, once it’s put in to that package to identify the person either is going to go home with significant modifications or looking for a specialist support accommodation that fits their support needs, that process, that assessment and process can take months, to look at home modifications and equipment prescribing, by the time you get the builder out there to do the quote and the quote then goes to the NDIS and gets all through, as Scott was saying, it’s a three to six month process and a hospital bed at that point is not the best place for that participant to also be, so transitional care I think is I think something that’s absolutely critical how we support transitional care, at the moment, we often use the transitional care program, TCP, but again, that’s predominantly aimed at an older population or aged care arrangement or an aged care facility with a real shortage in market around this transitional care accommodation for younger people.

**Beverley:** We heard Helen talk how you felt how they kind of drawn a line, that you were forgotten about very quickly, so Scott, coming to you, we did at the Royal Commission hearings, there was an issue raised around how people felt forgotten very quickly and we don’t have adequate data as to who these young people are, where are they and have circumstances changed, could you possibly help them? What are your thoughts about tracking data, keeping information so we’ve got a much better handle on what’s happening?

**Scott:** Yeah, it’s a really good question, having a really good sense of where all the young people in residential aged care are is number one priority for us because it then that allows us to get our planning teams in there and work with them and make sure that we’re able to get them, their initial NDIS plan and their initial NDIS supports, and there were a couple of people who presented at the Royal Commission who what we’ve been able to do because we haven’t been able to get suitable accommodation where they lived in regional Victoria, we’ve been able to put more supports in their plan so that they can actually access community during the day, they can get additional personal care, they can actually leave the aged care setting during the day and go and do things in the community and that was working okay for them, so if we can’t find suitable accommodation, there are more supports the NDIS can provide to people in the short term. We actually get data every quarter from the Department of Health and Ageing that says who’s in aged care at any given point in time and then our teams across the country, so what we’ve done is centralise and create a specialist team within what we call our complex support needs team and then we’ll hire skilled and trained staff members who are out then are working with the participants in the aged care setting and getting a sense of what does that participant want to do? Where would they like to live? What would they like to do in terms of their community participation or social engagement and making sure their plan is keeping those up, so the data’s really important, the other thing the data will eventually allow us to do is to signal to the market how many people would like to move and where they would like to move to and then what you can do is start to signal that to the housing providers and say we’ve got 10 people in Bendigo, five people in Albury, I’ve got 15 people in Fitzroy, we’re all looking for SDA in these types of areas and that’s where the supply site starts to match up, so the data is really important for us to be able to do that, so we are very, very, I should have preference this by saying, we’re all about participants here and this is a very participant focused scheme, but having that data is really important because it helps us get outcomes.

**Beverley:** So what I want to ask you is Helen, is she in either of your systems any longer, because she left the health system well before the NDIS started, so where would she be represented in that system?

**Scott:** I don’t want to talk about you while you’re not here. I hope Helen’s been supported.

**Helen:** I’m an NDIS participant.

**Beverley:** Right, you are now.

**Scott:** And we are working with Helen to find more appropriate accommodation and it’s going slowly and we need to do more about that, she’s now got my card.

**Beverley:** Personal contacts always help, Helen, I can tell you.

Iain, so back to you just quickly on that point, do you feel the health system and the NDIS are properly connected in terms of keeping track of that data?

**Iain:** We submit regularly to the DHHS and also to NDIS data around the number of people who are currently in beds whose discharge has been held up as a result of being unable to find suitable discharge destinations or accommodation for them on discharge or the home modifications not being able to be completed, so we constantly feed that data back both to DHHS and also to NDIS.

**Beverley:** Terrific. All right, Shanais Nelson, now she’s up in the front here, now you moved to Melbourne for work, you’re now living in a specialist disability accommodation or SDA, we heard a little bit about that this morning which is an apartment in the inner eastern suburbs. Now I know that that took quite a long time, we’ve heard about those issues, but I suppose it gives us a really great idea of how young people can really have high physical support and how those needs can be met, let’s take a look.

Thank you for letting us in to your apartment; let’s take a look at what Shanais’ apartment looks like.

**Video plays**

I’m Sinead, I’m 25 years old and I’m originally from rural New South Wales, but I now live independently in an accessible apartment in Melbourne.

I love my apartment because it’s in the perfect spot, it’s right near work, it’s right near the train station so I can go in to the city and go and meet up with friends when I want to, I can go to the local shops.

For me as well, I love that it’s so close to local parks and especially local bell parks so I can take my dog, Meikh to the local park before and after work in to the local area and even though I’m in the city, living where I live doesn’t, it doesn’t feel like I’m right in the city, but it’s still so close to everything.

It’s really good, it’s amazing.

**Beverley:** Isn’t that wonderful to see and it must have such a difference to your life; give us a sense of how it’s changed for you.

**Shanais:** Yeah, for me, it’s honestly been life changing and I mean when I say that, I know it sounds very cliched, but it has, to be able to wake up in the morning and turn the lights on myself, to be able to open the door, it’s all the little things that you don’t really think about, you’ve been able to do it for your whole life, but for someone with a disability, to be able to do the small things like turn on the lights and open the blinds, it makes a huge difference and the location is amazing, it’s so close to work and so close to the city, it’s right near the train station so it’s central to everything, since I can remember, for me, my goal has always been able to live independently, to move out of home, to do everything that everybody else does, go to work during the week and go out with friends on the weekend and go for coffee, so for me, before moving in to the apartment, independence was having to have someone with me 24/7 and being 25, I want to have my own space and live like every other 25-year-old does, so now that I have my own apartment, it means that I’ve cut down on a lot of the support that I need and I can have my independence and it also means that Mum who cared for me for 25 years, she has been able to move back to New South Wales and live her life and for me, that was so important for her to be able to get her life back and go travel or go and work, so I mean it when I say it is life changing and it’s amazing.

**Beverley:** So give us a sense of what support you now need, you talked about having somebody there 24/7, what support do you now have and does it make you feel secure in that you have the support you have?

**Shanais:** Yeah, it definitely does, I have my core support workers who help me get up in the morning and throughout the day when I need it, but in the apartment, there’s also the 24-hour on site supports, so if someone doesn’t show up for a shift, if someone can’t make it, I know there’s always going to be someone there for me to support me which reduces anxiety massively and I know that in the event of a fire or something, for me, that has always been an anxiety, that I would be there by myself and be trapped, but knowing that there is the 24-hour support, it’s really does take away that anxiety and the stress of not being able to support myself when I am alone.

**Beverley:** And to have that freedom must be so liberating in a way, of course, you want people around you as well, but just having that freedom and independence.

**Sinead:** Yeah, just like everybody else, you get home from work during the day, I need people there to help me, but afterwards, when I need my alone time, I can have it, I can have my down time.

**Beverley:** Which is such a wonderful outcome, thank you so much for telling us your story.’

Now Court Walters is an accommodation specialist at Milparinka Disability Services and Caroline is doing a fabulous job sprinting after Court. Court, thank you so much for joining us, tell us about the delivery of timely and effective disability supports or how is it critical in terms of fitting together that puzzle for people leaving hospital with complex needs?

**Court:** Yeah, well, it goes without saying that moving in to accommodation in SDA and having that wonderful thing in your plan that gives you that golden ticket to make that move is not much use to you if you can’t do those things that Shanais was talking about, open the blinds and to have the assistive technology and to have the home modifications funded in your plan and ready to go so that when you do make it, you’ve got that in place and also having those things in place that you can learn how to use it and how to effectively, so having those things in your plan in the right timeframe is really important, yeah.

**Beverley:** So when you’re having that assessment process, do you think that the questions you have all the right avenues to explore to make sure that assessment is thorough at the time?

**Court:** Yeah, so having the right supports in places in terms of having specialist on site with you to make those decisions about your eligibility really affect long it’s going to take to actually get the eligibility in your plan, so you may have an occupational therapist working your whole life, you may have known them really well and they may be really important going forward in your transition, but having someone on site who really knows how to pitch those questions about funding is really important and that can help to really reduce the time that you need to work towards getting eligibility in the plan and to being able to move out to SDA.

**Beverley:** Terrific, thanks, Court, thanks for coming along. Allanah Kennedy, welcome, you’ve been waiting very patiently on stage here for us, but you have such an interesting insight in to this whole conversation because Allanah is the Senior Manager Independence Division at Victoria’s Transport Accident Commission or TAC which we all know it as which has a lifelong responsibility for the costs of clients supports needs, so really from the very beginning, you’re part of their life, but you are going to be responsible from go to woe which is a completely different concept to what we’ve heard today. Does that fact that you will be responsible for that whole journey impact the way you make decisions early on?

**Allanah:** I think it probably does, I don’t think it’s too dissimilar to the NDIS where a client or a participant has a lifelong need and the need is identified and the need is identified and the client’s goals are identified, TAC absolutely has a responsibility to provide supports to enable a client to meet their aspirations that their peers would meet, but would be unable due to an impairment or disability, so absolutely, the important thing that we have found is to get engaged really early, so the challenges that we heard previously from a health perspective and also from a time it takes to plan discharge and to find suitable accommodation, they are challenges TAC also faces, so one of the most important things is the engagement very early and the investment in the client early to ensure we maximise recovery and we maximise independence and as has been pointed out a number of times by a number of people, one of the very big factors that supports independence and recovery is the environment in which you live, so the challenge that we have in our situation the health situation is that often it is for a defined period of time and as Iain mentioned, health is often about medical circumstances and then potentially long slow stream rehab or something like that, but there is this transitional living component which is a real challenge. At the TAC has a centralised team work very early with clients, we have a centralised team who also manages home modifications, so we have tried to get that as streamlined as possibly can, however, as Scott mentioned, council approvals, getting project managers and builders does take time, so it is about that investment and it is about being really close to understanding, what does the client want to achieve? What does the person want to achieve? Where do they want to go and not making assumptions that the person always wants to live at home in a town where they might want to move somewhere else to work or to experience a different life, so they’re the sorts of things that we’ve found to be really important and beneficial to inform how do we support the clients for their life journey with us and then how do we step away from that also. I think that was one of the other things that Iain mentioned managing about risk on discharge, I think that’s one of the things that our early support coordinators work really tirelessly with health and also clients and clients’ families about yes, we absolutely need to do due diligence to manage risk, but also people have a choice about how much risk they want to take and sometimes they may not feel comfortable with people, but at the end of the day, we have to listen to what the person wants and help to facilitate that while putting some supports around them.

**Beverley:** And how do you set up a system that allows you to do that? What sort of systems have you put in place to make sure you are really listening?

**Allanah:** Yeah, so we have an individualised planning approach where we work with clients one on one, as soon as we hear of a client who unfortunately sustained an injury and requires TAC support, then we allocate that client to a support coordinator, that support coordinator will then work very early with the client, their families and also the hospital staff to understand what is the clients need and the most important thing there is when it is appropriate is to work with the family first obviously because the client are very unwell, but then to work with the client as closely as we can to actually get their voice and not just hear from the health professionals around the client, but definitely getting the voice of the client.

**Beverley:** So what do you think the NDIS can learn from the TAC in terms of the strength that you’ve had and some of the catch ups that obviously trying to have within the system?

**Allanah:** Yeah, look, I think Scott alluded to some of the things that the NDIS is already attempting to put in place, but I don’t think you can underestimate the power of having someone face-to-face and available to have the conversations to get the voice of the client and not rely on others speaking on behalf of a person who’s sustained an injury or has a disability, I think one of the things that has worked really well for TAC is once we acknowledge that young people in a nursing home is not a suitable solution, it then we created some rigour around a decision, so there are circumstances sometimes when nursing homes, when a family has have requested a nursing home as a transitional option because it is the closest thing to a community or to the home, but it has a rigour around that, so no one within TAC is supported to move in to a nursing home unless it comes through me, so it’s a senior management delegation and that means people work really hard to make sure all alternatives are explored, so that’s really helped, centralising, we also have a centralised accommodation team, so anyone who’s in congregate care is managed in a central team, so those people become very expert in SDA, in accommodation options, in what a nursing home or shared supported living arrangement should look like, ensuring that we’ve got the right supports in at the right time. The other thing I think is the home modification space and I know that NDIS is working on this, but it is a time consuming, very specialist approach and technology is advancing all the time to enable independence, so we need to be at the front of that so we can modify existing homes, but also influenced design for transitional living opportunities or other accommodations.

**Beverley:** Scott, I can see you nodding vigorously, does that make sense to you?

**Scott:** Yeah, absolutely, I think obviously the TAC’s a bit more of a mature system than the National Disability Insurance Scheme at this stage, but there’s certainly a lot to learn from that and we’ve been thinking about some very similar activities that Allanah’s been talking about as well and I don’t know if anyone’s solved the issue of how to expedite and make it doing home modifications as quick as possible, but I think TAC’s got lots to learn from that.

**Beverley:** Right, well, the Aged Care Royal Commission as I mentioned earlier is going to deliver its interim report to the government today, now based on the evidence at its hearing last month in to younger people in aged care, we may able to draw some inference about what the commission is going to say about just how urgent this commission is, let’s take a look.

**Video plays**

**Beverley:** So Iain, coming back to you briefly, how do you think health services are building their capacities to work together with NDIS at this point?

**Iain:** So I’ve led the Peninsula Health Strategy around NDIS and how we build capabilities within our business and some are systems around our process, some are around our workforce and training and developing our workforce, but I think partly it is understanding working very in a shared decision making with a participant or patient, being really quite clear on what their choices are and how we might be able to support those sort of choices and one of the other key elements is actually working very closely with NDIS very early and that’s been one of the challenges of the health service around that greyness between when is it a health care responsibility, a health responsibility versus when to transition across to NDIS and sometimes because for a period of time, they will have a health need as far as a medical need, so potentially acute rehabilitation needs, but when does that person transfer across to the responsibility of NDIS and we’re working with the TAC, because they’re a whole journey, they’re engaged at the very beginning, what some of the challenges we have with the NDIS are engaged later in the journey about a patient and I think if we could have greater engagement around supporting and planning to ensure the plan best meets the individual’s needs because at the moment, up until the plan is approved, all of the activities up to that point is funded and delivered I guess through the health service and health care, so it’s about trying to get NDIS involved early would be really supportive to try and ensure we can meet the choices of those individuals, but it’s also building capabilities within business or within the health service of that shared decision making, and that’s something as a health service, all health services are working very closely to be able to deliver on better person centred care or better engagement with that patient around shared decision making.

**Beverley:** Thanks, Iain. Mary-Lou, back to you, practically, what are organisations like yours doing to stop this process of younger people going in to aged care?

**Mary-Lou:** So health’s working really hard to upskill all our staff and making that we have the right and up to date relevant knowledge about the NDIS, we’re working very closely with other health networks as well to see what are they doing, what’s working, what can we learn from them, it’s really seen us band together to work together with the NDIS, we’ve really welcomed the introduction of the complex support needs pathway, health is very, has high hopes for the introduction of the health liaison officers, we hope to work really closely with these new roles and be able to communicate directly with the NDIS to work through these practical issues that we have on a patient by patient basis to get some good outcomes.

**Beverley:** That’s great to hear and Allanah, the connecting health with other services sounds like that’s a critical part of the puzzle.

**Allanah:** Absolutely, I would say one of the most critical is to get engaged early with whoever the funder is, whether it be NDIS, whether it be TAC, to ensure that the expectation setting is really clear at the beginning so that people understand what’s possible because I think that’s one of the other challenges is sometimes, when you’re in a circumstance, it’s difficult to understand what’s possible and the other really important thing is to stay engaged with the client, the patient or participant to continue to work on goals, even if a solution is a solution for a short time, it doesn’t mean it’s the solution for a long time.

**Beverley:** And Scott, that’s so critical as we’ve just heard from Mary-Lou, the workforce is such a young organisation and we’ve learnt from such a short period of time which perhaps you haven’t got enough credit for along the way, but how do you build that work? How do you build those connections?

**Scott:** Yeah, Mary-Lou’s comments there around the rollout of our health and hospital liaison officers, that’s a new initiative, we’ve trialled this in South Australia, we’re about to deploy five or six in Victoria over the next month or so, we’ll have a network of those liaison people right across the country up and running soon, we’ll then start with the justice system as well, we’ll have a liaison officer at the justice network and as Iain said, this is about us being with the participant or patient in a hospital setting around what’s next. How do we work on discharge? How do we work on rehab in to recovery, all those sorts of things when we’re at the table much earlier than we are and have been in recent times, so we’re really looking forward to that, too, we’re significantly increased the staff in our complex support needs pathway, so their planning are more highly skilled, higher trained, often Allied Health backgrounds, understand their way around the systems, the planners, the specialised planners will be working with young people in residential aged care and also people at risk of entering aged care, but again, this is about us building the NDIS and increasing our workforce, the government, our minister announced just last week an increase in our staff overall, so that’s really important for us.

**Beverley:** And are there people out there for you or is that a factor as well?

**Scott:** Some markets are different than others, we’ve been lucky in places like Victoria and in fact, a lot of the main states and territories around the country where we’ve been able to get good staff existing state and territory government systems, but also we’ve been able to get staff from Allied Health and other places but we certainly as you go in to some other regional areas, the workforce challenges do start to get a bit more acute.

**Beverley:** Well, as we’ve heard today, there have been many enquiries, initiatives, and commitments before aimed at stopping young people going in to aged care, I’ll give you a snapshot.

A Senate committee report back in 2005, a five year COAG initiative that began in 2006 and a further Senate enquiry in 2015 from the Royal Commission which we’ll hear from today.

If we look at those statistics, those initiatives and commitments, they’ve ultimately not been successful.

Now, what is going to make the difference hopefully, the Royal Commission interim report today focuses that attention on the urgency of the problem, so an open question to all four of you on the panel, what is your level of confidence so we can get this problem finally resolved and what timeframe do you think is required to get the job done, Allanah, I’ll start with you?

**Allanah:** Look, I really do think that our ability to prevent people entering residential aged care, we should be able to achieve. I think that we should be able to identify different transitional living options if we’re waiting for home mods or whatever it might be, but I do think we need the support of other government agencies and organisations, housing, community housing options, because that is one of the biggest challenges, homelessness we know is a broad problem across for all people in Australia so I do think that’s something that we should be able to achieve in the timeframe, I think the challenge of the people who are already in nursing homes, I think that we need a united effort, I agree with Scott, understanding the statistics and I don’t mean that to depersonalise it, but the information from NDIS, from TAC, from any organisation that supports people in aged care, it helps provide the information to potential providers out there who are willing to build specialist disability accommodation, so the more information we can give the sector, the more likelihood it is that they will go and build which is really what we need.

**Beverley:** Briefly, Iain, is it going to happen and when by, do you think?

**Iain:** I agree, I think it’s a monetary approach and I think it’s about a number of departments and agencies getting involved to fix this issue and I think we’ve got a greater chance of actually avoiding sort of long term residential admissions for young people, I think that potentially happen earlier rather than later as far as the short term transitional care, but I think the commitment the NDIS is showing and the need is obviously identified with the Royal Commission coming out today, I think there are a lot of external drivers to actually really facilitate this work to happen at a multifactorial approach, so I would hope five years but we would start to see some changes, but it does take time for SDAs to be built and there’s a fair piece of work that needs to happen and it’s not going to happen overnight, unfortunately.

**Beverley:** Okay, and Scott?

**Scott:** Yeah, well, I think Iain and Allanah have answered it really well and from our perspective, of course, we think the NDIS is really different to previous initiatives, as you said, we’re building a scheme, pretty significant, over three hundred thousand people in the scheme already, a hundred thousand people getting supports for the first time in their life, we know we’ve got more work to do, but we think the NDIS is really an important game changer here, but it is multi level, we can provide the funding, provide the supports, get the right plans in place and really need multi level of governance and the accommodation sector to come along with us.

**Beverley:** And Helen, finally to you because we started the conversation with you, you’re our poster girl today, what do you think is the single thing that’s going to make it happen and how confident are you having heard today’s conversations?

**Helen:** I’m incredibly hopeful, yeah, hope is the overriding thing, confidence is a little bit, I think that I can expect something to happen in the next year, I think, and people can assure me, but for the broader issues, I’m really concerned that the goal is only to halve the number of people being admitted to aged care in 2025.

**Scott:** Yeah, 2022 halving and 2025.

**Helen:** Yeah, I don’t understand as such, I don’t understand why that target is given that it’s, I don’t mean it’s easy, I know it’s really hard, but the people who are going to go into aged care and just suffer the same sort of things that people have suffered over the years and I’ve suffered over the last six and a half years, if you can prevent that, you can prevent that deterioration in their social and emotional status and physical status, it would be so much better, it’s, I don’t understand why it’s a zero target, it’s not a zero target, it’s, that would be mine.

**Beverley:** Helen, I think people have heard you today and let’s give her a round of applause. Perhaps the sentiment from today is that there enormous will, there is enormous goodwill that the systems are having to catch up a little bit, there is a lot of positive, let’s hope that the Royal Commission finding don’t become another statistic like we’ve heard of some of those other enquiries we’ve heard about the need today and let’s hope that with confidence and with that vision that this can finally be something that was put behind us, so thank you to all of our wonderful panelists and to all of our audience participants, please thank them again for their contribution. And thanks to all of you as well, let’s hand over to Di.

**Di:** Thank you so much, Beverley and what a terrific and insightful discussion, thank you to our panelists and everyone who participated.

A special thanks to our guest speakers for sharing their experience, their wisdom and hopes for a better future for younger people currently living in or at risk of living in aged care.

We want to encourage you to keep the conversation going. Also, we’ll have a video of today’s forum on our website as soon as possible, but in the meantime, we welcome your comments, your feedback and your suggestions via social media channels and please use the hash tag how long?

Before we wrap up I’d like to remind everyone that the Summer Foundation is hosting its Breaking Down the Barriers seminar in this space at 1.40 today, immediately following our short break for lunch, and on your way in this morning, you would have received a USB card that contains the most recent and up to date NDIS and housing resources that are developed by the Summer Foundation.

The USB also contains our annual report which I’m proud to release today as well as detailed submission to the Aged Care Royal Commission.

You can also view the hard copies of the contents of the USB card by visiting Joy and Helen at the Summer Foundation resource table at the back of the room.

If you haven’t received your USB card yet, please pick one up at the resource table.

You can also keep up to date with the Royal Commission developments as well as our latest resources for discharge professionals on our website and also via social media. So that concludes our annual public forum for 2019 and thank you so much everyone for your interest and your attendance today, so thank you and good afternoon.

**END OF TRANSCRIPT**