**Episode 3, Part 1**

**Supporting a person in aged care to live a better life**

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# Introduction

**Andrea**: Hi, I’m Andrea Lockwood, and welcome to episode 3 of our “*Best Practice”* series being produced by our UpSkill program. Upskill is a capacity-building program for NDIS support coordinators and allied health professionals who are working with people with disability. This episode is made up of 2 parts - this is part 1.

In this episode, we hear from 2 support coordinators - Jamie Woodman from Melbourne City Mission, and Laura Schutz from Independence Australia - who describe best practice in supporting people with disability living in a nursing home who want to explore moving out.

It also includes an interview with Phi Tran who has a disability. Phi talks about what support coordination has meant for him and achieving his goal of leaving a nursing home and living back in the community.

Other topics covered in part 1 include establishing what’s most important to the person in aged care, key supports for the person to exit aged care, collaborating with aged care staff and how to establish the person’s preferences.

First up is Jamie, who shares his approach with establishing what’s most important for a person living in aged care.

# Establishing what’s important for a person

**Jamie:** So almost every single person that I’ve gone into an aged care sector and asked what they want, what’s the most important thing to them, it’s very hard to get past them to say “I just want to get out of here”. A lot of the people I worked with didn’t have their disability before they ended up in hospital, and they went straight from hospital into aged care.

So as for establishing what is important, it’s very hard for them to know what they want. So it’s really about suggesting what can be on offer because obviously their whole world – anyone who’s just been introduced to a disability has obviously had their whole world changed. But their first fight, their first main focus, is to get out of aged care because for them it’s a form of institutionalisation. And a lot of the people in aged care that I’ve been working with are in high dementia wards with people walking into the rooms, a lot of screaming, a lot of shouting in the background. You’re not allowed out to just go for a walk by yourself, the doors are locked. Even going out to the backyard can be hard because someone needs to open up the door for you. And there’s shortages of staff and all that.

So to work out what a person wants, their whole life has started off anew, a lot of people don’t know what they want. And even some of the participants I have who have lived with a disability most of their life don’t really know because they haven’t had NDIS services before, and they don’t know what the NDIS can provide for them, and they don’t know what having someone, even a case worker, a lot of them haven’t even had onboard case worker throughout their lives. They don’t know what’s available to them.

So sitting down and going through everything can be a bit difficult for participants because they still don’t understand why they would need it, and what the outside world looks like, and that is really, I think, the major complication. So sitting down with them and working out what’s important. It usually comes down to environment, so what area do they want to live in? If they’ve got family, to make sure that they’re close to that area, and that’s one of the more important things. Having - what public transport is nearby? And obviously making sure that that public transport - if they’re in a wheelchair, for instance, a tram where you have to step up into is going to be very difficult.

So there’s a certain amount of things that they need to have, and describing to them the importance of those things and just going through everything is important. But I bring back to that first bit, it’s very, very hard for anyone to get out of the mindset of just get me out of here first and let’s go from there. And it doesn’t sound like an intelligent answer but that’s the hardest thing to get over for everyone that I’ve dealt with. Everyone is just focused on get me out and we’ll work on the rest later.

**Andrea:** Now let’s hear from Phi, an NDIS participant who was supported by Jamie to leave aged care.
So the time you spent in the nursing home was pretty difficult, Phi?

**Phi:** Yes. Yes. I don’t have my freedom as here. I can go out and then come back.

**Andrea:** Yep.

**Phi:** Yeah, and at the nursing home, you can’t go by your own unless you’ve got a carer. And/or if they reckon that you can look after yourself then you can go for a limited amount of time and be back.

**Andrea:** Okay. So I just want to make sure that I’ve heard everything that you said, Phi. That at the nursing home, you didn’t have your freedom. You couldn’t go out on your own. You had to go with a carer.

**Phi:** Yes.

**Andrea:** Okay. And that restriction on your freedom would have – very difficult, Phi, for you?

**Phi:** Yeah. You just have to be in the nursing home and can’t come out.

**Andrea:** Yeah. Phi, when you were talking to Jamie about moving or living somewhere else, what was really important to you about this new home?

**Phi:** Because I have lack of knowledge of what accommodation is like, and I don’t know about that sort of thing.

**Andrea:** So were you saying, Phi, that you didn’t have knowledge about what was available? Is that what you mean?

**Phi:** Yeah. Yes. What you can do, what can you do.

# Key supports required for exiting RAC

**Andrea**: Following what Phi shared, regarding not knowing that there were alternatives to a nursing home, we talked to Laura about what to consider when working with a person with disability who is living in aged care.

**Laura:**  Firstly how safe someone is, and how comfortable someone is feeling at that point in time. Because there are instances where someone is acutely unsafe, and it is quite critical to find an alternative. So that again is working out what is actually a priority. If someone’s unsafe in their environment, it’s going to be a priority to get out. If that person is not unsafe, and all their immediate support needs are met, in RAC quite often it’s ‘better the devil you know’. And a lot of the time participants or their family members generally are more hesitant to explore an alternative because it’s safe. It’s a structure. It’s a set facility. And the people come in and support. You don’t have to organise anything. You know that they’re bringing – or even consumables and products are being met.

Generally RACs have access to their own GP and out-of-hours support, and on-call support. Everything is just simpler in terms of the daily support needs. So quite often you feel – you can feel that little bit of hesitation from families about the idea of this amazing new opportunity to get out of aged care. But at the same time, you're looking at what that participant wants, and ideally where they want themselves surrounded by. So it’s a similar approach in terms of with the health system, with how we try to help someone to explore the potential, and really hone in on what someone wants.

And a similar – very similar process in terms of the profile and template that we build based on that, but with a focus – a lot of the focus on what’s actually age appropriate as well, and socially – what someone socially wants out of their environment. Because that’s one of the main differences is that obviously in the health system, in the hospital, you're generally landed in there because of a medical issue. Everything’s focusing on getting you well and getting you out. Whereas aged care, it’s actually preparing you for going nowhere. So there’s a very big difference not just with how the participant is feeling, but with how the staff are acting and how they approach their supports. Because no one’s going anywhere. And that’s the stark reality of an aged care facility. It’s the end of life care.

So it’s also a really big psychological impact on participants and family members, and it’s not often picked up on. It’s that underlying thing that you're not thinking of because you're just looking at the framework of it. A lot of people are just, “oh, aged care, oh no, they’re a younger person in aged care. That’s not appropriate.” Okay, why? Let’s dissect ‘why’ and let’s focus on that, and really hone in on why someone needs to get out of there, and then help find that suitable place to move to. Because often it’s just one of those things that people just flippantly say: “Oh, aged care is not appropriate.” And it’s not.

But to actually be able to identify why, and help someone to recognise if that’s not appropriate, what would be? What’s the alternative? And so when people end up somewhere that they didn’t get a choice with, it’s not just, “oh, well, we’ll go try the other options now,” it’s, “well, what do you mean there’s a new option? How’s that going to work?”

And it’s such a – it’s an amazing process when it works and it happens. But the extent that you need to try to help work through that, right from the start, it’s actually a completely different process to the health system. You're talking about shifting gears from what’s expected, being in that environment. And the people around you are not supporting to get that person out of aged care. The people around you are the aged care staff, who are expecting that they turn up and the residents there are staying. So it’s not like the hospital where the health system is actually also putting pressure on, “let’s support this person to get out so that they don’t come back.” Aged care is expecting that that person is going to come back at some stage anyway.

# Communicating with RAC staff

**Andrea:** So Laura, given there’s a focus on end of life care in the nursing home environment, what do you think is really important in working with the aged care staff?’

**Laura:** The first thing – and this is also a really tricky point a lot of the time, because quite often the families and the participants don’t actually want to have it known that they’re looking at exploring other options. People are often concerned that they’re going to be judged or treated differently if the facility staff know that they’re looking elsewhere. So a lot of it is about supporting the participant and their family member to really pinpoint and identify what they want first. And then look at the immediate environment and see what can be changed within the environment. What can be brought into that environment to help support and maintain that whilst we’re exploring it separately?

And a lot of the time it’s just about trying to find that connection; that good connection with someone at the RAC, who can help support and maintain, and really just get the most out of what they can provide. And then again, similar to with the health system, where you're working with someone to try to see where the gaps are, and how you can help enhance and optimise it, with the aged care system, often if you just ask if something can be changed, the RAC service is expecting that you're telling them they need to do it. And quite often the immediate response is, “no, we can’t do that”. And often it’s just you're trying to open up the communication so that you can introduce something new into there, and establish another option for that participant. But it’s often just met with that complete shutdown, not even resistant.

So it’s a different approach where you're just looking at trying to enhance someone’s social connections. So a lot of the time it can be something as simple as working with that aged care facility to see if they can send you through what their social and rec activities are for that week. Can we have a look and see whether there’s anything that that person is really enjoying contributing to in the facility? What do they always want to participate in in home? And then find a potential community activity and just broach that as, “oh, such-and-such really enjoyed the music activity that the RAC facility put on last week. We’ve actually found a weekly community one down the road that they’re really interested in going to”.

And then that RAC facility is more motivated to support you to help put something in place, so that that person can access that external one. Because it can even just be a difference between the RAC facility recognising that they’ve got to be able to make sure that person can be up and showered and dressed and ready for a taxi in time. It’s about bridging that gap. It’s about breaking those barriers down. Because a lot of the time we can help set up all these engagement activities and supports and services, but unless that facility is going to support the person being able to get out of the facility for a couple of hours, it’s not going to work.

And connecting that – transferring the information back and forth, a lot of the time it’s just working out how the RAC facility wants to receive information. And potentially compromising how you’d usually approach something, to make sure that you're maintaining that rapport. A lot of the time you do have to step back and forth a bit, and work out how it’s going to be met in an accessible format for the RAC.

**Andrea:** Yeah. it’s working in their context, isn’t it? It’s understanding that context and working with it so you can get the best outcome for the person that you're ultimately wanting to achieve.

**Laura:** And if you don’t know, then you ask. If you're very clear and upfront and say to the RAC manager or whoever’s on staff, “look, I’m not sure how you guys usually do it, how you prefer it to be done. We can work within whatever’s the easiest way. Feel free to let us know if this is not the approach. If you haven’t done it before either then here’s a few ways that we’ve tried it. What do you think sounds best?” And you're empowering the facility then to explore it, to look at that, and feel like they’ve got a bit of control over their facility as well. And in the end, you're bringing every conversation back to the participant. You're putting them into the centre of it, because otherwise they’re going to be sitting to the side.

And then you don’t want it to just be an ‘us and them’ situation. And that goes across the board. That’s with health, that’s with aged care, and it’s with NDIA. We try to make it collaborative so that we don’t use wording such as, “they said this,” or, “they won’t let you do that,” or, “we’d be able to sort it if they weren’t involved.” It’s about making it that team approach, and really following through on that.

**Andrea:** Jamie, what’s your experience of how RAC staff and NDIS providers coordinate and communicate what’s happening with a person with disability that they’re all supporting in aged care? There might be a number of NDIS providers coming on-site to support a person in aged care, which could be a daily support worker, or an allied health professional such as OT, physio or speech pathologist? How do they all work together?

**Jamie:** It’s a hard one because really with aged care you have a care plan and that’s their main thing. That is the system they know, and that’s what they rely on.

I’ve been told by quite a few of the aged cares, it’s like “Well, why don’t you just get our physio to help, our person on board?” And it’s like “That’s great. Do they have an hour to spare once per week to visit the participant, and to also do the documentation, and to write up the report that I’m asking for? And do they also, if he was to have a fall, then also dedicate an entire hour to helping them and supporting them and going in each day?” And the answer is always no. They get like 5 minutes, and they only get really attended to if they fall, and they don’t have the knowledge or understanding of the NDIS system and the type of reports needed to request further hours and supports for the participant. So bridging that gap is really, really important.

**Andrea:** Laura - in your experience, can you tell me about whether daily support workers can come into aged care facilities to offer support or training, or to build rapport with someone before they leave the nursing home?

**Laura:** There are a few more limitations in terms of what the aged care system – or not even the aged care system as much, but even the individual aged care facilities, I think particularly because we’ve been assisting people in the last year and a bit with quite a few transitions. So what we’ve got on top of all of the initial – all of the pre-existing issues with having insurance issues or WorkCover issues with external people coming into a RAC facility, we’ve also had COVID. So RAC facilities shut down and locked down. And we weren’t able to, a lot of the time, have therapists, external therapists, come in. The RAC facility was providing their own internal ones, and they were siloed.

And then as we’ve gone along in the last few months we’ve checked in all the time and tried to adapt and adjust things accordingly. But a lot of the time, when someone is coming out of a completely different environment that you couldn’t access properly, you're just guessing.

You're just making the best assumption that you can, knowing that you're better off being able to step back from that, and do a step-down approach. And that’s often the easiest way, is to say, “look, we think going into this new environment, any new environment, it’s going to require a little extra support. So what if we aim for overnight support every night, and then we’ll – once we know that it’s safe, we can start trying to step back so there’s one night that you don’t have – you just have on-call support. And then we step it back again. And if you're not needing any support at all overnight, then we can just set up something that’s on-call.”

**Andrea:** Within a new environment, you mean?

**Laura:** Yeah, yeah. Or in a change of circumstance. So obviously we’re talking about people who might have not had that support need before, and then something’s changed with their situation. So they might need to have another step-up approach, bring in extra support for a certain amount of time, and then try to withdraw it back again if it’s safe. So it’s just about knowing that you can’t ever have anything static.

# Understanding someone’s preferences

**Andrea:** Let’s hear again from Phi about what some of the important things were for him before moving out of the nursing home.

Were there any things that were really important to you, Phi, like living with other people, or having a pet at home? Was there anything really important to you that Jamie looked at for you?

**Phi:** A pet, no, he did help me get a membership for the gym. Yes. And he helped me with NDIS. Every 2 years I got to go and see NDIS and talk about [inaudible] or the money that can help me live.

**Andrea:** So Jamie helped you put your NDIS plan with the money together to fund things that help you, Phi?

**Phi:** Yes. He’s come and then we talk to NDIS. Yes.

**Andrea:** So he’s making sure that you are getting what you need from the NDIS? Yep. When you were thinking about moving out of the nursing home, Phi, did you want to live with other people?

**Phi:** Oh yes.

**Andrea:** That was something important to you?

**Phi:** Yes.

**Andrea:** And was there anything else that you wanted, that you had in your mind about the new home you were moving to?

**Phi:** No. After I had one visit then I really like. When I come back to the nursing home, I had a think about it, and then I chose it.

**Andrea:** So you were able to come and see – where you’re living now, you could come and see the home before you moved there, so you got to see it before you moved there, Phi?

**Phi:** Yeah. And lucky they accept me.

**Andrea:** When you went to visit this new home, Phi, what did you like about this new home?

**Phi:** Oh, to me it’s more – I like that I can go out on my own and everything change from a small amount of carer. I talk more with carer. I got physio, OT and Jamie behind me. Yes.

**Andrea:** Is there anything else that you love about where you’re living now? Anything else that you wanted to share?

**Phi:** Oh, just that you don’t know how much appreciate it, to be in a house or a home. Living with 4 or 5 people. Yes.

**Andrea:** So you really feel appreciative, Phi. And you feel like your life has changed now?

**Phi:** Yes.

**Andrea:** In lots of ways?

**Phi:** Oh, it’s just like, in the nursing home, the room is too small. It’s not living in a room. It’s just half there – half of my room. No, a quarter of my room. Yes. And they have a curtain that run along the back and then 2 person is living in the one room.

**Andrea:** One room?

**Phi:** Yeah.

**Andrea:** So you had a curtain between your bed and another person’s bed?

**Phi:** Yes.

**Andrea:** So you didn’t have a room to yourself?

**Phi:** No.

**Andrea:** Now you have your own room?

**Phi:** Yes.

**Andrea:** And do you have your own bathroom, Phi?

**Phi:** Yes. Own bathroom. You don’t have to share with. Yes.

**Andrea:** So different to what you experienced before.

**Phi:** Yes.

**Andrea:** Jamie - how do you approach establishing what a person’s preferences are in relation to housing? Do you look at what people might want to do, where it’s located in relation to the things that they’re interested in doing? How do you explore those preferences and incorporate those into their NDIS plan?’

**Jamie:** Yeah, so when you are creating a new NDIS plan for a participant you need to start from the ground up for someone who is moving out into an SDA. You start off with obviously the area that they actually want to move into, the transport that’s around, the services that are nearby. Everything’s going to be influenced in regards to do they have a wheelchair, is that going to be accessible? Taxis obviously are going to be more expensive. How much transport funding they’re actually going to get through their plan in particular. What supports do they actually need? One of the participants I work with wanted a gym nearby so that was absolutely vital.

So you’re starting off from the central point which would be the home, the area, and then expanding from there. How far do you want to be away from the city? How far do you want to be away from certain services? What do you want to do? Do you want – what is your main interest? Is it art? Is it creativity? And then expanding beyond that.

It’s very hard in many ways when people are in aged care, and certainly through COVID-19, to get people to find these places and experience and trial them out. But putting together a plan, and then finding out the funding that they’re going to need based on that, is part of a support coordinator’s role, to break down every component because yes, core supports comes in one bunch of funding but it needs to be broken down into community access, connection supports. Do you need an AHA worker, or a community access worker can actually take them to the gym if need be?

Putting in a plan and working out what a participant wants takes many different sit down sessions, collaboration with the occupational therapists who are also going to do their own studies into what’s actually needed,including the physio and the speech path and so forth. But it’s really – it really just – to be honest with you, I just sit down with the participant, I just chat with them for ages.

**Andrea:** Talk it through.

**Jamie:** And this happens over a period of time, and you try to get past that stage of yeah, you want to move out, that’s great, but what’s that look like to you? And you really try to break that down. What’s important to you? What did you do beforehand? Getting a history of an individual is vitally important and trying to just bridge that gap between, would you like to get back to that, what part of that would you like to do? Would you like a step by step process to get through there? And just asking a bunch of questions with no ends. So no ends, if you had no issues with money, if you had no blockades, whatever, what would you like to do? And then they give you an answer and it’s like cool, how are we going to get there? And that’s what our role is designed to actually work out for them.

**Andrea:** Jamie’s summary of how he establishes housing preferences for a person in aged care brings us to the end of Part 1. We’re going to take a break and when we return in Part 2, we’ll cover how support coordinators support a person to transition out of aged care into their new home, preparing for the move and then establishing if the new home is working for the person.