**Episode 2, Part 1**

***Supporting a person who needs to leave hospital***

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**Jenny:** The support coordinators is just so vital. They can do things I can’t do. There’s nothing that’s too difficult for them and that’s what I really appreciate so much about them. I couldn’t imagine doing this actually without them. I don’t think I could. They are just such a vital link.

# Introduction

**Andrea:** Hi, I’m Andrea Lockwood, and welcome to Episode 2 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 - Alex Foote and Laura Schutz from Independence Australia - who describe best practice in supporting people with disability in hospital, who want to return to the community and avoid aged care.

It also includes interviews with Sally Messer who has a disability and her mum Jenny, who talk about what support coordination has meant for them and achieving Sally’s goal of leaving hospital and returning home to her family.

Linda Hughes, who is the lead for the UpSkill program, also joins us in this podcast, talking briefly about the COAG Agreement which defines responsibilities between health and NDIS.

Other topics covered in Part 1 include establishing what’s most important to the person in hospital, the differences in working with a new versus existing participant, key areas of focus for SCs in the hospital setting and working alongside health.

First up is Alex, who shares a little about her background and work at Independence Australia, followed by Laura who shares how she approaches mentoring other support coordinators.

**Alex:** Yeah, so I guess my background is probably similar and then not similar to where support coordinators have come from. I’ve been a support worker which I think helps bring a certain set of skills and experience to the role that I do now because I understand some of the day-to-day implications of what we do and what we talk about with participants so some of that stuff is really relatable. However the background that I feel has given me the most resources is really in sales and customer service and the training that I did in my Diploma of Community Services. It’s the communication skills that you learn and that’s primarily where I’ve spent most of my working life up until about 4 years ago and then I arrived in disability at Independence Australia on a placement and that’s when we had case management and then transitioned over to support coordination and have been there ever since, so it’s fantastic.

**Laura:** As the lead support coordinator I support and mentor and coach our team of support coordinators. So we have 5 support coordinators within the team who all carry a pretty full caseload. But I also make sure that we have coaching and mentoring sessions that are separate, as well as the training focus. Because one of our main roles is to help participants to navigate through a scheme and how it relates to their life. And we’re not able to do that unless we have the tools and unless we have resources. So a big part of what we need to do is make sure that we’re equipped so we can support others. And we need to factor that into our time.

A lot of it is really knowing where to look for things. Because it’s okay if you're not completely all over the latest bit of information, or the latest data, or the latest number, or wording. But as long as you understand how to look for something, how to follow it up, and how to translate it and how to direct other people to it, then you're halfway there.

# Establishing what’s most important to a person in hospital

**Andrea:** So working with people in hospital, it can be a pretty overwhelming environment and for some people, they may have been in there a really long time, months, sometimes even years. Can you tell us a bit about, as a support coordinator, how you establish what’s most important to a person that’s in that kind of environment?

**Alex:** Yeah so look, to be honest in my experience by the time you meet somebody they’ll tell you straight off the bat what is the most important thing to them and it’s getting out, they just want to go home most of the time. It’s not a pleasant place to be and often people have got families and responsibilities or they’re just fed up with the day-to-day rigmarole, not being able to leave the hospital and through COVID that was even worse because people weren’t allowed to leave the hospital, visitation was extremely limited and non-existent for a period of time. So I always listen, so watch body language, listen, listening to the participant who will tell you what their priorities are in terms of – like I said it’s getting home but then you helping to unravel “okay, so what does that mean for you? And why do you or what are you going home to?” Because that’s how you unravel what are their main concerns? Is it I haven’t seen my kids in months, I’ve got a dog that I need to get home to, I need to work. So really listening and trying to help them unpack their priorities from the top down.

Then secondarily it’s “what's making you the most uncomfortable right now?” Thus I try and help people express that. What are the biggest pain points or what is it that you've been asking for and you’re not feeling like is being heard? So I think it's coming in and having a think about how can I best support this person through a really heightened situation where they will need help to understand and unpack what their own priorities are. I wish I could have just said “oh this is how it’s done” but that to me, being able to hear and be sensitive and be in that moment with some and people are often frustrated, and it’s being able to sit in that with them because it’s a traumatic thing, it’s a hard conversation to have.

So it’s a balance I think of listening, prompting and giving information all in a very sensitive way and I think it takes experience like each time you assist someone through this process you are going to have learned something really useful, lots of useful things from the last time. So there's no right or wrong way but it’s an informed approach.

**Laura:** And the approach changes every time. This is probably one of the main skills that we need to have as a support coordinator, is to be able to adapt that approach and understand that every single situation is going to be different. So it doesn’t matter how many times you work through that discharge process with someone, there’s always going to be something new that pops up. There’s always going to be a different way that you have to approach it and be prepared for anything. But in terms of working out how you gather that information, it’s really about opening those communication lines yourself.

What we tend to do is try and provide as much information to someone as possible. Because we really want to upskill and inform and make sure we don’t miss anything. But at some stage it can overload and overwhelm people. And then you tend to find that’s where things go missing, because people either zone out or shut down.

That’s how I start pretty much every conversation with every new participant or family member, or hospital as well - “we’re going to probably need a lot of information. Some of it we’re going to be able to obtain from other people, or paperwork. But a lot of it is more just establishing that there will be a heap of things that we need to go over, and it can be tiring. So we can go at your pace.”

On the flipside, it’s very difficult for participants to feel confident and comfortable that everything is being ticked off, if they don’t have a bigger picture. So we tend to try to map out what the bigger picture might be, and then hone in on what someone’s priorities are; what the details are that we really need to focus on first, and do a bit of a flowchart, or a running sheet. Sometimes it’s a visual. Sometimes it’s dot points. And sometimes it’s just a verbal conversation to try to grab that info. But yeah, in the end, the priorities that people have are different too. So what’s urgent for one person is not even going to be applicable – someone else may not even want to hear anything about it.

**Andrea:** So the kind of things that you're doing with each person might, in principle, be similar. But the way you go about it and how much information you give is going to really vary across each person.

**Laura:** Absolutely. And the process – the standard tick boxes, what you have to work through to make sure someone’s going to be safely supported to discharge home are quite similar. But the order that you do them may also be different, or the order that you receive the info can be very different. And a lot of that is also very dependent on what stage we come into that situation. It’s a very different approach if we’re coming into a situation where someone already has an NDIS plan; they’re in hospital, they’re ready to discharge home. There’s no reason why they’re needing to be in hospital medically. But there’s 1 or 2 barriers to being able to actually get home. And it could be environmental. There could be home mods needed, or there could be support services that need to be coming in and trained up.

On the other end, we might sometimes be involved and engage right near the start of someone’s process towards discharge. And we might actually be involved in the proper planning, and working really collaboratively with the allied health team and the social worker at the hospital. And that’s a very different approach. And you tend to find, in those circumstances, you're going to uncover a lot more little details and a lot more potential risk that you can try to prevent before someone’s ready to come home. Otherwise, if it’s very quick discharge home from the time that you become involved, you don’t actually start to unravel things and peel back those layers, until someone’s already in an environment that might not be suitable, because one tiny little detail wasn’t covered during that process before you became involved.

**Andrea:** We talked to Sally, a person with disability, about her experience of being in hospital for 17 months and what was most important to her at that time. You’ll hear from Sally throughout the podcast, as well as Sally’s mum, Jenny.

**Sally:** Hi, my name is Sally but known more as Sal. From October 2017 to February 2019 hospital was what Mum and I called home. We were an hour and a half drive from my own home and all my friends and family in country Victoria. This was a challenging time but what we had to do. But with the wonderful support from my family, the community who raised funds to build a customised room for me, the local paramedics, support coordinators and the agency who provided the staffing I needed to look after me so that I could come home and not end up in a facilitywhich would have been further away from my family and friends and left me quite isolated. The process wasn’t easy but worth the fight as home is where I wanted to be.

# Working with a new NDIS participant versus an existing NDIS participant

**Andrea:** We asked Laura and Alex about any differences they’ve experienced when working with a person who is already a participant versus someone who has a new disability. They shared how they approach different individuals, as well as working with different parts of the health service.

**Laura:** So generally, the majority of time we’re working with people who have a new injury. And with that, there are quite a few different complexities and barriers that exist before you step in there. Mainly because when someone’s going through a new injury, they’ve had a major change in their life, in their circumstance. And even if they’re able to go home to their previous environment with some adjustments, it’s not the same person or situation going home. And quite often you're trying to help support that participant and their family members as well to be able to identify how they can think about the concept of going home to this new life, or a new environment. Let alone try to deal with and talk about funding and support needs and levels and intensity, and how to process invoices, working out what clauses they need to be aware of in a service agreement.

Most people in the midst of that situation are just trying to focus on their rehabilitation, being able to get to that optimised level where someone can go home and try to start living that new life as best as possible. So having to try to navigate that circumstance change, as well as a new scheme, it becomes a very – it’s like a dual complexity, because you're working with someone who’s going to have psychological impact as well. And the intricate dealings with family members and dynamics; you're working with people who previously might have been in a partnership relationship, and now all of a sudden the other family member is now seen as a carer, rather than a partner.

So it’s very difficult for those involved. And quite often we work with people with new injuries who have young families, so that adds an extra layer, and that parental role is then brought right to the forefront. And I think the extra layers, when you're talking about someone who has a new injury, as opposed to someone who has a change in their functioning, is that that person previously saw their life as something different. They know what they can no longer do, and it will potentially change in an instant. Whereas, on the flipside, we work with other people who have neurological or progressive diagnoses, and we’re looking at a continued degeneration or progression in that decline.

So there’s a very different frame and a different mindset there, and a completely different set of psychological impacts there where someone’s knowing what their future may hold. They may end up requiring more and more support,

**Andrea:** Laura, you were saying, the emotional and psychological impact that goes with a new injury, that exists for someone with a change in their circumstances, but they’re different at the same time. it’s interesting that you're talking about that’s such a big part of what you're doing. It’s not just helping someone put a plan in place, but also really being so mindful and addressing, where you need to, those other aspects of how they’re managing with what’s happened in their life.

**Laura:** Yeah, and just being mindful that you're only one tiny little part of that person’s whole progress home, and whole step to getting home. You're just one tiny part of that, and you're not the most important part of it.

**Alex:** If somebody’s got a new injury they’re generally going to be in rehab by the time you’re starting to work with them because that's the journey, that’s the pathway out when you have a new injury and it should be the process if you’ve had a change in function as an existing participant as well. However it’s not always clear-cut, so depending on where that person is, makes a hell of a lot of difference as to the process. Because I have found, in my experience, rehab teams have I think, much more access to education and support around the discharge planning process for NDIS participants, even if they’re existing participants.

I have found in other situations if we’re working with other wards within the hospital where somebody may be because they’ve either got multiple disability-related health conditions or they weren’t eligible for rehab or they’ve chosen not to go to rehab, I have found that that’s a little bit more challenging because some of those wards don’t necessarily have the resources probably primarily to work as maybe collaboratively, and the communication can be harder when you’re trying to speak to someone directly on a ward in a hospital as opposed to a rehab unit. So like I said it’ll be depending on where that person falls within the hospital system and I think sometimes if somebody is an NDIS participant, the health system doesn’t always recognise that rehab is still something that they’re eligible for or they might see that this person’s got supports at home so that’s okay.

So I think it just takes a little bit more time and things can be missed if you're not all over and really pushing or trying to drive what needs to happen because if the support coordinator misses that, that there’s been a change in circumstance, the hospital knows if somebody’s got a new injury that this person’s not going to leave until they’re an NDIS participant and they’ve got a plan and they’ve got supports in place. But if that person is an existing NDIS participant they may not even know what support that person's got on the outside, they may just think, oh yeah, this person’s an NDIS participant, they’ve got support workers, they’ve got a support coordinator, that’ll be fine. But you may miss a great opportunity there to help gather really important documentation and have them actively involved in a process to escalate that within NDIA and have better supports in place for that participant.

# Person-centred communication

**Andrea:** Building on the approaches that Laura and Alex take with different people, Laura also shared how she communicates in a person-centred way.

**Laura:** the communication lines need to be open with every single person who’s involved, be it the participant in whatever way they want or need to communicate - and that in itself can be a physical thing or situational. Being mindful that there may be family members or representatives, nominees involved, and what the dynamics of that relationship may be. And then obviously the stakeholders, the hospital team, in particular the allied health team. We generally need to try and open up those communication lines between the social worker, and generally the OT is the main contact for information. And trying to work out how someone actually prefers to communicate, how much information they want to receive, and what level of participation they want to have; what sort of involvement.

…what we try to do is adapt however someone needs that support, but to also keep someone involved. Keep someone linked in. So whether it’s through a text message each time that we action something, whether it’s being in a Zoom session – we quite often go through in a Zoom session with someone and actually action – type out emails to someone whilst the participant is giving us input.

Or whether it’s just cc’ing someone into an email, just so that, “this is what’s been done. Just so that you're aware. You've got the information you can come back to later, and we’ve supported it to be actioned. But you can go back at your pace and find out exactly what the steps were, and if you ever need to recall it, you can go back to it. So it’s available.” That’s what we see as that empowerment, is someone being able to work through it at their pace. Have the tools to do so. Be supported to do that.

# Key areas of focus in hospital

**Andrea:** Alongside person-centred communication, we talked to Alex and Laura about the key areas they focus on when beginning to work with a person in hospital. First, here’s Laura.

**Laura:** Well, firstly, to find out what the participant wants. So there’s no point us rushing forward with trying to get everything in place for a circumstance or situation that someone doesn’t actually want. And sometimes it’s not quite as easy to work out what someone wants, or whether it’s actually that person’s decision. Quite often someone’s influenced by what’s going on around them, or what they think they might be supposed to say. So a lot of it is – that priority is just focusing on how we can have someone’s voice heard and contribute to the conversation. And then map out what the initial priorities are to be able to get that person home.

And generally we’re needing to focus, as a combination, on what someone’s ideal goals are in an ideal situation, but at the same time what those barriers are. And what would happen if we can’t assist to get those supports set up. So you're looking at a lot of risk factors as well, without trying to dwell on it too much. Just – it can be quite overwhelming if you're having a conversation with someone about what someone wants, and then say, “all right. What’s stopping you from getting there? And what’s going to happen if you can’t?” It can be quite overwhelming to have to try to delve into what is preventing you from going home, especially with the emotional aspect attached as well.

So a lot of it is just, again, working out how – what level of information someone wants and needs, and filter it through at that right state. And then link it to an action that’s required.

**Andrea:** Yeah. Communication is key, isn’t it, with everything that you do. What’s coming out super clearly is how important communication is, but how different that is, how varied with each participant, but then also between the participant and the staff that you're working with as well.

**Laura:** And that’s the thing, because every single person who you're communicating with has a different focus. They have a different role, and they have a different expectation. So to be able to bring those 3 together, and make sure the participant’s voice isn’t lost in all of that, particularly if the participant doesn’t have a verbal outlet for that voice, that’s where the challenge becomes quite evident. Whilst having the communication lines open is absolutely paramount, it’s also about making sure that you're managing those expectations.

**Andrea:** We asked Sally’s mum, Jenny, about her experience of how Sally’s support coordinator and the hospital staff focused on what Sally really wanted.

**Andrea:** Jenny, you were the main contact point for the support coordinators to be representative for Sally in the hospital?

**Jenny:**  Mm, yeah. I was her advocate I guess in that respect. We got to the point of coming home, it was really up to the social worker. So then the social worker took the next step and then she involved the support coordination into health in the next step of getting home. So they were included in a lot of meetings that we had to set up this idea of getting home. It was met with a little bit of resistance from the hospital staff because they just didn’t think that it was possible…

I guess eventually we got them to a point where they started to understand what community meant because once the building started...they then got on board a little bit more....

...Once Alex and Laura did come into the picture, the support coordination, their incredible letter-writing and advocacy on our behalf was incredible. Eventually the Health Department came round also and could see how important it was to us to get Sally home and not to go to a facility.

**Andrea:** Here’s Alex again, sharing what she focuses on first when working with a person with disability in hospital.

**Alex:** I think being a really pragmatic thinker and someone who is just really methodical is a really good natural ability as a support coordinator. But for somebody who tends to think of everything at once and think there’s so much that I'm concerned about first up, you probably need to help yourself, have a more strategic approach just entering that. But anyway that’s just me personally.

So the priorities are obviously making yourself known to the participant and confirming – usually it happens beforehand but just confirming that that participant is comfortable with you being their support coordinator and making sure that straight off the bat they understand because coming from a hospital environment where people we know become very quickly institutionalised and they don’t have a lot of choice and control in hospitals, they don’t necessarily realise that they’ve actually got a choice in who provides their supports from here on out.

So basically it’s a lot of feeding off the conversation about what’s a participant’s priorities, informing of my role, but then basically trying to set up a conversation with the most relevant people in that hospital team. So making yourself known, making yourself available and also at least starting up a conversation with whoever the main contact is going to be. But then I think it's really valuable to propose if they haven’t already, that all of the allied health and nursing if possible, and medical if possible, may not be needed, but relevant stakeholders meet initially. I think that’s a good place to start because as a support coordinator that will give you an opportunity to get in front of all of that team and figure out what all of their individual priorities are because they all have different priorities for that patient.

# Working alongside hospital staff

**Andrea:** We asked Laura and Alex about the approach they take to working alongside hospital staff, and navigating between the responsibilities of health versus NDIA, including organising disability related health supports.

**Laura:** A social worker is generally a very pivotal part of that whole process. And if they’re not then that’s the first thing we try to identify, is why a social worker isn’t involved yet. So firstly, just identifying who the key players are, who those important people are involved in that everyday situation. Who’s going to hold the actual information? And then work out who’s going to action it. Because it’s all well and good to have all the information, but if nobody’s actioning it, it’s just going to sit there.

Generally we would be having initial contact with a social worker or an OT. And then we might also become involved and link in, either directly or indirectly, with the rest of the allied team who are involved. So sometimes we might set up, or they might already be set up with a key contact at the hospital. And then our communication would be primarily through them as the liaison, and they would then be working and communicating through with their team as that point of contact, and then coming back to us. Other times, we have direct contact details for every allied team member. That can work sometimes, it just depends on the situation, on the individual, and also on the people.

But it can be quite a lot of people involved, just internal in the hospital, let alone externally. You can be in communication with the social worker, an OT, a physio. There can be a couple of different types of physios involved if they’re neuro-physios. Some may be seating specialists. So they might come in just to look at a certain prescription. There might be a physio attached to someone who has respiratory support, so that’s an extra specialty.

People might also have other medical associated issues, such as they might be involved in the renal team. Someone might be diabetic. There’s a lot of people who can potentially be involved. So to really be able to identify who those key people are, and who you need to directly communicate with, as well as work out how you're going to be able to filter the rest of the information through. That’s one of the key parts of communicating. Because if you don’t have that, you can’t collaborate with everyone.

**Alex:** In my experience, primarily it’s the occupational therapist who I have dealt with as in been the main contact for that participant. So the hospitals are starting to actually allocate people roles inside this discharge and NDIS collaboration space, so generally there’ll be one person and they will probably coordinate from their end who’s available and when they’re available and facilitating that communication because trying to have contact details of 5 different people in a hospital and then communicate with them separately, it’s not really effective.

I find that that can actually work against you, so I tend to encourage a main contact to help set up a meeting with the participant because they also will know the participant’s schedule. Because as we know participants in hospital are often in different appointments and also they’ve got different routines, when they eat, when they’re having self-care which we would think is in the morning or the afternoon but people have got to get through a lot of patients so they might be having a shower or a bath at a random time throughout the day. So you’ve really got to be mindful that people on the ground in a hospital, if you're not there obviously, are the best people to coordinate from their end, I think, but being really clear about when you’re available, how you can be involved and taking as much of that responsibility. So setting up maybe a bit of an action plan and offering to run the meeting if that’s what’s needed. Just basically assisting to make it as easy for them as possible.

It’s probably relatable for a lot of support coordinators out there, it took me a while to I think build my understanding of the hospital and health system. The hospital teams are not actively trying to work against anybody. They are extremely limited in resources, they have targets, and it’s never going to be perfect and everyone’s just trying to do what they can within their role. They experience just as many challenges as we would in assisting that person so it’s really important to go in with that open mind that there’s going to be things that are going to frustrate you as a support coordinator because you’re going to think well why can’t they just do this or why is this not being done or the participant should have this.

But I think if you get people offside you’re going to lose a huge opportunity to grow this system together with those people that need help to learn what is it like for that participant when they go home, and what can they do slightly differently in their role to help streamline those processes. Going in and trying to learn from people and offer your support and focus on the main priority, which is the participant getting home, but at the same time keeping in mind that you may have to have some challenging conversations or have ways to communicate really effectively about what you know is health’s responsibility and the NDIA’s responsibility and what may be available to that participant from both. I think you have to just keep perspective, be collaborative, go in with the aim to actually collaborate and offer your support, within the limitations of your role obviously, but act as if you are all facing the same challenges because you actually are, really. You’re not against each other, you're facing the same issues.

**Laura:** Every situation we come across where there is that crossover, which is almost every situation really, there’s always something that’s going to be seen as a sticking point. And there is no black and white with what is disability related health support overall, and what’s not. Because it’s all dependent on the situation and the participant as well; what they need that support for, as to whose responsibility it is. And there are – one of the big sticking points is nursing, community nursing, and catheter care. That’s a massive, massive block for a lot of people.

And it’s been an ongoing challenge to try to obtain some sort of clarity between both the health and NDIA systems as to whose responsibility it is in different situations. So a lot of our work is trying to help someone navigate through something that there is no clear pathway for. So being able to interpret things and link them and align them to what the fundamental principles of the scheme are, and the operational guidelines, and obviously the legislation, is what we try to do.

Just trying to really identify what the details are, identify what someone’s needs are, and identify why. And then the main thing that we need to sometimes focus on is how to present that to NDIA and how to present that with the hospital, how to try to understand and unpack it in a way that’s clear enough that even if there is no specific determination, then we can come to some sort of resolution that’s going to work for everyone, and fit within the scheme guidelines.

I think familiarity with the system and who’s able to do what is the starting point. Building a rapport and building confidence and respect across teams is also a really important part of collaboration.

There's a particular situation with a very complex circumstance, where someone had been in hospital for quite a few years. High support needs across all facets of their life. And there were a lot of stakeholders involved. And we had to try and gather a lot of information in a very short amount of time. And also this person was going to be one of the first people who was going through a plan review since that disability health-related change.

We established initially just a meeting with the social worker and the participant’s family really high-level, just to look at overarching, what timeframe are we looking at, what the big flags might be at the moment with risks and barriers, and what the outcomes need to be. What the actual purpose of this all is. Because I think we lose that a lot, what the purpose is. And then from that we established together – that’s the big thing – the social worker and I worked together to establish that timeline. And at each pivotal point in that timeframe we worked out who was already involved, so we wouldn’t duplicate anything that’s already being done, and who could become involved to action that next item. And then at what points we were going to actually meet up and evaluate it again, review it, and see if something needed to be adjusted.

It’s about realistically sitting down and going, “well, I’m not going to be able to get that done in time. Who else can support that?” Or, “this is way outside the scope of what we can do. This is not our responsibility. And we’re not trying to handball, it’s just actually outside the scope of what we can do.” But that mutual respect and expectation is a really big factor in making that work properly.

**Andrea:** We talked to Sally’s mum, Jenny, about her and Sally’s experience of the support coordinator working alongside the hospital team.

So it seems like the social worker at the hospital was also the main contact or connection point for the support coordinators? That Laura and Alex mainly worked through her, that social worker.

**Jenny:**  Yeah, that’s right. I had many, many meetings in Ivanhoe with Laura to start with and then eventually Alex because they work basically hand-in-hand, but then Laura was able to take on other cases while Alex kept going with me. So there was lots and lots of meetings to get things up and running because then we had to go into the consumables and there was a lot of things that needed to be put in place, also within the home to make it functional. All the consumables Sally needed was unbelievable but, it is like setting up a mini hospital in the home. But without them being behind that, I would never have known where to start, they were an absolutely vital link and they still are. If I’ve got any needs or troubleshooting it’s the girls that I go to.

**Andrea:** So through that period too, Jenny, were you able to sit in on meetings between the social worker and the support coordinators involved, Alex and Laura, or was there quite a lot happening behind the scenes, I suppose, that they just updated you on?

**Jenny** There was some behind the scenes which was quite unsettling, because you weren’t quite sure what they were saying. It was a little bit unnerving some of those meetings that we weren’t involved in. We were updated. But when it was all of us in together with the medical staff as well, we were able to have much more of a say and Sally actually – one of the important links that we did was we videoed Sally and she had her say as well and she told her story in that respect and what she wanted. I think that was quite a turning point in the understanding from the people that were trying to organise us to either go into a facility or home. But that was the big turning point, I think, that Sally had her say and they started to understand a little bit more what it meant to Sally.

**Andrea:** We talked to Linda, our UpSkill program lead, about the COAG Principles that define health versus NDIS responsibilities.

Linda, can you tell us a bit about COAG, and what that means in practice for you, and as a support coordinator?

**Linda:** Okay, so the COAG Principles, it’s sort of like part of the toolkit that you have as a support coordinator. COAG stands for the Council of Australian Governments. And even before the NDIS started, they got together – the state governments and the federal government got together, to really work out who was responsible for what. So, the idea of the NDIS isn’t that it does everything – there’s other services, other mainstream services, community supports etc, that are available to all Australians. And that includes people with disability.

So really, this is an important document that really outlines the who’s responsible for what. There’s some parts there we always find the I call it the ‘argy-bargy’ in the interface. There’s often the state government is saying that they’re not responsible for this, it’s the NDIS – and the NDIS is saying it’s the other’s responsibility. It’s sort of that kind of, it’s difficult to determine. Some of those decisions have gone to the Administrative Appeals Tribunal, and been determined at that level as well. So, this is complex stuff. Sometimes whose responsibility is it, but certainly these guidelines, the principles of responsibility, really give you a lot of direction in who should be responsible for a particular service or support for a person with a disability.

**Andrea**: Great, thanks Linda. Building on what you were just saying about those responsibilities, can you tell us a bit about the difference between what health is responsible for, and then disability – particularly in relation to the disability-related health support?

**Linda:** Yeah. So, this actually, some of the disability-related health supports, came about from an AAT decision. I think there were 2, fairly crucial AAT decisions around the same time. And this is where it gets really interesting, because the Administrative Appeals Tribunal had actually found that the NDIA was responsible for some supports that were related to health. These were supports the health system generally didn’t meet, and were considered to be disability-related health supports. And those sort of supports were around a person with an intellectual disability requiring support to manage their diabetes. Most people without an intellectual disability would be able to manage that themselves quite easily – but because of a person’s intellectual disability they required some disability health-related supports.

The other situation was people who have difficulty swallowing, and really needed thickeners, and assistance around mealtime management. And once again, this is considered a disability-related health support. Initially the NDIA was saying this is health’s responsibility – but ultimately it was found that this is an NDIA responsibility. And we had some changes made at that point, where disability health-related supports were included in a participant’s plan. There’s a couple of rules of thumb around it – the health support has to be related to a person’s disability. And it has to be ongoing in nature – so, it’s not an acute thing that just happened for a short period of time, but it’s a support that that person’s going to need ongoing, because of their disability.

So, that’s just some good ideas to keep in mind, when you’re trying to navigate that interface between health and NDIS.

**Andrea:** Linda’s summary of the COAG Principles 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 establish a person's housing and support preferences, including exploring short versus long-term housing, the value of short-term NDIS plans in hospital, establishing if the new home is working for the person, and pushing through to achieve the impossible.