**Interview with NDIS participant Leila Bowheen, and Adam Horsburgh, CEO at the Austin Hospital**

**George:** Hi and welcome to Reasonable & Necessary, Australia’s premier podcast series on everything you ever wanted to know about the National Disability Insurance Scheme, brought to you by the Summer Foundation. I’m your host, Dr George Taleporos and in this episode, I’m speaking with the CEO of the Austin Hospital, Adam Horsburgh, about why so many people are stuck in hospital, waiting for the NDIS decisions. But first, we’re meeting NDIS participant Leila Bowheen and her sister, Helen who’s been stuck in hospital for almost a year, waiting for housing and support.

Check it out.

Hi, Lei, welcome to the show.

**Leila:** Thank you.

**George:** Now, you’re in hospital, aren’t you?

**Leila:** That’s right.

**George:** Why?

**Leila:** I had a stroke.

**George:** How long have you been in hospital?

**Leila:** Since April last year.

**George:** Okay, and now it’s March, so that’s 11, 12 months.

**Leila:** Yes, by the time I leave.

**George:** That’s a very, very long time.

**Leila:** Yes, very long time, very frustrating.

**George:** Why? Why have you been in hospital for so long?

**Leila:** Because - can I say? It’s because of NDIS.

**George:** Helen, do you want to tell us a bit more as to why Leila is in hospital for so long?

**Helen:** Sure. There was an application for support under the NDIS which was actually submitted on behalf on Lei, pulling together all of the various reports and assessments as is required and that was submitted in August. So, there was a lapse of time from the point of admission to the point of submission of a support application to the NDIS; however, it took until just before Christmas in 2021, so 8 almost 9 months after Lei had been admitted to hospital for the outcome of that application to be confirmed by the NDIS.

**George:** Eight or 9 months in hospital, waiting.

**Helen:** Yeah.

**George:** That’s extraordinary and really unacceptable. I’m sorry about that, Leila. That would be very hard. What’s it like for you being in hospital for so long?

**Leila:** Well, my daily activities, George, is I do PT which I love and arm therapy which I love also and the staff are fantastic and I don’t begrudge the staff at all. I begrudge NDIS.

**George:** It must be very, very hard to be inside that same room, especially during COVID. You were there when the lockdown - when there were restrictions on who could come in. What was that like for you?

**Leila:** Well, I contacted my family via Zoom or via Messenger but it was horrible. It was horrible. I couldn’t see - I couldn’t have visitors, which annoyed me.

**George:** How was that for you, Helen?

**Helen:** I think it was challenging for all of us. Seeing someone over a screen is absolutely no substitute for touching them or smelling them or just being tactile with them and it’s just a completely different medium. It almost - it doesn’t feel as meaningful to be communicating in this way. It has been incredibly challenging for us as a family to feel as though we’re supporting Lei through what is a very, very difficult time for her.

**George:** I’d like to understand a bit more about what it was about the NDIS and what went wrong in terms of the NDIS process. Helen, are you able to help people to understand that a little bit more?

**Helen:** Well, I guess I feel that there was perhaps a bit of a disconnect in terms of what the expectations were by us as a family. The time that it took necessarily to pull together all of the reports and all of the threads of information that were required, that took some time, but I appreciate the time was necessary at that point to be sure and confident that that information was as comprehensive it could be. I think though that once it was submitted, you kind of felt that you’d suddenly - you weren’t in control. You weren’t even able to influence anything and it took time for a meeting to be scheduled and to get people together for that meeting to be held and then when that meeting was held, everyone was absolutely lovely. You might remember, Lei.

**Leila:** Yes, they were.

**Helen:** It was a really lovely conversation but then subsequent to the conversation and in a follow-up call with the case manager who hosted that meeting, I kind of understood and it was sort of jarring. What our expectations were, were very different to what was ever going to be entertained under the NDIS and the NDIS made a decision and that initial decision was - so, our application centred around 24-7 care for Lei in her own home and we were - I feel we were led to believe that that was a possibility and it was rudely apparent that that was never on the cards.

**George:** When you think about the process, the time, the time is what really stands out to me, the fact that - I imagine that there would’ve been a real sense of, “Is this ever going to happen? Will I ever get out?” Is that right, Leila?

**Leila:** Yes. I felt I was trapped. It was like a prison.

**George:** What do you think about Helen, the process though, how do you feel it should’ve gone? What would’ve worked?

**Helen:** Well, I work in compliance George, so we have processes and there are - all of our processes are built around a basic assumption and that is that any matter referred must be dealt with within a specified time so there is absolute clarity from parties to a complaint about where the beginning and the end is, and the process is made to fit.

I’m not suggesting that it’s always possible to fit square pegs into round holes but there must be, there has to be, for people’s mental and emotional health if nothing else, a sense of what a calendar looks like for the purpose of an application and its evaluation and assessment and I feel that there was just a massive disconnect between the hospital and their expectations of the NDIS and what the NDIS were ever going to do for my sister and as a family, we were prisoner to that expectation because we didn’t have any benchmarks.

God forbid, families following us are possibly experiencing those same pinch points of frustration and helplessness that we have because there is a lack of a process map of what you can expect and when. It beggars belief for me, George. It beggars belief.

**George:** I think that you’re absolutely right, that there needs to be a really clear understanding, but more so, a clear sense of urgency that if you’re in hospital, if you’re healthy enough to leave, that your plan is ready for you to exit. It’s costing the government a lot of money to keep someone in hospital. Why would you want to drag that out?

**Helen:** Yep. So, our original application was rejected. We then had to retreat and re-evaluate, but we are then provided with another case manager by the NDIS which to me was a basic flaw in the system.

**George:** Why is that?

**Helen:** It’s the lack of continuity. It’s like an insurance claim. If you have an accident in your car, you want to be dealing with the same person at the insurance company because they’ve got your history there. Having to repeat your history and go back to Go and not collect $200 every time is not efficient. It’s also dehumanising.

**George:** It would be and it’s also - I imagine that for you, Leila and for you, Helen, that it would’ve felt like you were back at the start, back at square 1.

**Helen:** The only thing added was that we had a better sense of where the boundaries were for the NDIS in terms of what they were prepared to entertain. That was the difference.

**George:** Leila, I’m interested in where you are now. So, 11 months on and I heard that very recently, you were told that you would get out of hospital very soon.

**Leila:** Yes.

**George:** Can you tell us a bit about that?

**Leila:** It’s not a house, it’s another -

**Helen:** Transition care.

**Leila:** It’s another transition care, from here to another place.

**George:** Why aren’t you - and Helen, you might be the one to answer this - why do we need another stop? Why can’t we end this? This is going on for a long time.

**Helen:** I think this is where a process map would be really interesting, George, because I guess the - I think you’re right. Should there actually need to be this step? And I think it’s a yes and a no answer. Because Leila has been in hospital for so very long, I think the idea of a transitional care stop is a very important one for Lei because it’s 1 dolly step towards her life beyond rehab and hospital. If Lei’s stay in hospital had not been as long as it has - and we are coming up to a year - I would be much more enthusiastic about Lei going into a more permanent accommodation arrangement. Because she’s been out of that environment for so long, I think there are some inherent benefits of a transitional care stop.

That being said, from a family perspective, our impetus and our motivation since the NDIS decision was delivered to us on the 23rd of December, it’s just been to get her out of hospital. We just want to get Lei out of rehab and we don’t have more permanent accommodation lined up for her yet. We are still searching for that, so the opportunity to take a transitional step to get her out of hospital and to get her in an environment which is more normal in inverted commas is just - we only became aware of that very late last week. It’s now Tuesday. As far as we’re concerned, the sooner she can get into transitional care, the better. But you’re right, it should not be an additional step for everyone and I hope it isn’t.

**George:** Yeah, I hope it isn’t too. Leila, it sounds like you’re going to get out of hospital soon. What are you looking forward to doing when you get out of hospital?

**Leila:** I’m looking forward to meeting friends and coffee.

**George:** Coffee?

**Leila:** Yes, I tend to socialise in a basketball stadium. I’m going to go into that basketball to build -

**George:** Oh, fantastic.

**Leila:** Yeah.

**George:** How’s the coffee in the hospital?

**Leila:** Shit.

**George:** I’d like to ask both of you this question and I’ll start with you, Helen. What message do you have for politicians and decision makers about your family’s experience of being stuck in hospital for almost a year now?

**Helen:** When I start, George, I’m not going to know where to stop but I do think that there is such a massive disconnect, even for staff working within the NDIS, between them, the clients of the NDIS, the families of the NDIS clients, there’s such a massive disconnect between them and the politicians who determined that this program is a good idea and the idea of it is very good. It’s the application of it that is now fundamentally and fatally flawed because there are people who sit behind every one-dimensional case file, and there’s a ripple effect. Every decision that is taken in relation to that one-dimensional case file ripples out to the community of the person that that file represents.

So, when they’re slow, when they’re inefficient, when their decisions don’t align with expectation, the ripple effect is enormous and to me, the only way that people can appreciate that without being patronising, don’t tell me you understand, you’ve got to live it to understand, you’ve got to experience it to understand and I’m not saying I do completely understand because this is just the beginning of our NDIS journey so I’m just starting it with my sister but they’ve got to just spend a day with a case worker and just hear it, see it, feel it and then don’t tell me the solution is money or, “We’re working on it.”

Just don’t give me the poly pandering speak. I’m not interested. Action and information that is honest information, that tells you what the turns and the twists and the pitfalls are, not just talk it up and tell us it’s a dream and lots of glossy brochures with photos of smiling people and smiling carers. It aint that, George. It isn’t that. It’s language that you don’t even know what it means and no glossary of terms anywhere. It’s a parallel universe.

**George:** Yeah and I think what stood out there is you want action, not words.

**Helen:** You’ve got to go for parliament, George.

**George:** Leila, can I ask you, as someone who’s been in hospital for almost a year and has gone through everything that you’ve been through, what’s your message to politicians, to the NDIS and to government?

**Leila:** Can I be blunt?

**George:** Go on.

**Leila:** Bullshit. They’re all bullshit. That’s my - well, you put them in my shoes. You put them in my shoes and you get them to live a day like me.

**George:** Absolutely, Leila. I think that that’s an important message. I want to thank both of you for talking. I know it is hard to have these conversations but it’s important that people hear what’s happening on the ground. I can see you there in hospital and I’m hoping that you’ll be out very soon, Leila.

**Leila:** Thank you.

**George:** And thanks for your time. Thank you, both of you.

**Leila:** Cheers.

**Helen:** Thanks, George, it was good to chat.

**George:** That was Leila Bowheen and her sister, Helen Milovanovic. So, why is this happening? My next guest, Adam Horsburgh, is the CEO at the Austin Hospital where this kind of situation is far too common. He’s here to help us understand the scale of the problem and what needs to be done to resolve it. Hi, Adam. Welcome to the show.

**Adam:** Thank you, George, a pleasure to be here.

**George:** So, how common is Leila’s experience?

**Adam:** Unfortunately, Leila’s experience is very common across the health system both here in Victoria and I think across all of Australia. At any given point in time, we would have a number of people here at Austin Health who are in a similar position to her and I think every major hospital in Victoria would be able to say exactly the same thing.

**George:** And how does that affect the hospital? The whole system is pretty affected in this kind of situation, right?

**Adam:** That’s right and as Leila’s story indicates, the main impact is on the individual themselves. It means that they’re not able to progress in the way that they wish to, and need to, because we’re really not as a hospital set up to meet her or similar people’s needs but for the hospital itself, it also means that that bed is occupied by an individual who could and should be somewhere else and therefore, we can’t use that bed to admit people who need to come into the hospital through the emergency department in a timely way to receive acute healthcare. So, it really does mean there’s a delay to other people being able to access the bed as well as that individual really not being in an environment that meets their needs.

**George:** Absolutely and I would imagine that the health impacts on the individual would be quite significant because if you’re in hospital, it’s not the best place to be to rehabilitate, is it?

**Adam:** No, absolutely not. So, we provide wonderful care to many patients for their acute or subacute episode but as you say, we’re not set up for someone’s long-term rehab goals. That’s not what hospitals and our staff are trained and expert in doing, so it really has impacted on the progress that individuals can make as well, as I said, meaning that there are beds available for those whose needs really suit the skills and experience of our staff.

**George:** I also think in a pandemic, this is especially problematic.

**Adam:** Yeah, that’s right. There’s no doubt that hospital beds are under pressure at any time but particularly during the past 2 years as we’ve been trying to focus our resources and our staff on our pandemic response and here at the Austin, we’ve admitted at different points in time, a large number of COVID positive patients and we’ve really needed are beds to be available to help with the pandemic response.

**George:** So, why is this happening, Adam?

**Adam:** It’s happening because in essence, in very simple terms, it often takes far too long for an NDIS assessment to be undertaken and then often even if that assessment has been completed, for the approval to be given for the package of support that that individual needs. So, while all of that is going on, which can take weeks and sometimes months or unfortunately in some individuals’ cases, years, we become the default place of residence for that person. So, this is a significant problem across the system. It’s affecting individuals, it’s affecting hospitals and it’s also impacting those patients who could otherwise get access to that hospital bed.

**George:** Is this a problem that’s getting worse or is it getting better?

**Adam:** I think if you looked at the past 3 to 4 years, you’d have to say the problem is getting worse in terms of we see more people in our hospital who are waiting for their NDIS assessments and their packages to be approved. There was some improvement during the early stages of the pandemic when a lot of emphasis was put on trying to fast-track some of those approvals but unfortunately that improvement was fairly short-lived and for most of the pandemic and certainly now, we’re back to experiencing very long lead in times for those approvals to be provided.

**George:** That’s really interesting. So, you’re saying that there was a period where there was fast-tracking by the NDIA and that that’s no longer the case? So, it seems like they can do it when they want to.

**Adam:** Yeah and I’m not entirely clear what form that fast-tracking took but we certainly saw reduced time in some cases during the early stages in the pandemic but that has not been sustained. We have little visibility into NDIA and their processes so it’s hard for me to comment but I can only say from a hospital perspective, we haven’t seen the improvement sustained and we’re pretty much back now where we were pre-pandemic.

**George:** So, what is the solution, Adam?

**Adam:** I think the solution probably takes many forms but in essence, what we would be hoping is that these assessments can be conducted quickly and that the packages can be approved much more quickly. There’s no reason why an NDIS assessment or approval of a package needs to take so much longer than for instance, the approval for someone to enter residential aged care. So, if we could try and get these NDIS packages approved in a similar timeframe that we can often achieve for residential aged care, then that would mean that people aren’t getting stuck in our beds for the current protracted periods of time that we currently see.

**George:** Do you think that’s realistic?

**Adam:** I think sometimes we have to be bold and set really hard targets because if we’re not, then we’re unlikely to change the status quo. So, whether ultimately that is achievable, I think that’s something that we really need to push hard and test rather than saying at the outset that it’s not possible. It’s definite that we can make an improvement from where we currently are and I’d like to see that improvement to be as significant as we can possibly make it.

**George:** I absolutely hope so as well, for Leila’s sake, for all sorts of people who are waiting for hospital beds. Adam Horsburgh, thank you for your time.

**Adam:** Thank you, George. My pleasure.

**George:** That’s all we have time for on today’s episode of Reasonable & Necessary, brought to you by the Summer Foundation. To be notified of future episodes, don’t forget to hit the subscribe button and the notification bell. Thanks for watching and until next time, stay well and reasonable.