Thursday, 12 November 2020

Summer Foundation Annual Forum

BEVERLEY O'CONNOR: Thank you so much. It is an honour to be part of a discussion the Summer Foundation has every year. Such a critical role the Summer Foundation plays in being life‑changing for so many people. Thank you, and welcome to Paul.

Thank you for your patience in bearing with us. I hope you notice we are all beautifully socially distanced and abiding by the rules in these challenging times. I hope you are getting us loud and clear and will be able to enjoy what we bring you today. As Paul mentioned, it's really a focus about finding our way home - navigating to specialist disability accommodation. We're going to call it SDA ‑ that is what you know and that is how we will refer to it in our conversation today.

We will hear from people with disability about how absolutely life‑changing SDA can be and talk through what has been done to make it a reality for many more. So, to kick off this conversation we're going to take a look at a short piece which goes to the very heart of the key themes that we'll be exploring today, let's take a look.

(Video)

Lisa has been living in aged care for 6 years. Her story was heard during the Aged Care Royal Commission.   
LISA: “My number one goal is the get the f\*\*\* out of the nursing home.” Lisa is now enjoying life in SDA. People with disability have more choice about where they live than ever before. With the NDIS, many have successfully navigated the journey to Specialist Disability Accommodation or SDA and are living happier more independent lives. There are, however, many more that are not aware that SDA is an option. Other people have experienced difficulties along their journey to SDA.   
SAM: “We all have a human right to a life and that life is living in the place you need to reach your full you.” Today, we’ll celebrate just how life changing SDA can be for people with disability and discuss what changes are in play to make SDA a reality for many more.

LIZ: “It’s nice that the dream is not a dream anymore, it’s a reality. It’s about living now.”

BEVERLEY O'CONNOR: Yes, completely transformational that has been for many people. I would now like to welcome Liz Ellis, who lives in an SDA apartment in Melbourne. Liz, lovely to meet you. Thank you for joining us.

LIZ ELLIS: Thanks. Nice to join you too.

BEVERLEY O'CONNOR: You have been living in SDA for more than a year now. Let's take a look at how you were feeling when you just moved in to the SDA.

(Video)

LIZ ELLIS: “I moved into my new apartment a month ago and it's exciting and the first time I live on my own and it's very, very cool. I was in shared supported accommodation for 6 years with people that were aged in their 50s and 60s and it just wasn't the right model or the right setup for me. Over the years I have yearned for something different and I have hoped it would come.

With the apartment, it's all back in my control. Coming here is the best balance between needing help but being independent as I could possibly get. It's a home instead of someone's workplace. I love living in this area because I love the landscape. It's got everything at your fingertips when you walk out of the apartment and it's got so many cafes, it's amazing. I feel relieved to have a place of my own. There's a massive sense of accomplishment. It feels to me like I've broken a glass ceiling. To know we've got a system with the NDIS and in conjunction with other organisations to make things like this happen, it's just so special.”

BEVERLEY O'CONNOR: Now, unfortunately, it seems as if we may have a few technical difficulties chatting to Liz. She's frozen on Zoom ‑ a common theme you have all experienced in the last 9 months and it happens to us every day ‑ but we had asked Liz what life is like at the moment because of the current COVID restrictions and limitations and how she was feeling being in her home.

Let's have a listen.

(Video)

LIZ: “One year on, living in my apartment as I reflect back, I've managed to change service providers, in the pandemic, which was an achievement in itself.

I have changed my employment, I have enrolled in study, which is proving quite challenging to complete.  I'm also looking a bit more after my health this year and what that looks like for me into the future and I get to do it from the comfort of my very own apartment. I've been, felt very appreciative and fortunate to have my apartment given the restrictions and the lock down that we faced and that I had my own private space to do that in.”

BEVERLEY O'CONNOR: In so many ways it's been perfect timing for Liz. Jono was going to be here but his reason for not being here is a joyous one, he moved into SDA yesterday, good news. Clearly, he has unpacking to do and things on the agenda but he was able to share his story with us via video a little while ago. So, let's take a look.

(Video)

JONATHAN BREDIN: “My name is Jonathan Bredin, but I prefer to be called Jono.

Even though I have cerebral palsy, my family never treated me differently.

This made me have the same goals and aspirations as most people.

As a result, I moved out of home, 3 days after I turned 26, into an independent unit.

My passion is assisting people with disability to take control of their own lives.

In my personal life, I have a wide variety of interests, such as, computers, cooking from nothing, and watching sport.

I love making curried sausages, I put the recipe together myself.

I'm sorry that I couldn't be here today, as I was really looking forward to it.

However, I am happy to say that when you see this video I will have just moved in to my new apartment yesterday!”

BEVERLEY O'CONNOR: As you can see Jono has been living for quite a while on his own independently but just moving into that SDA yesterday. Let's get a sense from Jono why he wanted to move into an SDA himself.

(Video)

JONATHAN BREDIN: “I have always dreamt of moving to the city, but I thought it was never going to be a reality because even 3 years ago it was impossible.

But with the NDIS implementing Specialist Disability Accommodation, SDA housing developers are now building accessible accommodation in the city.

My dream of living in the big smoke just became a reality.

A few years ago, my good friend Stuart who was the same age as my mother, passed away.  I was still living at home and my mother was my primary carer.  This got me thinking about what I would do if something happened to her.  I didn’t have the structure to live without her so I decided that it was time for me to move out.  As well as this, I was starting to struggle with privacy & independence.

 4 years ago I moved into a complex of 6 separate units, which have 24hr support workers.  I require assistance for daily living so having access to these workers is critical for me.  This living arrangement meant that I could have my privacy & freedom.  It was a great 1st step.

Around March last year I began feeling like I needed more out of my housing situation and started to think about moving somewhere that was more suited to my needs.

I told my support worker what I wanted. Then he asked me a question I didn’t know the answer to.  He asked me what my dream home would look like?

So, we sat down and we nutted out what I was actually looking for in a new place.

I wasn’t even looking at the city because I still thought it was impossible.

Now that I have a clear vision of what I wanted I needed to find the right people to make it happen

Before Covid, I needed to be in the city for one reason or another and while there I would at times, impulsively decide to see a sporting match.  I can’t wait to be more spontaneous now that I live in the city.”

BEVERLEY O'CONNOR: Just wonderful reasons to hear there from Jono as to why he wanted to move into an SDA.

I'd like to now welcome Gerrie Mitra, who is the general manager, provider and markets at the National Disability Insurance Agency which, of course, administers the NDIS.

Welcome Gerrie, and thank you for joining us. As we just heard from Liz and Jono, SDA can be life changing. Can you give us a sense of an overview of what SDA is all about and the positive impacts it can have?

GERRIE MITRA: Sure. Thanks Bev. It is a relatively new support started in July 2016 and it has, just as we just heard from the 2 stories we just heard it is about providing a different pathway and opportunity for people with extreme functional impairment or high support needs to give them a different option for their housing needs and their supports.

For those who are eligible, it is quite a life‑changing and different way of being able to live, which is really exciting and really positive. It's not ‑ SDA itself is not about the supports that are provided in a house. So, we fund those separately and differently. SDA itself is also not an answer to homelessness or lack of housing availability. It is a very specific support that says that the building and the way it's configured and the physical build allows the person to live in such a way that they can meet their goals better and their outcomes, combined with all the other supports available in their lives. It's a new support, I think it's a very exciting thing and it was possible because of the NDIS and the introduction of the NDIS.

BEVERLEY O'CONNOR: Yes. I was going to ask about the background as to why they felt it needed ‑ this type of housing needed to evolve to this point?

GERRIE MITRA: For those participants who are going to be eligible, they are the people with very high support needs or extreme functional impairment. Really, this was a transition from the old system in states and territories and the accommodation there often wasn't purpose‑built and fit for purpose for this small cohort of people, we estimate 6% of NDIS participants, we have more than 400,000 people in this scheme. So it's not for everybody, but for those who have very high needs it is a good option and a great solution.

BEVERLEY O'CONNOR: Liz, I'm going to come back to you now. I hope you are back and unfrozen. As we saw earlier you are living in a beautiful apartment in Melbourne and look so happy to be there. But the journey wasn't completely smooth along the way. Give us a sense of the challenges you have been facing in that transition?

LIZ ELLIS: No. Thanks. It wasn't all smooth sailing. At the time when I was applying for the SDA, the SDA plan, in the NDIS plan, it wasn't a simple and clear pathway and it required to have the certificate of occupancy. It was a frustrating, challenging time, not knowing whether you had a secure ‑ the housing secured to move into.

BEVERLEY O'CONNOR: Did you find it very bureaucratic?

LIZ ELLIS: Yes, absolutely. It reminded me ‑ I like to go out to music a lot and there's a song that was regularly played called Stuck In The Middle With You and it reminded me of a tug-of-war and there was the NDIA and the SDA provider and I remember having a bad day and I heard this song and I cracked up laughing.

BEVERLEY O'CONNOR: It sounds like you found good coping mechanisms through music. But, I guess, is your message to be persistent? What do you think could improve?

LIZ ELLIS: I believe now the legislation has changed in that you do need to be persistent, but the legislation has changed in that you can apply for your relevant SDA category payments before a dwelling is registered as an SDA provider, which is different to when I went through it. If that is the case, it should help people moving forward to not have the same political issues and restrictions that I had in trying to move in. But, yes, you do have to be persistent and determined and know what you want.

BEVERLEY O'CONNOR: And have a little faith, if I can quote another song!

LIZ ELLIS: Absolutely.

BEVERLEY O'CONNOR: Great to talk to you. We will be back to talk with you as we progress. But let's hear from Jono again.

(video)

JONATHAN BREDIN: “In May of last year, I talked with the Tenancy Matching Service team to tell them what I wanted and to help me find a place that was suitable.  I told them I wanted complete control of my support workers.  They asked me where I wanted to live.  I said the city, but I thought there was no way.  This is when they told me about a new apartment building that was being built on Docklands that was exactly what I was after.  I couldn’t believe it.

The Tenancy Matching Service team helped me with filling in the application for the Docklands and Southbank apartments and gave me some advice on SDA.

I then started the process to get all the necessary paperwork ready for my SDA application.  It took a while to get everything together but in September I submitted my application to the NDIS to get SDA in my plan.

I knew SDA would be a critical part of my next house move so I started the process before I was even offered a house.  In December, whilst I was out Christmas shopping I received a phone call informing me that I had received a conditional offer for Docklands.  Subject to getting SDA.

I was already confident I had met the eligibility criteria to receive SDA,

However, you need to keep on top of the NDIA case with the progress of your assessment.  Mine took 9 months and it was with me checking in with them weekly.”

BEVERLEY O'CONNOR: A similar story to Liz in a way that you need to be persistent to check in regularly and to have SDA as part of your NDIS plan.

Well, let's welcome our first guest with me in the studios here. And it is Toni Rowe, who is a support coordinator with Disability Collaborative. Toni, welcome to you. Thank you for joining us.

No doubt you are in touch with people with disability on a regular basis that are facing big hurdles as we heard from Jono and Liz, that ultimately are trying to navigate the NDIS and move into more independent lives. What do you see as the key role of a support coordinator?

TONI ROWE: Look, I think it's about helping people with complex disability to imagine what's possible. And like both Liz and Jono were talking about, a lot of people just don't think it's possible. So, I think that we all have a role, anyone working in the NDIS space, has a real responsibility to educate themselves as providers about what's possible and it's not just one model, really understanding the SDA model and giving some thought to the support needs as well. I know they are currently broken into 2 very different categories, when funded by the NDIA. But you really need to get your head around that before pursuing a particular type of SDA for a client. So, yeah.

BEVERLEY O'CONNOR: In terms of what you can offer or how to navigate the system, what do you think the best way forward is?

TONI ROWE: All I can talk about is the way I approach it. You'll see, I think you've heard from Lisa earlier and I actually was involved with Lisa, I met her when she was at the nursing home. And that's a really good example. Because I think there's an opportunity for particularly the NDIA to slow things down a little bit with these really complex people who will be eligible, as we said, 6% of ‑ a very small portion, really ‑ but to really tap in to people's experiences every time someone moves in. Because I think from doing that and taking a bit more time to understand all the barriers and the stresses, I consider in this market that people like Liz and Jono are early adopters. They are the ones, and Lisa ‑ they have got the courage, they're going into this new frontier, they don't fully understand when they're doing it exactly what they're going to be facing but they have got the courage to go out there and give it a go. And I say to my clients that are on that journey, that you are paving the way for other people. And...

BEVERLEY O'CONNOR: What would be benefitted by slowing the process down a little bit? What could happen? What could change?

TONI ROWE: Really understanding how much time and therefore NDIS money is wasted having to get through the bureaucratic processes. And there really are some great planners at the NDIA working in these specialist teams. But I get the sense, and I think it's actually unfortunately, the pressure has got more intense over the past couple of months. If we don't slow it down and take the time to really connect with people with disability about their experiences, I think we run the risk of, yeah, leading it down, you know, where we've been in the past and for me, NDIS is something different. And it is a new opportunity to create a different future.

BEVERLEY O'CONNOR: And not to be wasted as well. Because you do see that concern that perhaps it will be wasted?

TONI ROWE: Yes. And I know there are constraints with financial considerations and the NDIS, but we don't want to be wasting funding. But we've also got to be realistic and each individual is going to be different. They're not necessarily going to fit neatly into the tick‑box approach, especially when first transitioning, like the people on the panel today have already shared via video link, you know, it takes time. You can't just pull someone out of a nursing home where they had absolutely no choice and control, they are institutionalised, we can't whip them out and go, "Off you go". There needs to be a bit more flexibility during that transition period. And we need to appreciate that a lot of people, not all, but a lot of people with disability have got trauma in their background because of their experience. And that risk, and that looming elephant in the room of one day I could end up in a nursing home if my mum passes away, if I... you know.

BEVERLEY O'CONNOR: It is big, is what you are saying. Toni, appreciate that. That is insightful.

Now going to move to Ben Gauntlett, the Disability Discrimination Commissioner. Thank you for making time for us. I know you are very passionate about making sure people with disability have choice and control for where they live and how they would like to live. Essentially though this is something we have to see as an absolute human right, don't we?

BEN GAUNTLETT: Yes. We all have a right to live a meaningful life. No matter what our background, no matter our level of ability, no matter what our race, our gender, no matter what our ethnicity or our sexual orientation. We all have a right to live a meaningful life. What SDA does for people with disability in the community is it enables them to live that meaningful life where their personal wishes are respected. But for SDA to work, there is a very difficult balancing act which must be effective from a policy stand point. First, the built environment. It has to be appropriate for that particular individual. And then within that built environment, the electronic environment must be appropriate for that particular individual. And finally, the communication environment that exists for that individual, again, must be appropriately set up.

And at the same time, there must be a workforce at that particular location, at that particular time, with the necessary skills and availability to ensure that an individual can live a meaningful life. So, in saying that we ‑ it is a human rights issue, it absolutely is, but the issue is how do we solve the problem? The problem is we need to work with people with disability to understand their needs, to support them to make decisions with all the information in front of them and then have the market adapt quickly to resolve those issues. And what we need to do is we need to very much open up a discussion to have clear data and information being made available but then also discussions of how can we improve? And those discussions must be forthright but respectful. Ultimately, we are dealing with people. People who have the right to a meaningful life.

BEVERLEY O'CONNOR: Yes, Ben, that really sets the boundaries really, really well. We thank you for that. I'm going to come back to one of our panellists here in the studio with me. We certainly will come back to you, Ben, during our discussion.

Justin Nix is the CEO of Guardian Living who is developing new SDA apartments in various locations. Justin, welcome. Thank you very much for joining us. I understand you have been involved in the space since the very early days of SDA?

JUSTIN NIX: Yes. It is so important for us as a sector. It is a very market‑driven approach. It's so important and now so more than ever that we need to listen to the voice of people with disabilities to understand their journey. And we need to learn from that journey. And I'll give you some good examples.

We continue to engage with who we think may move into our SDA dwellings and they're not always the people who do. But once a person does transition it's really important that we receive that feedback which then influences future design. And a good example of that is an accessible bathroom is a very personal space for a person with high support needs. So, by getting feedback like, "I love living here but if I have a mate or my mum comes over I prefer to have a second bathroom", that's the information and feedback that is going to drive the market and inspire innovation and keep us on our toes.

BEVERLEY O'CONNOR: Are you having those conversations? Do you feel, as a housing provider, there is enough of a flow of information between the people like we've seen like Liz, Jono and yourselves?

JUSTIN NIX: That's challenging. It's really important that processes are streamlined as much as possible so that ‑ when I talk about "processes", SDA approvals are not just about the SDA approval itself. We're talking about the supports that people, the tenants will need living in that environment, assistive technology that they need. It's really important that we have streamlined and efficient processes and decision‑making which enable us to plan and transition people smoother into the accommodation.

BEVERLEY O'CONNOR: OK. Let's welcome Alecia Rathbone, the general manager of the Summer Foundation Housing Hub social enterprise. Lovely to have you with us. In your role you have been exposed to the provider experience that we have heard from Justin and the people with disability. What do you feel some of the key challenges are across the area?

ALECIA RATHBONE: Absolutely. There are 2 main ones that I would touch on. The first is around the people with disability and their housing needs and preferences. We hear a lot of people talk about the data that we need for demand data in the market and it has been great recently we have seen some data come out as a first step from the NDIA. But what we want to see is many more people with disability having the opportunity to find out about SDA and then say what their needs and preferences are.

So, like you were just saying, Justin, how can we understand those at a broader scale and then we provide that information, in a deidentified way, to the market, so people with disability can start informing what is developed so that is a next step we think is really important, so that people with disabilities' voice is really represented.

The other thing I would mention is around the number of people with SDA in their plan. Like I mentioned before, it is great to see data from the NDIA - the last data set in September showed there is 15,000 people so far with funding in their plan. That is excellent and a good way forward towards the estimated 28,000 people that Gerrie mentioned before. However, we want to try to find the other 13,000 people as soon as we can. Thinking about ways we can help people to see what's possible. Looking at what Lisa and Jono and Liz have done, how can we get other people to see that, imagine what's possible and then take that way forward to explore SDA and start to realise the vision of SDA?

BEVERLEY O'CONNOR: The 3 of you sitting with me here, how do you think that is going to happen and be possible?

JUSTIN NIX: If I can spend, from a market point of view, the one thing we need to do for a healthy SDA market where participants do have choice and control is we need to deploy capital into the market to build the infrastructure. The best way we can do that is by clear and consistent policy from government and the agency and we also need to understand supply and demand.

So, Alecia was saying, one thing we crave, for us, it's a sector that is full of risk from an investment point of view. What the government is asking us to do is to buy land, borrow money, build and develop to fulfil what has, until recently been, a hypothetical demand. We need to understand what that actual demand is. Of the 15,000 people that have SDA in their plan at the moment, what is the demand and the preference for the 15,000 people? We've got a lot of people living in existing stock SDA or really old poor quality shared housing. We need to understand where that demand exists so that we can respond accordingly.

BEVERLEY O'CONNOR: Gerrie, I think this would be a perfect time to come back to you to get a sense of how do you think the process can be improved for people looking to access SDA and to get this better communication between the providers and those that need it?

GERRIE MITRA: Yes, thanks. And it's a good discussion because it highlights the different perspectives and therefore the challenges as we continue to both develop and stabilise and implement the policy that we've got in this area.

So, Justin is right in the sense we have recently released a lot more data, right down to a more granular level. It was SA4 and is now SA3 which means it is easier to see people who have SDA in their plan and still looking for an opportunity. That allows investors and developers to come in and start to pay for and build new properties, which is fantastic. I think also, it's really interesting to listen to the conversation because sometimes we get asked to slow down, we heard that on the panel, and sometimes speed up and the decision takes too long. And it is a complex process. The thing we have done most recently and we will be settling in the last couple of months is to bring together more parts of the agency who make those decisions.

There are 4 or 5 different steps we need to go through and we are bringing them together in one team to try to improve and streamline some of the decision‑making points to make it simpler and easier. There is more work we can do on where we think the next lot of demand will come and we'll continue to work on that with various people, including obviously people with disability themselves. What is lovely today is to hear the experiences and stories and reflect on how we feed that to developers so they can take that into account as they're doing their building and their design.

BEVERLEY O'CONNOR: Gerrie, I have to ask, at a time like this with COVID having uprooted so many other systems, has that interfered with streamlining the services more, or have you been able to continue pretty much unaffected?

GERRIE MITRA: The NDIS has done remarkably well in actually pivoting, if you like, the services, for people who are in the scheme, to make sure that they can still access the scheme. Done a lot of things like using technology to still connect with people. It was great to hear of Jono moving in, still, now. Obviously, there's been more restrictions in Victoria but we have done a remarkable job of continuing service delivery so people are able to access their supports. In some cases, the supports have changed. But I think, I don't think that's slowed us down from the SDA perspective. I do think, though, it is causing us to have another good look and think about everything we do and how we do it and best meet the needs of people with disability and have the choices to access the supports they need. It is important process.

BEVERLEY O'CONNOR: I'm also interested in that legislative kind of security that Justin was talking about. I mean, has ‑ there has been so many other priorities that the federal government had to take on board. Has that been sidelined, or do they need to be made aware of what is needed?

GERRIE MITRA: Justin was referring to policy settings and we are also working on policy settings. We have a really strong and robust process of consulting with people, so we do have a reference group of people who come together. We are just doing another core of expressions of interest for people to come on to the reference group. So we work closely with the sector and it includes participants in the scheme and advocates of participants in the scheme and investors as well. We work very closely to consult to make sure we've got our policy settings right. I don't think those things have slowed down.

BEVERLEY O'CONNOR: Good to hear. Let's look at the solutions we need to focus on and would like to come back to, we are connecting the dots every day. In your minds are the people with disability being properly connected to the providers?

ALECIA RATHBONE: It is vital and at the core of what needs to happen, and great to hear Justin talking about that. Our view, and actively with the Housing Hub, we are launching a platform that is co-designed by and for people with disability and we are calling on people with disability to start using that and sharing their needs and it can be done through the platform and resources on the website. We want to support people with disability to believe that it is possible. But, like Toni said, to go through the journey together and actually say what is it you want, start imagining all of the things and actually write it down and say that's where I want to go and start from that point.

Part of that work that needs to be done to be able to do that is capacity building for people with disability. Like you mentioned, Toni, a lot of people have lived in different settings that haven't meant they can be independent and people might not realise what is out there and what is possible. I think a big piece of that work is reaching as many people as we can to provide that opportunity to learn about lots of housing options and sit back and say what do I want to do? Write it down, have a conversation with their planner and their support coordinator and start to put it into action, and that is important as the first step.

And then the part of not only doing the capacity building and providing the tools and resources, but if people do want to share their data with us we can work with providers and the market and put it out to make sure people with disability are driving what is developed.

BEVERLEY O'CONNOR: Is that resonating with you?

JUSTIN NIX: Absolutely. One thing we crave is data. We want to understand what people want and need in housing. We should never assume we know and understand always what people want and need in accessible housing. Certainly, data, absolutely.

And Alecia mentioned capacity building. This is important not just for people with disabilities but for the workforce as well in supporting people with disabilities to make these decisions around choice and control. If I reflect on some of our tenants moving from shared supportive accommodation or residential aged care into independent living models, whether they be apartments or units, some people have absolutely thrived in that new environment and been connected to community, while others, they have found out it's not for them. There's a sense of loneliness. It's really important we empower people with disabilities to understand what choice and control is and capacity building is a big part of that.

BEVERLEY O'CONNOR: Very interesting.

TONI ROWE: I'm wondering if I can ask a question?

BEVERLEY O'CONNOR: Go for it.

TONI ROWE: When you say people have found it's not for them, do you have a sense if there were other opportunities for capacity building and better quality supports that could have connected them to community? Because that's the thing. Housing is the foundation for people to self‑actualise and that takes time. But what I notice is that social dissection and the opportunity in SDA to transition out of these previous models into there and how important for things like deinstitutionalisation to really connect the person to the community so they have the sense...

BEVERLEY O'CONNOR: Without the loneliness?

TONI ROWE: Yes.

JUSTIN NIX: I agree, and there is gap in the market for people experiencing other forms of housing and support, whether it is medium term accommodation. But in transitioning from shared living arrangements in very institutionalised settings, what does living independently for me look like? It is an issue for all of us whether we have a disability or not. For some people, the opportunity to try different living environments and housing and support models is a really important part of that decision‑making and process.

TONI ROWE: That's what I look forward to, when we have a market where people are looking at SDA, like, for me, if I wanted to go and rent a house, I look and walk in.

BEVERLEY O'CONNOR: And be aware what you're getting yourself into.

TONI ROWE: And experience it. Because people can't experience it, even providers, when I raise, have you thought about SDA and a catastrophic high risk living for a person and SDA and they go, no, no, no because they are the experience of group homes.

BEVERLEY O'CONNOR: Liz, is that resonating with you as you listen to this? What do you think would have improved your experience?

LIZ ELLIS: It certainly is, thanks. There's roadblocks but I think in light of the conversation that's been had I think it's important that people not let other people's views of them living independently negatively impact their experience of trying to do so. That is a key to it as well. I know for myself before I moved out of traditional group housing, it was the only option. I had a support worker eyeball me and say, "Do you really think you can live independently?" And I said, "Sure, but with the right supports". Because people, if they don't know and they're naive and they live in the old sector thinking, they're not going to realise that people have potential and traditional models take that potential away. It took me 8 weeks living back in my own home. It is the different models and not the traditional model of SDA which is the one people often think about. And that's, I get to do my own things now, it is a passion and I love it and I get to show it to people in my week now.

BEVERLEY O'CONNOR: Having that sort of communication, would that have made a difference from the beginning or the early stages of your process?

LIZ ELLIS: Yes, I have been on the Housing Hub and I think it is fantastic. I think it's got great potential. I think it helps people to see, visualise, there's something at the end of the tunnel. I know for me, like Justin was mentioning, it is elusive until you're there and it gives people a visual before you're there. I agree it would be nice to get to a market where you can see an apartment or whatever dwelling it is before you have the funding in place.

BEVERLEY O'CONNOR: That's terrific. Toni, I'm thinking back to your facial expression when you mention SDA and talk to people about this. Why is there this lack of awareness? What needs to be done to increase the awareness of SDA as an option?

TONI ROWE: Look, I don't know a straightforward answer to that, honestly. I think that probably it starts with anyone working in the NDIS. If you're taking home income from working in NDIS, I have a personal belief that you have an obligation to keep yourself as best informed about the opportunities and the differences in NDIS and it's, look, again, it's appreciating that everyone has an individual journey. I can think of one participant of the scheme and this is another interesting thing, we've got this forecast, a nominal figure of who will be eligible and the numbers. I challenge those numbers.

BEVERLEY O'CONNOR: Do you think they are higher?

TONI ROWE: Yes. And, again, the high physical supports. We were talking about them. It's not there to fill gaps for housing affordability and all these other really big issues that we've got across the country at the moment. But even for those people who do fall into high and extreme physical supports categories, there are a lot out there and they're just not visible. Those are people I connect with and have touch points with and I talk to and explore and show them videos online of the properties and sometimes it takes people a while to come, you know, I had one of those clients who was at risk of going to aged care, got discharged from a big hospital about 12 months ago, categorically was not going to do it. Went home, terrible home, not accessible in the slightest! And she just called me the other day and said, "You know what? I'm ready. Let's go".

BEVERLEY O'CONNOR: Opening their thinking. Slowly taking them on the journey.

TONI ROWE: It has to work with people. My job is not to tell people what to do but to explore options and their journey and their history and life and what they want and what is their appetite for taking a risk and support them.

BEVERLEY O'CONNOR: The numbers, what is your assessments of the numbers at NDIA? What are your thoughts?

TONI ROWE: How many minutes have I got?

BEVERLEY O'CONNOR: As succinctly as possible.

TONI ROWE: If I speak for my experience, this year, I have found there have been improvements. I am seeing improvements in processes but I wonder from an external perspective if there's enough done to educate planners within the agency and I'm still seeing issues with really complex clients being not streamed correctly and still getting their plans done by a local area coordinator, which is an outside contractor meant to be for less complex people.

I was excited and we had a change earlier in the year where senior planners could put forward the SDA application, and that's a cost saving. I don't have to spend 15 hours writing up a really complex report that we're talking about that usually goes to the SDA Panel. And I thought, we'll try this out and it was disastrous. It was absolutely disastrous. I guess what I think is that, again, by bringing down some of the bureaucracy, whenever you can, we are going to have a more cost effective scheme and it is going to be a lot less stressful for people in really bad situations. And unfortunately, there are people right now that are not in good housing situations and really at risk. And I don't think we're being quick enough with that.

BEVERLEY O'CONNOR: Alright, Ben, let me come back to you. Of course, with human rights central to this. How do you think, what do you think the importance is of ensuring people with disability are front and centre when it comes to policy decisions are made like this?

BEN GAUNTLETT: I think it's critical that when we make policy concerning disability in Australia we make policy with people WITH disability, not FOR people with disability. That is that the policy framework and the questions that are asked are informed by the lived experience of people with disability, so that issues such as the right to fail, the right to take a risky decision, the right to ask for something to live in a way that you hadn't thought possible, are all respected. To do that, we have to make sure when we look at a person with a disability they are to be viewed as people, not as a charity object, but as a person who can contribute to the discussion. With SDA, one of the great challenges in this, if you don't ‑ if you ask for specialist disability accommodation and you don't get it, what do you get? What happens to the seventh per centile? It's a bit like with the NDIS itself, designed for 10% of people with disability in Australia. What happens to the 11th percentile that doesn't get on the NDIS?

These questions require us to be really sort of policy, structure driven and disciplined and to approach this as we would the most nuanced policy debate regarding taxation or the building of infrastructure. Because the National Disability Insurance Scheme is built upon the national disability strategy and we need to be really disciplined that when we look at disability policy, we ask questions of people with disability to inform the debate to create solutions with people with disabilities.

BEVERLEY O'CONNOR: Very solid advice there. Gerrie, let me come back to you. Can you share any plans that you have for trying to ensure a smoother journey for people into SDA?

GERRIE MITRA: Yes. Look, I think I'll just bounce off what Ben just talked about. A good opportunity. We are definitely thinking more about and doing more about what are the housing needs of a broader set of people and participants? And therefore, it isn't so much about can I get SDA or not get SDA but what other supports are available in this scheme. We are currently just about to pilot another ‑ look at something we are calling independent living options, which is that more flexible, broader, you can live with different people in different ways rather than just in a group home. A model that's very popular in WA and we have been kind of working through.

So again, what we are looking to do in the future is have much more of a choice and a suite of housing options and pathways. We do a lot around complex modifications and home modifications and removing barriers to live with family members and Ben's comment about where the broader scheme goes to is what I'm excited about. The question is not can I go down one pathway, but as Toni said exploring people's needs, options and choices. And that's where we're headed to in the future. There are many bureaucratic challenges, of course, because these are complex decisions and we need to get them right for individuals and we focus on individuals and choices, but getting a good sense of consistency and equity and a good support for people as they make decisions.

BEVERLEY O'CONNOR: Thank you very much. Of course, we've heard a lot today during our session as we are sort of getting to the end of it about how beneficial SDA can be. Jono has been working with people with disability for a number of years sharing his knowledge. Now, in the next little piece we are going to see, he shares his advice to others who may be feeling overwhelmed or unsure about the process of applying for SDA. Let's take a look.

Liz, let's come back to you, of course, because you've been the star of the show here today as well just telling us about your experience. What, again, do you think is your major takeout from what you've learned along the way?

LIZ ELLIS: I think I agree with Jono. People need to be aware it's a lengthy process and it would be nice if it was shorter and nice to prove you didn't have to prove to try every other option before applying for SDA. I also would say to people, enjoy the experience. Move with your essentials but don't worry about everything because it will all come together in the end. Don't move on Christmas/New Year... put all your supports in place properly. It was hectic. There's agencies going into caretaker mode and that was the time, but that's just a little bit of friendly advice. But just enjoy it. Once you get past all the obstacles and you put the wins on the board, just enjoy it and go with ‑ I found you got to go with it for a little while to find your feet and find your voice and yourself again.

BEVERLEY O'CONNOR: That is terrific advice. Thanks, Liz, for being such a central part of our conversation today. We're going continue, of course because we have been looking at getting your questions throughout the forum, as we have been going through this past hour, getting your ideas to what you would like to hear from our panellists.

We are going to take a short break in a little while and we're going to compile all those questions and come back and hopefully answer that with our ‑ the colleagues we have got here today and some of the decision‑makers who are going to make the journey to SDA a lot smoother for more people. Get your questions in straight away now. And I should remind you that links to resources and information about the steps you can take to start the journey to SDA will be available on the screen during the short intermission. So, take advantage of that. Get down all the information you need to know and then we can all assist you in making that journey. So, stay with us. We're going to take a short break and back shortly.

(Short break)

Welcome back, everybody. I hope we're back. Are we back? Yes, we are back. Lovely to have you rejoin us. Thanks to Lisa Corcoran for sharing her story during that short break as well. We are going to move on to our question and answer session now with our panellists and I am going to go first up to Ben around issues, Ben, of a question coming in on choice and control. What if your adult child has high physical disability but also has an ID and mental health and is not able to express their needs around housing? Are their parents able to express what housing is appropriate, do you think?

BEN GAUNTLETT: Perhaps I can give you 2 answers to this. The first aspect of the answer is probably what is the legal position. The second answer is what is the position we want to get to. The legal position is if a person is unable to make the decision for themselves, someone in Australia, or their parents is able to make a decision on their behalf provided certain criteria is met and you expect that to be in the best interests of the child, but ideally they would support the child to make the decision themselves. That is, they would give the child the information to enable them to hopefully, to the fullest extent possible, describe their needs and workshop what some of those needs are. Have that debate what would or would not work. Now, at a human rights level, what we want to get to a position is that to the fullest extent possible? People with disability in Australia are always supported to make decisions for themselves rather than having someone substitute their decision for them. Again, it's the issue we want to work with people with disability to make the decisions. On a practical basis, not for people with disability. The answer is that they will definitely have a role. The role we want them to take is support, not substitution.

BEVERLEY O'CONNOR: Thank you. A question for you, Liz. What recommendations on how to support someone who is in need of SDA but perhaps is a little bit ambivalent about it and a bit uncertain. What do you think would help? If somebody is trying to support a person into SDA?

LIZ ELLIS: I really feel that you need to take the time with people and unpack what those reasons are and I often find with people a little bit of informal conversation with someone like myself that's, you know, been there, done that and everyone's had different life experiences. It helps people to be a bit reassured to hear it from other people that are like them rather than other people telling them what they think they should feel. But I do think at the very start, we need to unpack what the reasons are so that we can then address those issues right from the beginning.

BEVERLEY O'CONNOR: Yes, understand why there is that reluctance. Gerrie, I would like to come to you. The question is around timeframes. Timeframes are excessive at times often with people left waiting in inappropriate settings, for example, nursing homes and hospital settings. We know the stories around that. What can be done around those timeframes in terms of assessing people to be eligible for SDA?

GERRIE MITRA: One thing is we would encourage people to start having conversations about their housing goals and needs as early as possible, with planners, with family, with loved ones and friends. Housing decisions are not made quickly. The more thinking and work that has been done over a period of time so when they come to the point of applying and working through that process things will move more quickly. But in answer to the question specifically, it is important to know that we do prioritise, if you like, put to the front of the queue, people who are in hospitals or nursing homes because of the level of risk. And in fact, our experience in COVID helped us to fine tune that process. Many people who were sitting in hospital we needed to move out quickly. So we really were able to kind of improve and speed up our timeframes for them. I think perhaps just useful for people to understand that that is the priority for us, absolutely, at this point in time.

BEVERLEY O'CONNOR: That is really comforting to hear. Alecia, how do we get in touch with a tenancy matching service to match the participants to the places?

ALECIA RATHBONE: It is a common problem because we don't know who the 28,000 people, and there is detail on the screen, through the Summer Foundation or the Housing Hub and the team is happy to help get in touch with providers.

BEVERLEY O'CONNOR: They have high needs properties in Sydney but that is different from market to market.

ALECIA RATHBONE: Yes, the markets have different levels of supply and demand and I think about the 2 sides of the market and we need to think about the market and other people looking for that sort of property and we can have that conversation and work out who can connect.

BEVERLEY O'CONNOR: Why are 2-bedroom apartments so hard to get? And give us examples where participants have been approved for 2 bedrooms? And, what is the second bedroom used for?

JUSTIN NIX: Real estate can be very expensive, is the short answer. Larger apartments, if we're looking at apartments in particular to incorporate a second bedroom, are very expensive. It's important to understand SDA funding is attached to the participant and they pay the same reasonable rent contribution no matter where they live, SDA or a different location.

As an SDA provider the one thing we are trying to do to ensure continuity of the funding to mitigate vacancy risk. The best way we can mitigate vacancy risk is have housing options that are close to shopping centres and public transport and the amenity of the built environment is a big part of that. Having a second bedroom is important because people will start to vote with their feet once there is adequate supply, and true choice and control. So what we've experienced is people with very high support needs, obviously, have a lot of equipment that they need to store in an apartment, a second bedroom is very helpful for that. A lot of people just really want that second bedroom to have Mum or Dad come over occasionally or a friend stay over and some of those people provide gratuitous support to SDA participants, which is important to acknowledge.

From a funding point of view, I'd say that SDA 2-bedroom apartment approvals are very difficult to justify and source. So, we look at it from an amenity point of view. We always try and develop 2-bedroom apartments but sometimes you're faced with a situation where the feasibility of developing that SDA is just not possible because of that second bedroom so you may sacrifice that to deliver an inner city SDA option.

BEVERLEY O'CONNOR: Terrific. That makes sense. Toni, when collating evidence for an application, should they cover options such as fully accessible, but provide the panel with options such as an apartment or 2 or 3-bedroom house or is it better to pinpoint one option only? Essentially, what will get timely and suitable results?

TONI ROWE: Look, I ‑ that's... um, I think the answer to that question isn't a direct answer to that question and it really starts with the participant, the individual. Again, the work I do and the way I approach it when I take on a new client and I sit down with them, and again, to sit there and just spend a lot of time really unpacking their daily life, why do you get up at that time, why do you live here? And just really starting to unpack it. Once you get to know and represent the person, that's how I write an SDA application is by really getting to know that individual and my goal is not to write down what I think their options are, it's to really have already thrashed out with that individual and really help them understand what is possible. I have never found myself in that position where I can say either this or this or this.

BEVERLEY O'CONNOR: There's no way, what I'm hearing from the question, is there a way of getting through the system more quickly? No?

TONI ROWE: I don't think I'm the best person to answer that question.

BEVERLEY O'CONNOR: Does anyone? Gerrie? Do you have an answer for that question?

GERRIE MITRA: A couple of things I wouldn't mind saying, it is important to remember living independently doesn't necessarily mean living alone. It is, as Toni said, about a much broader understanding of people's lives and what their goals and hopes might be. Different stages in life, different needs as well. So, I think that's a really important thing. If you come fixed with one view about, "I need to have this", that can be problematic. Because equally, there is a community expectation around how funds are spent and rules around how we can spend funds and we do have to take into account the sustainability and the costs of single versus shared models. There's no one way fits, because we have to take into account the individual's circumstances. But those things all come into play which is why broader thinking about housing options is so important.

BEVERLEY O'CONNOR: OK. Alecia, coming back to you, I have been told by DHHS, sorry, I thought there was one H ‑ I am wasting my time searching for SDA options unless it has SDA approval therefore I can't support an applicant without approvals first. They have been informed it was implemented in July this year. Why are my participants blocked from searching for options?

ALECIA RATHBONE: I can talk about it from my perspective and then Gerrie. From our experience with the tenancy matching service that we talked about before, we supported over 370 people to get SDA funding in their plan and based on good evidence. If someone is told they aren't eligible for SDA or ‑ I would also ask the person who is telling them. If DHHS is telling them, maybe being the landlord and not the NDIA, who is telling you this? Can you talk to your planner and your support coordinator and get good evidence in place? Toni was talking around what your needs and preferences are and lifestyle and therefore what housing you require is my view.

BEVERLEY O'CONNOR: I think we need you, Gerrie.

GERRIE MITRA: Just because you found an empty SDA property, if you find the house and are disappointed because you don't meet the threshold tests of extreme functional impairment, high support needs and a consideration about your personal circumstances and the way we can put the mix of supports together. I think that is probably what the person is experiencing, the frustration perhaps I won't be eligible. And it makes it important the housing options, the flexibility, the home modifications and different equipment and so on we have all of that as part of the conversation so people don't feel they have missed out.

BEVERLEY O'CONNOR: You have gone through the process, which is key to the individual and having decided a person is eligible because they have high support needs or high functional needs, what assessment tools, example, WHODAS are used and understood by the reviewers to determine design level which absolutely matches the individual being assessed by the reviewers who have in fact not met the individual?

TONI ROWE: To do with the assessment?

BEVERLEY O'CONNOR: Yes.

TONI ROWE: Occupational therapists' reports are the one to go to. Because it is a new market it is important to seek out OTs who have a really good understanding about this. You do see some reports and not just SDA but NDIS more broadly there is language that NDIA doesn't want to hear and it is not speaking the same language. If you get those reports, whether it is a neuro psych, whatever the allied health professional, you will run into issues. It will take time and needs more work in that space. Again, it really depends on the individual. It's building up your knowledge of the individual, their life, all of the people around them that support them, what their challenges are. Again, a lot of people that I work with, with extreme and very high support needs also have psychosocial issues, it depends on, you need evidence whether it's a sleep disorder special, whether it's domestic violence, social workers, it is helping the NDIA SDA Panel who don't have external contacts. They are getting swamped with all the reports, what do I have to do to really give them, on paper, a really good understanding of who this individual is? I think there is always this ‑ ever since the start of the scheme, the pushback on criticising the NDIA. And the NDIA is not going to come up with all the solutions. We have an obligation to help them. That's it. We've got the time to really dig in and sell the...

BEVERLEY O'CONNOR: Cut through. Indeed. I'm going to put this to everyone who might be able to answer this question. What if you have been funded for SDA at a lower category than you wanted?

ALECIA RATHBONE: Similar to before, if you have put in your SDA application and you believe you do have the extreme functional impairment or very high support needs and therefore you believe you're eligible, you've passed the threshold for SDA eligibility there, then if you didn't get a determination that matches what you believe you needed and what you put forward in your evidence you can go back and review that with your workers, whether it is allied health professionals or support coordinator and you can ask for it to be reviewed and checked. What everyone needs to live on their own but making sure you've got the case and what it is you need and why and what that evidence is the way to progress that.

TONI ROWE: I was going to add, one of the suggestions I would like to make from the NDIA perspective, it would be really, really helpful to get clear guidelines from the SDA Panel how they are making the decisions. Again, if we are in the market, at the coal face with the client and it's my job to actually guide that person through, understand what they want and talk to them about what's possible. This goes back to what Gerrie was saying, NDIS is not a free‑for‑all, it is not whatever I want, it is ordinary life. I talk my clients through it. I had people say, "I can't believe I can't live exactly where I want right now. It's not fair to me." Well, I don't do that. I've got a criteria, like my idea of what I want to achieve, but I've got to do it within certain rules and constraints, like my personal budget, for example. I try and apply that. But it would be helpful to have clearer communication about just how these SDA decisions are being made. We can guide from the beginning and set expectations.

BEVERLEY O'CONNOR: It doubles up on another question for you, if I wanted to live on my own but then approved for sharing. It comes to that same issue. Gerrie, we might have to throw back to you here again just in terms of how can we simplify the processes and get clearer guidelines?

GERRIE MITRA: Recently, if it hasn't already gone up, put the first process of the form to capture a lot of information, we are making that publicly available. But they are such individual situations. I do think it is something that we need to continue to develop and work on. Particularly as we have more housing options that we think people should be able to consider. I think it is really important that we continue to share that sort of information out publicly. It is great feedback.

BEVERLEY O'CONNOR: Well, thank you, Gerrie. You will bring our conversation and question and answer session to a close. We have been getting fantastic feedback and questions and we will continue to collate those if we didn't get to your question today. They will be incorporated into a Q&A resource which will be published on the Summer Foundation Annual Forum webpage and the resource will also be circulated to all of you that were with us here today. Thank you to all our fabulous panellists, remotely on Zoom and here. Finessing needs to continue but a fabulous starting point and exciting to hear how much it has transformed people's lives. But now back to Paul Conroy.

PAUL CONROY: Thank you. And thank you for your participation today. A special thanks again to our panellists and contributors both in the room and on screens from where we sit. We do encourage you to keep the conversation going. So, please, a video of today's forum and a Q&A document will be on our website in the next few days but in the meantime if you have thoughts or questions, use the hashtag journey to SDA. The Summer Foundation released its Annual Report today and there will be a link on the screen for that and other useful documents. Finally, this concludes the annual forum for this year. And thank you for your participation and keep well and keep safe. Thank you.