**Episode 4**

**Key features of using a person-centred approach**

**Contributors**

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# Introduction

**Andrea:** Hi, I’m Andrea Lockwood, and welcome to episode 4 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.

In this episode, we hear from Linda Hughes who has previously worked as a support coordinator for people with complex needs. Linda also founded Mind the Gap in Newcastle, and more recently who became the Summer Foundation’s UpSkill Lead. Linda is a parent to Jacob who is 28 years old, has complex needs and is now living in his own home with supportive housemates.

You would have already heard a little bit from Linda in episodes 1 and 2 but in this episode we talk in more detail about things like working with a best practice framework, supporting capacity building and the importance of circles of support and making friends. First up however, I spoke to Linda about the key role support coordinators play in supporting a person to apply for Specialist Disability Accommodation, or SDA.

# The support coordinator role in the SDA process

**Linda:** I think the first thing is to really understand a person’s dream and their vision for themselves. What does living in a new home mean to that person, and really unpacking their goals, their aspirations, their housing needs and preferences. Really having a solid idea of what that looks like for the person. And this is often detailed conversations with the person, it might be with their family, it might be with other trusted people around them, to really unpack that idea of what does this mean for you.

Often the people that we are talking about have got complex disabilities, they might have complex communication needs, a person being able to articulate that might be a little bit problematic. So really listening to the person, and listening to how they indicate what their preferences are and trying to get a really good understanding of that. So really, just maintaining that very person-centred approach from the get-go, and using that as your touchstone as you go through the process.

The SDA process is really, really technical – and it’s not a lot of fun really, because you’ve got to address all the criteria in the SDA rules. But really actually using that person’s, their housing needs and preferences, their vision for themselves, as your touchstone as you go through that process. And I think that actually then makes it a much richer document as well, if you are documenting how this housing option will better support a person, will better meet their needs, will better meet their preferences – actually makes it a much more rich document. As well as including the important things as well, like the therapy reports, the functional assessments, and other evidence that you might have – that once again, having that touchstone with the person as your focus, as you go through that report.

**Andrea:** Great. Are there particular resources that you’d suggest that people access to help guide them through this process?

**Linda:** Yeah. I’m a real fan of the PATH planning tool. So, PATH is an acronym – it’s Planning Alternative Tomorrows with Hope. And there’s another similar person-centred planning tool called MAPS – and again, they’re really great tools for working with a person, bringing together other people who care about them, family members, trusted others, to really help with some of that planning.

When you think about moving to a new house, or buying a house et cetera, we often seek advice – it’s a big decision in our lives, and we often seek advice. And really helping a person with a disability, who may be wanting some advice about the important parts of their move as well. So, I think that these planning tools are really useful, once again in unpacking a person’s preferences, their needs, their vision for themselves, and how they would like to live their life.

And it kind of brings it together in a holistic way. We’ve actually used PATH planning information as part of the evidence as well in SDA applications. So, it usually becomes this rather large butchers paper graphic as ideas come together, and we have actually taken a panoramic photo, et cetera, and transcribed some important bits to inform some of the evidence that we provide to the NDIA, with an SDA request.

**Andrea:** That’s really interesting too Linda, that you’ve included pictures as part of the application – it’s not just all writing, but actually having some imagery that adds to the person’s application.

**Linda:** Yeah. We use videos as well. Particularly when a person isn’t able to communicate with words really readily, we’ve used videos where a person is talking with their support worker, and being animated and excited when he’s talking about living situations which are that person’s preference. But the person was also able to indicate, when they started talking about some other living situations, he was very able to articulate that that wasn’t a preference. And we included that in the SDA report. We uploaded it to Vimeo, password-protected it, and included that in the report with a password. And we know it was viewed. That was the really, really cool thing about it is, that we could actually see that other people, beyond the people involved in the creating of the video, had viewed that. So, presumably people from the agency.

**Andrea:** Can you share what the outcome of that particular -

**Linda:** Yes. It was a very successful outcome, yes.

**Andrea:** That’s great.

**Linda:** Yes. It’s taken a long time, but hopefully the person will be moving really soon – really like weeks now I think, before the move.

**Andrea:** Fantastic. Haven’t heard many examples of applications including those kind of elements to them, so that’s really fantastic to have that shared today for people.

**Linda:** Yeah. I think it’s really important. Quite often when people don’t communicate easily with words, or have complex communication needs, their voice and opinion can be overshadowed by other people. And it’s not necessarily people deliberately doing that, but it can be well-meaning family and friends and others – but really actually finding ways for that person to indicate what suits them, what’s their preference, what floats their boat in their life. And that requires a pretty creative approach.

**Andrea:** I asked Linda to talk more about the support coordinator role in understanding more about what’s important to a person.

**Linda:** I think really that person-centred planning approach is really, really useful. I think though if you look, sometimes I feel like we’re slotting people into services still. We’ve got individualised funding, but we still have a bit of an approach, well here’s a gap and here’s a service, then we’ll slot that person in. And sometimes that works okay, people can slot in, and that suits them. But sometimes it’s pretty awkward, and it’s not quite right for a person, or it can be just really uncomfortable, just not a good fit.

And I think what we really are doing that is sometimes putting the cart before the horse. And what we really need to be doing is actually looking at the supports the person requires. Looking what they require to fulfil their goals, their aspirations, what’s important to them, what do they need to be included in the community – and starting there, and then designing the services around the person. And I think at the moment we still haven’t quite got that right – which is disappointing, because I just always imagined the NDIS with individualised funding, would automatically just create these opportunities that hadn’t been possible before.

So, I feel like creativity is a really important skill support coordinators need to have – really having that ability to look outside the box of what’s currently available, and walk with the person in finding ways of having their support needs met. It sometimes might mean that not all supports are NDIS funded as well. If we actually can do this job well, and it does depend on a person’s support needs, and again their preferences – but there’s certainly situations where we’ve really helped a person take part in a mainstream community activity, which then flowed on to delivering some informal support from other community members in that group.

So, initially someone was, she was going to a music group in the evening, and initially a support worker was going along as well, and it was very expensive – then it was adapted so that the person was able to get a trusted taxi driver to drive her home. And then someone in the group said, “hey – I live not far from you. How about I drive you home?” And really creating those opportunities for the new relationships again to develop. And that’s what we all do – I’m going one way, and someone else is going the same way, I’m like, “hey – do you want to share a ride?” We don’t do it with strangers, but people that we are getting to know in a social context, we often do that, as just part of being friendly. So, I think that’s really opening up those opportunities for people with disability as well.

And another really important tool to include – once again it’s part of your toolkit for a support coordinator, is to have a look at the Housing Needs and Preferences. And this is a document produced by Summer Foundation, and it really is quite a comprehensive document. But it enables a person with a disability to sit down, it could be with their support coordinator, it could be with a family member, once again a trusted support worker, and really go through and unpack their thinking about where they want to live, who they want to live with, how they want to be supported, types of housing et cetera.

And it’s a long document – there might be times where you adapt it a little bit, or go through it in steps so that the person has enough time to do their really good thinking about what they’d like. But it’s a really useful document. And again, it’s something that we quote in our SDA reports, as evidence of a person’s needs and preferences. And again, it’s that touchstone, making sure that what we are doing is being driven by that person, and that their wishes, their dreams for themselves, are the focus of what we put to paper, in support of their request for SDA.

**Andrea:** So those tools are fantastic, as you said, for guiding the way that you’re approaching those conversations, and your support for a person – but it sounds like they also really then inform the kind of reports that you are writing, that they’re good evidence for that report that goes in to NDIA.

**Linda:** I think what I really like about the Housing Needs and Preferences Form is that it’s just comprehensive – it means that you’ve covered off all your bases. You know it’s really easy to have a conversation, and then miss bits, or I understand that’s your preference, but not actually unpacking why that’s a person’s preference. I was working with somebody who really valued their privacy, and that’s important – but actually having that deeper conversation as to why, what’s that about, and why that’s really important. So, it gives you an opportunity to really unpack at a deeper level. And then of course that gives you more information to writing about a person, and their needs and preferences.

**Andrea:** Have you had feedback from participants that have been through this process with you Linda, feedback from them about what this kind of conversation means to them, what it’s like for them? Because like you said, they are deep conversations – I’m interested in what kind of feedback you’ve had from participants about this approach.

**Linda:** Yeah, I tend to work with people with really complex communication needs, so sometimes the nuances of those conversations are not as easy for that person to articulate. But what I do understand is that people appreciate working in that person-centred way. As a support coordinator, sometimes we’ve got limited hours, and it can be really tempting to do things that’s quicker and easier not to involve the person. But that’s not the right way of doing it. It’s really tempting to do the quick and easy way, but actually coming back to the person. And once you get to know them, some of those processes become much quicker and easier as well.

But I think the people having their needs and their preferences, and their goals and visions – it’s like honouring them, in the way that most people I suppose, who don’t necessarily need support, are able to honour their own goals and aspirations, and go and pursue them. This is again the same as, my role is to assist a person who has a disability, and a disability-related support need around this – and therefore what I can do best is honour their goals, the same way that they do themselves.

# The importance of capacity building

**Andrea:** Can you talk about the importance of capacity building? And we know that’s the key principle of the scheme. What does that mean for the approach you take as a support coordinator, but also what it means for the participant themselves?

**Linda:** Yeah, I think it’s pretty interesting, and particularly when we’re thinking about people moving to a new home. We all do capacity building when we move to a new home, we build our capacity to get to know the area, et cetera. So once again, it’s worth really thinking about what most people require, and then additionally what a person with a disability may require. But I feel like it always opens up new opportunities.

I really believe that if someone is moving to a new home, where we can start the capacity building beforehand. If there’s an opportunity to start using assistive technology before the move, even if it’s not in the same way that will happen in the new home – but just starting to build a person’s familiarity with the assistive technology for example. Or building a person’s familiarity with the area, starting the travel training, the navigation around the area. Starting that community mapping as well – finding what’s local, what’s something you can walk to, or be involved in, or not far to get too, that’s going to really float that person’s boat.

So really starting to do that capacity building and linking before the move, I think is really, really vital. It depends as well on the skills that a person’s going to need, really identifying what new skills a person will need in that new home as well. And I think this is where working with a support coordinator, working really closely with the allied health professional and the person again, to understand what skills need to be developed, what skills can be developed. And then really helping that person navigate that very often, tiny incremental skill building, that will enable them to be more independent, enable them to have more opportunities in their new home. And more choice and control as well.

I think the other part of really moving to a new home, particularly if someone’s been living in a situation where they haven’t had a lot of choice and control, where people have lived in perhaps, very institutional settings – whether that’s residential aged care, whether it’s a group home that’s run in an institutional way. Moving to a new home can be a really great opportunity for a person to have more choice and control over their life. But sometimes that even requires a level of building of confidence – more support around decision-making.

So really, when a person is looking at moving, part of that capacity building might be around that person having some support for decision-making, that helps them have more control over their life, to make sure that they have access to the information to make informed decisions. And this is something that’s important for all people, regardless of whether they have a cognitive impairment or not – but it’s really important that people have the opportunity to develop their decision-making capacities, and be supported to do that.

# Supporting someone to build their own support team and setting up shared management agreements

**Andrea:** I was just going to say in relation to what you just said Linda, building capacity around choice – what’s been your experience of supporting people to build their capacity in choosing, and then managing or coordinating their support team?

**Linda:** It’s one of my favourite things to do Andrea, is to assist someone to build their support team. And I’ve had some really great experiences with some people doing this. Quite often, the approach once again seems to be with a lot of services, it’s a person on roster – whether they’re well-suited to the task or not. I’ve done this with my son as well, so I’ve been doing this with my son for a really, really long time, so I sort of feel like I’ve got some good runs on the board with him, as well as a number of people that I’ve assisted.

Really, we need to think more nuanced about the support worker role, and what in particular that is. I think the perfect personal care attendant might not be the best person to be assisting you – they might not necessarily have the skills to assist you with social connection, or cultivating community connections. So, really looking at the skillset that’s required for a particular task. There’s a person who I was assisting who absolutely loved the surf, and wanted to learn to surf – so obviously, her support worker needed to be able to be confident in the surf. We looked at people who’ve got a bronze medallion, who were already surfing, and had the skills that were required to support this woman safely – this very young woman, safely in the surf. So, really looking at people being able to recruit support workers who share their interests, and have the skills that are required to support them.

It’s pretty interesting working with service providers around this. I’ve at some point, reached out to a number of service providers in my area to say, “would you like to organise a shared management agreement with a person with a disability?” And by shared management, it really is the service provider entering into a partnership with the person with a disability, and really outlining the roles and responsibilities of both the support provider, and the person – and perhaps any family members or trusted others who are involved in managing.

Even a person with really, really complex needs, we’ve been able to establish a shared management agreement. It’s an agreement on top of the standard service agreement, and that person’s been able to put ads out, recruit their own support workers. They’re employed by the service provider, and the service provider maintains the statutory obligations of employer – but the day-to-day running of the team is done by the person with the disability, this man and his family. And it really makes a lot of difference to the quality of his support, and him being able to pursue his goals. If you’ve got a goal to be a surfer, if you’ve got a goal to play music, if you’ve got a goal to make films – you need someone who has the skills to assist you. Very, very often anyway, you need someone who has got those skills, to be able to assist you, or assist the person in pursuing those goals.

It’s really interesting. And I think the thing that I find even more so interesting, is that sometimes the people who are found for these roles, might not have disability experience – but they share a passion with the person, and they’re interested. And they train up really, really fast. So, someone whose maybe not had any experience with a person with a disability, but knows a lot about surfing – can then be trained to provide the support that that person needs as well. Again, good training budgets are useful in a person’s plan as well.

**Andrea:** Yeah, absolutely. And is it right that the shared management agreement is about a support worker that understands the person with disability’s support needs working with the person with the expert knowledge or experience in whatever topic is relevant. Those 2 people working together with the person with disability – is that what the agreement is about?

**Linda:** The agreement really is the roles and responsibilities between the provider. There’s situations where we’re looking at shared management, we’re talking about situations where a person’s not necessarily able to self-manage, or to recruit or employ their own support workers. It might mean that that might be too complex for that person, or there’s not enough safeguards around that person. So, it’s a situation where you are still using service providers, but you’re asking service providers to operate in a different way – in very much in a partnership way. And this is negotiated.

There’s a really great document produced by WA Individualised Services on Shared Management, and really kind of outlines how shared management works. There’s a whole continuum of each situation, each shared management agreement’s probably like a fingerprint – they’re all individual, and they’re worked out between providers and the person. The other interesting thing is that it can change. So, if informal supports around a person are a bit sketchy for a period of time, or they’re just not as available – then it might mean that that service provider might need to take a bit more of a hands on role in organising the support roster for example. Where that might have been previously done by a family member.

So, you’ve got that ability to move across the continuum, renegotiate responsibilities, renegotiate roles to suit the particular situation.

# Supporting people to make friends and develop relationships

**Andrea:** The other question I wanted to ask was when you are working with participants, how you support them as a support coordinator, in terms of developing friendships and relationships, that are really important for people to have.

**Linda:** I think this is something that often gets seen as sort of the sugar on top, rather than the cake, part of the fundamental support that you provide to somebody. And I think if you ask most people what’s important in your life, what gives your life meaning – people will answer saying friends, or family, or those relationships they have. They’re certainly really, really life-enriching.

The other part of these relationships is that they’re a safeguard. They’re really important for all of us, to have friends and family, and people we can call on when things aren’t going well. It might be someone you can call on to pick you up late at night – a friend you can call on to pick you up late at night when you can’t get a taxi, it might be someone to pick you up from hospital, it might be just someone who’s just checking in to see if you’re okay, if they haven’t heard from you for a while.

But these become even more fundamentally important – these type of relationships become more fundamentally important, when we consider people with disability. And they’ve been left off in that regard. They’re often seen as something too difficult to achieve, we don’t have time. And this is really quite legitimate – it’s very, very hard to think about establishing relationships, helping someone establish relationships, or cultivate relationships, when you’ve only got a certain amount of support coordination hours for example.

It might be that you really need to think about how you can work with a team of people working around that person with a disability, how you can work with the providers of the day-to-day supports, so that support workers start to become much more aware of their role. Not as a paid friend, because there’s no such thing as a paid friend, but as somebody who is there to help facilitate, to help a person cultivate, to be a smart communication partner.

And to really seek those opportunities – to help a person seek those opportunities, where they’re going to meet other people who share their interests, who are like-minded, and just starting to really set those early seeds for developing a relationship or new friendship with a person. Just even being known in the community, having a regular café where a person might go to, or a regular shop where they buy their groceries, where they get to know the people there.

Even just doing some good community mapping, and seeing where that person can be known in their own right. And start to once again, start to plant those friendship seeds, those relationship seeds – sometimes they need a bit of cultivating. Sometimes it might be that a person might need some support to make the first move, in perhaps taking a friendly hello relationship, to a cup of coffee at a convenient time. It’s really one of those sort of things, where you really need a skilled support worker, often to assist a person with those developing relationships.

**Andrea:** Yeah, it makes so much sense, Linda. The other question in relation to what might be important to consider, that people might need in their plan, apart from hours from a support coordinator, or support worker, to help facilitate opportunities, like you’re saying – is there anything else to keep in mind that people might need in their NDIS plan, to help develop those friendships?

**Linda:** I think what we’re seeing is, within the agency, I think we’re hearing a little bit of some renewed interest in helping people establish circles of support. And circles of support are, it’s an old concept, and I think most people without a disability or without support needs, have our circles around us of support, in a very informal way.

The circles of support were first initiated by, or first started by a woman called Judith Snow, who was a Canadian woman with very significant disability. And when her life actually hit crisis, her friends rallied around her to help her navigate that crisis. And she called her friends, ‘The Joshua Committee’, because they blew down the walls of Jericho – which is a biblical reference.

And that was essentially the first circle of support – and ultimately, that ended up with Judith Snow being the first person in Canada to have individualised funding. I think this is back in the ‘70s, so it’s quite old. Sadly, she’s passed away – but Judith’s gone on and really established a movement for circles of support around a person. And it really is cultivating those relationships – again, bringing people in who, they may include trusted support workers who are in paid roles, but bringing people together to brainstorm and take action, alongside that person with a disability, who is the focus of the circle of support.

**Andrea:** That’s great. I imagine just something as logistics in terms of transport funding, that’s a key component of this too.

**Linda:** People need to have adequate transport funding, and I think it’s really hard to be included in the community, if it’s going to cost you too much to get out there. And I think we’ve got to realise, or the agency should be realising, that most people with a disability, have very limited access to transport, very limited access to accessible transport. It’s really, really one of the factors that really impact on people’s ability to be included in the community.

And it’s expensive – people need to have decent allocation of transport funding in their plan. And also having a really good idea of how that flexibility can work, and making informed choices about how they access that transport funding. At the moment there’s not a great deal of understanding – it’s actually really messy and complex, and it really shouldn’t be that messy and complex, but that’s what we’re seeing at the moment, in regards to transport.

At the moment there’s 2 options for having transport – one could be as a periodic payment, which actually goes into a person’s bank account. The other option is to have it as part of the core budget. The advantage of having it as part of the core budget, is that it then is flexible amongst all the core funding. So, if you require more money for transport, then you have access to that through your core budget. If you’re receiving the periodic payment, and there’s 3 different levels. The first level is around $1,500 a year, $2,500 a year, $3,500 a year – and they are paid fortnightly into the person’s bank account. But that’s actually where the NDIS, that’s the extent of your transport budget. Any additional costs for transport, need to come out of your own pocket.

So, it’s just really important that people understand the difference, when they go for a plan review, or the support coordinator assisting, understands the difference, and can help a person make the choice that will best meet their transport needs.

# Working within a best practice framework

**Andrea**: To finish the podcast, I asked Linda if a best practice framework exists for support coordinators. Linda is currently producing a practice guide for support coordinators due for publication in August, but in the meantime, I wondered if there’s any particular framework that’s guided Linda in the way she’s approached her work as a support coordinator?

**Linda:** Look, I don’t know if there’s a best practice framework as such – but I think what I’ve put together that informs my practice, and it’s what I believe is really, really useful, is working from a human rights framework. And there’s some really important parts to having a human rights framework, is that you believe that everybody is entitled to determine their own life, and how they live. And that people should be and allowed to be, and are encouraged to be, included in the community in ways that are meaningful, and meaningful to that person.

Really operating from the social model of disability as well, where we understand disability doesn’t necessarily result from the impairment in a person, but from our society, from access, which can include access to information, physical access – like we can all very often see the steps in the way that will prevent someone’s access. But once again, access to information, wayfinding – there’s a lot of attitudes that separate people with disability from our society as well. And really, really starting to challenge those, and ideally, we will see that people with disability, through a social model of disability, will have an active presence in our community.

I think the person-centred practice falls nicely within that, where we are actually always guided by the person. And then we tailor the supports around the person. And the third component that I think is really important, is having a trauma-informed practice. And that really is recognising, that really sadly for many people with disabilities, their life has included trauma, and that leaves a mark, it leaves a scar. And really ensuring that our practice is not re-traumatising people, but is actually helping people in the healing process, and working from that perspective as well.

And there’s good information available on all 3 of these components, and as I said, it’s been what’s influenced my practice, and the way I approach the work of support coordination.

**Andrea:** Thank you for listening to Episode 4 of the *“Best Practice”* series. The Summer Foundation would like to thank Linda Hughes, our UpSkill Lead, for sharing her expertise relating to *“Best Practice”*, as well as all the other support coordinators and people with disability, for their very generous contributions. We would also like to thank Gandel Philanthropy for funding the development of this series.

You can find out more about the UpSkill program, for support coordinators and for allied health professionals, on the Summer Foundation website.

If you’re a provider and would like to connect with the professionals in this podcast series, or with other support coordinators working with people with complex needs, please consider joining our free online Community of Practice.

If you’re a person with disability, or are supporting a person with disability, and want to search for a new provider, you can do this through our new provider directory, that’s being launched in August.

You can access the Community of Practice and Provider Directory through the Summer Foundation website. There’s a link to these platforms, and other resources that Linda mentioned, in the podcast notes.

Thank you for listening.