**Transcript – Deafblind Hub Webinar #8**

MICHELLE: Hello, everybody. Welcome to today’s webinar. I’m Michelle and I will be hosting the webinar and introducing some of the speakers. I’d like to thank you for your time today and acknowledge the lands and the country that we are on today.

If you need to, please pin your interpreter and they will introduce the speaker and you can pin the speaker.

The first speaker we have today is Jessica and she is going to go through her experience as a participant on how to read your plan. Thank you. Welcome, Jessica.

JESSICA: Hi, everybody. Who is interpreting for me while I’m signing?

SARAH: I am.

JESSICA: Great. Hi, everybody. My name is Jessica. This is my sign name here. It is lovely to see you all tuning in today. Is it all right light for you guys? Is everything okay? Carol is saying it might be a bit bright in the background.

MEREDITH: Are you able to shut the blinds Jessica?

JESSICA: Is it all right here? Shall I go back? What about that? Is that a better? Beautiful. Lovely. Perfect. All right.

I want to explain a little bit about my experiences with the NDIS and certain issues, positive and negative things I’ve experienced, not all problems, but I want to start from my first year. I think that was, roughly, quite a few years ago. I was pregnant at that time with my daughter. So it was when I first met my NDIS planner. I didn’t really know a lot about the NDIS until I went there for the first time, and I went there with my support person, Karen, and she came along to support me in the process. I said I need an interpreter and certain things like that and going to the hospital and these were essential. We took a lot of time discussing that and I got quite a bit of funding for family support, which was really great. We had a big discussion. At that time I didn’t realise what her situation was and I thought that maybe it was just, like, there wasn’t much that we were going to need to discuss.

Anyway, we met and we had a discussion and that was really fantastic and quite positive, and we got a certain amount of funding and I thought, okay, that is great, but then what is the process moving forward?

I didn’t think I would run out of all of the funding within the one‑year period. I didn’t think that that would happen. I kind of took my time when I got the ‑ you know, I was having a baby at that time and I was a mother and had baby brain and things like that. The NDIS reminded me that you need to actually use your funding because we’re getting to the end of the funding period. I told Karen and we negotiated a lot of time and support during that time.

We were also working with Senses at that period of time and meeting with them, and we have had a lot of engagement with them in order to find interpreters and other support that I needed. At that time I didn’t realise that that was all included but it was great to have that experience at that time. It got very close to when I was going to be having my child and I thought, look, I can keep my funding for the future. I actually didn’t of any realisation that that funding was only for a one‑year period of time. As it came closer to the end there was a fair amount of panic which was at the exact time of my child’s due date.

My child was born and I had a lot of support with interpreters and things like that coming to the hospital. We had OTs, I got my flashing light for the house and everything that my baby might need. The money from the NDIS was used within that period of time. I didn’t realise that that was one thing you had to do.

This is my daughter. She has, obviously, grown up a bit now as you can see. Sorry, she is interrupting. Sorry about that. She wants some chippies. Sorry about this, guys.

Just one minute, so sorry. I just have to sort her out. Sorry, I’m a mum, but any way, what can you do?

The second year of having my NDIS I got some new things put in the plan and re‑organised a few things. I thought one of the bad experiences that I had from the previous year was managing it, so how to smooth some of that managing and supports.

The third year with the NDIS I felt like I wanted to use an NDIS manager. I didn’t want to manage it myself. I thought it was too much work, so I thought maybe I will get NDIS managed. At that time my daughter was three years old, and so I was chasing her all over the place and I thought I needed respite so I will get the NDIS to manage in the third year which they agreed. I feel like that wasn’t the best decision. When I booked an interpreter or OT or a commguide or any of the related services, I would receive an invoice. I would look at the invoice. The NDIS would have my funding. I couldn’t touch the funding at all. It wasn’t portable, it was just within their system, so I would just get the invoice and mail it and pass it on and their role was actually to pay the service provider or the interpreter at that time. I didn’t actually know what was going on. I just thought that this would be an automatic process that I didn’t really need to worry about. The interpreter organisation would actually then organise me at a later date and alerted me to the fact that I actually owed a lot of money. I said no, it was the NDIS that should be managing that payment to you. They said they had never actually received any communication from them and I couldn’t believe it, so I had to then contact the NDIS and really hassle them to pay the interpreting service. You know, I don’t want to have a bad name. I want to be managing myself in a professional manner, so I had to really negotiate through that process.

I felt really trapped at that time because the agency was, obviously, very upset with me because it wasn’t getting paid and it was the department that was I was owing a lot of money to. I kept explaining I have money, I’m with the NDIS, this is meant to be paid through them. I asked them to call the NDIS. I had to get Karen on board to help with negotiations.

Finally it did smooth out and then when I had my new plan, I decided that’s it, I’m never doing plan managed again. I’m going self‑managed because it was just too much of a hassle. So from that point onwards, because of that terrible experience, I thought, no, I’m going self‑managed from now on in.

That includes commguides, interpreters, OTs, any of the services that I need. You know, I need gardening in my home, so I do that all myself now. I get that support from Karen. She is always supporting me through the process with the NDIS and I find it a much easier process now. The NDIS working with the NDIS was just way too hard. It was just they don’t understand what it means to be a deafblind person and what we need. So having Karen actually coming with me to support through those conversations was really fantastic. Deaf and deafblind are not the same. Deaf people can’t hear, obviously, but deafblind, we can’t hear and we have limited vision or if any vision at all. So that can affect a lot of parts of our lives including driving and things like that. So our access is very, very different and trying to explain all those access needs is very, very difficult. So having someone there who could advocate with me for, like, Karen was really beneficial to get the NDIS on board and understand my experiences because they don’t have experience with deafblind people and there were a lot of issues related to them not understanding my circumstances.

That’s been my experiences over the past five years. This year is going a lot better, I think, compared to previous experiences in my previous five years.

I have had to follow things up and I have had to really learn how to use the process, so that I can make it a smoother process for me. Also understanding the different funding types, like the core funding and what that means and what it relates to. It doesn’t make sense to be honest. I’m a strong Auslan user and a lot of the NDIS is heavily English‑based and they’re really long sentence structures and I kept reading through it and I had no idea what it means. I kept asking Karen what it all meant. She would have to sit down with me and explain the content of the NDIS forms and things like that, and so now I feel like I will never forget the information I’ve learnt, but I always have to say to Karen, you know, “Can you just remind me again what this says and what this says”, and I have to look at the different budget lines and find out which is core and where interpreting fits. So she has honestly really helped me a lot. Up until now, I can’t say it enough. So there are NDIS funding for family, for Auslan. You know, I have hearing parents and they use a lot of English and so to be able to have that funding for family so we can find better ways to communicate, that’s really made a huge difference and that’s improved things vastly for me compared to in the past. I’m really hoping that things do improve as the years do go on.

So thank you, everyone.

MICHELLE: Thank you, Jessica. Does anybody have any question they would like to ask Jessica at this stage? If so, you can put your hand up or write a little note in the box.

CAROL: I think I have had a similar experience as a deafblind person looking at my plan and having to ask for clarification of what that plan actually means. I think I really feel like I had a similar experience and it was lovely to hear that from you. I’m down in Tasmania, so a similar experience here. Nice to meet you.

JESSICA: Is there any other questions from anyone else?

MICHELLE: There will be another opportunity to ask Jessica at the end should you think of any other questions.

The next speaker is Justin and he will ask some questions and have some time for questions at the end also. Thank you, Justin. If you’re ready, we would like to hear from you. If you want to pin Justin and the interpreter so you can see. Thank you.

JUSTIN: I will give everybody a quick couple of seconds to pin. All right.

Hi, everybody. It’s been some time since I’ve seen this group. I think I was in part of webinar 1 with Ryan as well, I believe. So it’s good to see some familiar faces again. I must admit I’m really excited to hear Jessica’s experience. As a support coordinator I find it really encouraging that she has reached out for the support that she needed to understand the system, and it is a big, big system.

Today I got asked by Michelle to explain a little bit about how we support clients to read a plan. I think Jessica really summed it up really nicely. We provide support directly to clients how they need it to understand. Some clients might want us to be really involved with them in a very detailed process of working out budgets, of working out costings, and other clients are a little bit more experienced or skilled in other areas and so they need us a little bit less. It is really personal and so we really encourage you to find resources that help you understand your plan as best as you can.

I think Ryan will touch on later some of the formats that the plan can come in for you and I really encourage you to access those. There are large print and a few other variations. The most important thing it is to understand the language in a way that makes sense to you. So we talk about things like core supports and social community access and those kind of things. It is really important that you educate yourself about how you link your life with those areas about the NDIS. So community access might mean catching up with friends and going out and having fun for you. That is maybe how you describe it. I think you should use your language that you use in how you understand the plan. You should ask people who have some experience with NDIS plans on how to link that together. That might be a planner when you first receive your plan and having a conversation. It might also be a local area coordinator, it could be a support coordinator, it could be a friend, a specialist, a cousin. It doesn’t really matter. As long as it’s somebody that you trust and they feel comfortable to help you to work through.

One of the biggest things about reading your plan is a lot of people get confused about what they can use it for. The budgets are quite broad and they’re to cover off large areas of people’s lives, and how do you take a person’s life and fit into three categories, you know, core, capacity and capital? How do you make that work? So think about how you describe your life is really important and I think understanding how that moves into the plan is a way that you can get the most out of your plan and buy the supports that you need to reach your goals.

One of the first things we do as a support coordinator is simply just ask the person to describe how they see their life and what they do, and then we give little cues and links as to where we think that sits within the NDIS plan. Then we might start to, as Jessica explained, over time the skill and the knowledge and the awareness of the clients grow and people do that at a different pace. Some people may time more time and others are super quick. There’s always little things that happen and unfortunately these things are called Federal Government budgets and CPI and all these things that change how plans are written and also funded. For example, we have a new price guide coming out on 1 July. There has been some changes. We have had COVID temporary loadings, we’ve had TTP funding, all these things that go what, how, when, where, what do I do?

You’re not alone if you don’t understand. There are lots of people in Australia that don’t understand all of the detail. Sometimes even planners don’t understand all of it either. Sometimes even support coordinators, myself, I don’t know everything. I seriously don’t. I rely on other people to help me. So reaching out to a person that you trust is really important. Using your own language and linking that in and finding a way that works for you. Your way will be different to somebody else’s and that’s okay. If you’ve got that set, it means when you go and have your meeting with your planner, you have a really great opportunity to get what you want and then you can use it how you want and not have to worry about bureaucratic systems in the background and dealing with the NDIA or a service provider that doesn’t understand, and you are empowered to then get the best out of your plan. So, ultimately, design a system that works for yourself, part of that, to support that, like I mentioned at the start, touch base with a planner to understand it, an LAC maybe, support coordinator, a specialist, support workers, family friends or other people who might be able to help you.

I would ask your friends in the deafblind community as well, what are they doing, how are they using their funds and how do they understand it? I think peer‑to‑peer support is one of the most underrated and most useful tools that you can have to understand the NDIS.

That’s it, guys. Simple, short and sweet and if you have any questions, let me know.

MICHELLE: Thank you, Justin. If you do have questions, please put your hands up or write a little note in the box.

Our next speaker will be Ryan. He, again, will share his experience. Ryan also has an interpreter, Michelle. If you want to pin Ryan and Michelle and then they can talk to you. Thank you.

RYAN: Someone has stopped my video, so can the host restart my video? It said that Michelle locked me out and I couldn’t actually get in.

MICHELLE: I didn’t press anything, honestly.

[LAUGHTER]

Sorry.

RYAN: That’s okay. That’s all right.

Hi, everyone. First of all, can everyone see me okay? Perfect, beautiful. All right. My name is Ryan. This is my sign name. I’m deaf and I’m from Melbourne. I actually work for the NDIA. So I’ve been working for the NDIA for around about three years now. It will be three years very soon. For a few years I worked as a planner myself. That means that I was actually meeting people, having those discussions about the plan, about their goals, what funding they needed and what goals they wanted to achieve over the life of that plan, and I’ve recently become a team leader. So I’m working, looking at the plans to make sure that the plans are of a good quality now, so that all deaf participants are receiving good‑quality plans.

So, first of all, I would like to say thank you to Jessica for explaining and talking about her experience, so I can imagine your experience was probably very interesting because many people don’t know Western Australia is a little bit different to the other States in Australia. Western Australia, they actually rolled out their own NDIS plans. They had separate from the rest of Australia. Tasmania, Queensland, Northern Territory, Victoria, New South Wales, Queensland, we were all pretty similar, but Western Australia were slightly different. So it was really strange to start with and then a few years ago Western Australia actually came on board with the national NDIS, so it’s all consistent all over Australia now. So it was a really interesting time for you because you said five years. For me I thought, hang on a minute, NDIS rolled out in Western Australia five years ago? No, it didn’t. That was actually the old NDIS. So thank you for talking about that system as well.

Also I wanted to say thank you to Justin for your explanation about support coordination. You’re right. So we did work together in the first webinar. I think it was the middle of last year, we were together both of us talking about this as well. So, yeah, I can’t believe it’s one year later already. This webinar, I think, is a fantastic opportunity for all deafblind participants to get a good understanding of the NDIS and hopefully learn more that is specific to deafblind as well.

So, Michelle, the host, sorry, invited me to talk about NDIS plans today. So it’s really ‑ I wanted to actually not repeat what Jessica and Justin have already talked about. So I thought what I would actually talk about was when you actually receive your NDIS plan, so when you get the paper copy, when you meet the person from the NDIS, when you have your planning meeting and everything is done, you’ve given all the information, when your plan has been approved and the funding has been approved, you get a copy of your plan, but what does that look like? You can ask for your plan in many different formats. Usually what they will do is they will give you a printed copy of your plan and the size is normal font. So it would be quite small, and it will be probably way too small for you to be able to see, so you can ask for a large‑print copy and that would be easier for you to read as well. If you are visual frame and you use braille ‑ sorry, if you’re not visual frame and you use braille, you can actually ask for a braille copy as well. They do actually have a copy that can link to the computer so that can be a digital copy, so you can use that as well, that can link to your technology to be able to read it in braille. You can also ask for paper braille, but it’s actually quite a thick copy that they will post out to you. So it will be printed braille that you can also use. You can have a copy of your NDIS plan to match whatever your needs specific to yourself are. All you need to do is just to ask for a different format in your plan. When you’re in your plan meeting or after your meeting, if you think “I forgot to ask when I was in the meeting”, it’s not too late. You can still ask for it after the planning meeting at any time. Just talk to your local area coordinator, the LAC, or your planning person, or your support coordinator, and they can actually liaise with the NDIS to make sure that they can get the correct format for you.

So the next thing I wanted to talk about, for some deafblind people I know some people can hear a little bit, so you can ask for a copy, that’s a sound file, so someone will actually read and record your plan and you can get the sound file and then you will be able to listen to that and know what is in your plan, but it really just depends. I know deafblind are not all the same. There are lots of different options available to hopefully cater for everybody.

So understanding your plan, it is similar to what Justin was talking about before. Your support coordinator can actually go through that with you and help you understand what each category means, how to actually use the funding. You can also after your planning meeting you can have an implementation meeting as well. So you will meet up with your LAC or support person or support coordinator and unpack your plan, so that they can explain what it means and explain exactly what each part of the funding is for. So you will get a good idea, I have money for interpreters or I have money for commguide or OT or whatever you actually need. It is your right to ask for that. You can say “I want to meet you face‑to‑face and I want you to go through and explain my plan with me”.

So now I am going to talk about the different categories of funding that are going to be showing on your plan. Most of you have actually received a plan already, so when you’re actually reading your plan, so you will see there’s a section that is called “About Me”. That talks about who you are, where you live, what you do every day, daily activities. Jessica, I can imagine your plan would say “I am a mother. I look after my daughter”, just a participant statement, things like that.

So it will be different for each individual. So it will be your story and that will be forming part of your plan.

Next it will talk about your support that you have. So it will talk about any friends or family who support you, the important people in your life who you see on a regular basis and can offer some kind of supports. For example, it might say your parents or it might say your children or you might have professionals like a GP, things like that. They will be listed there and the reason that they actually put those in your plan, so that the NDIS, they want to remind everyone, it’s not all about relying on you. It’s related to the disability. They are not trying to replace family and friends. It’s important that we recognise that we recognised those family and friends as well and they’re all listed on the plan so we know who is important in your life.

The next part you will see are your goals, so what you’re hoping to achieve throughout the duration of your plan. You can have a few ‑ it might be one goal that you want to achieve or you can have a great list of goals, but it’s linked to your life, what supports you will need to achieve those goals, so for myself being deaf as a participant, I have a goal that I would like to be able to access the community. So I want to be able to be involved in community gatherings and things like that. That’s one goal that I have. To be able to do that I need funding for interpreters so that I’m actually able to be involved and understand what is happening at those gatherings. So you can add your goals. The funding will actually be linked to those goals.

So the next part it talks about the budget, how much money and funding you receive, and sometimes it can be a little bit confusing. So the money, the budget, is what the NDIS actually approves for you. So after you’ve had that planning conversation and you’ve explained all of the things that you’re hoping to achieve, these are my goals, and you’ve talked about yourself, after that the NDIS will approve funding.

There are three categories that that funding will be approved, so they’re quite general, but the first one you will see is core funding. So that’s core supports. I know that’s a really strange name, but over time you will get used to what that means.

So in core funding, core supports, that might involve interpreters, so if you need an interpreter, it can be include deafblind interpreters or Auslan interpreters, it could be live captioning. Some people prefer to read the information so that they can be involved, so they can have live captioning. That could include support workers such as commguides, any other supports that you need, if you need help getting out into the community or if you need supports at home as well. Some people need transport. So that can also be included in core as well.

So it’s quite broad what can be included under the core funding.

I’m just trying to think. For core what that could actually mean. So what I usually think is what I need every day and that relates to my core funding.

The next group of funding is capacity building. Again, some people think what does that actually mean? That means that your personal skills, things that you can do every day, things that you need to do every day, so it’s really about yourself, you know, how you can improve those skills, how can you become more independent as well. So that’s capacity building and that’s linked to that funding. So that means that funding could be for a professional to do an assessment such as an OT, maybe you need an OT to come to your house and do an assessment, you know, how it could be improved whether that be safety, that actually empowers you, things that you need in the home environment or that could be a person to help you manage your NDIS funding, so that person would actually be able to organise to pay invoices once they were received. They can also, same as Justin said, someone like Justin, a support coordinator, that falls under capacity building as well. So his role is to help you understand the NDIS, help you navigate NDIS and become more independent and confident about the NDIS as well, and link with services.

It’s more about helping you to connect and improve any skills that you have or want to improve.

So the last group of funding is called capital. So, again, I know it’s a bit of a strange name, but capital funding means basically expensive things. For example, equipment such as hearing aids, cochlear implant, maybe it could be a braille device that links to the computer. It could be a magnifier to enlarge things that you want to read, things that are quite expensive. So the money falls under capital for that kind of equipment. It could be something for your home if you need something specific, maybe the OT comes and does an assessment and thinks that there’s some modifications that you need, you know, better lighting or specific doors or things like that, any changes or modifications to the home. If it’s anything expensive it will fall under the capital fundings, so it’s usually home modifications.

There’s a lot more in depth explanation over the three, but I wanted to give you an idea. Core is basically everyday life; capacity is linked to skills, personal skills, anything that you want to improve on; and capital generally is for expensive equipment and things like that, just to help you in your everyday life. Maybe that could help you to get out of the house or maybe things that would help you within the house.

I want to repeat again, if you’re ever unsure about anything that is in your NDIS plan, please make sure that you is, please ask your LAC to explain or support coordinator, anyone that is available if there’s something that you’re not sure about, if there are any barriers that you’re facing, please let them know, “I need more support. I want to understand what is going on”. It is important that your understand your plan and what is in your plan. So when you actually understand everything and you know how it works, the NDIS can actually be a positive benefit for you and have positive impacts on your life as well. So it’s important for you to be involved and also take that on and understand how the NDIS can work for you.

MICHELLE: Thank you, Ryan. If anybody has any questions? Carol does.

CAROL: Fantastic. When I receive my invoices, I find that the writing is just so small on them that I have to use a magnifying glass to be able to see them and be able to submit them for payment. So I find that quite difficult and I get invoices often for interpreting services. I just find that sometimes they’re just so small, the font, and I can’t access them properly, so that’s definitely an issue that I’ve had and I’ve raised that with Able Australia. I’ve raised that as an issue to say that I need to have the font size be made bigger so it’s more accessible.

RYAN: I think it is really important that you can read your invoices and understand everything that’s going on, it is important for you to talk to your provider who is actually giving you the invoices and let you know it is actually too small and you would like them to make the font bigger so you can access that. It gives you the power and you have the right to advocate for that as well.

CAROL: I understand that. I think my interview was in May, and we were talking about my funding and why my funding had been used so much and I said it must be the interpreting services and I had to explain about how interpreting services had moved to VRI through the lock down, so we had a fair bit of discussion about the funding that I had for interpreting because of the impact of the Coronavirus. We talked about the impact on my plan and I had to explain about VRI services. There was a fair bit of negotiation that went on through that to try and make sure that the planner understood the situation.

RYAN: It is good that you had that opportunity to have that discussion and explain your needs. I remember the variation, not all disabilities are the same. Sometimes the LAC or the planner might not really understand what is going on, so they will ask you to please explain a little bit more about your situation, so they have a better idea, so it is fantastic that you did actually explain all of that as well.

CAROL: It took a little bit. I had to help them to understand how it worked and get them to look into everything so that they had the right understanding to write up my needs and submit them correctly so I could have the right funding going forward. Thanks for that, Ryan.

RYAN: Fantastic.

MICHELLE: Thank you, Carol, and thank you, Ryan. Does anybody else have any questions for Ryan at this stage?

Would anybody like to offer any questions to Jessica or Ryan or Justin.

RYAN: The problems that you said, you’ve said you’ve had a few problems over time with the NDIS and I hope after five years, Jessica, that it is a little bit more settled. It is a big system and it is very complex and they are slowly improving, but when you think about the impacts that the NDIS has had, you know, are there any positive impacts that you can tell us about?

JESSICA: I’d say there has been a lot. Having more funding and access to funding for interpreters. There’s next to no problems having that funding there, so that’s great, that’s a big positive. It is hard to have an interpreter to be available all the time. That is, I guess, a negative that is linked to that, but the funding is there, so that’s good. I do still get stuck without interpreters sometimes. In terms of managing the plan myself, I would say that was definitely a better fit for me rather than having an external plan manager. That was good. Getting the funding to be available and then being able to use that throughout my different services, I found that was great and also having someone around to be able to help me directly and provide support with that process was fantastic. Because I think knowing the deafblind people are all different and have specific needs, that’s very important to recognise and the professionals working with NDIA are not always aware of that, so it’s nice to have people around you that are aware of that and aware of how the NDIS works. Once you sort of get that understanding, you know, across the board with everyone involved of how NDIS works, it can be much easier, especially when we’re talking with budgeting. Sorry, that’s my daughter again. It is nice to be able to have the same person to go to as well over a period of time rather than having too many professionals to go to.

MICHELLE: Great, thank you.

RYAN: Thank you.

MICHELLE: Any more questions? Justin?

JUSTIN: It wasn’t actually a question specifically, but I suppose in understanding what your budget is doing, understanding budget and planning skills, it is not an automatic thing that everybody learns how to manage funds and budgets and things, and I think Jessica was talking about having the control of what I’m doing with my funds and where I’m going is really important. One of the best things that I ever saw a client do was set up on their tablet a budgeting app and literally just putting their funds into the budget app and like a draw‑down on their funds with a core budget or something, and they could forecast in advance themselves about what they were spending based on getting a quote from a provider for a holiday or a technology device and things or some training and stuff, and so finding a budget management strategy that works for you with your plan is really important, knowing where you sit financially about what you can buy and how much you can get out of it is all empowerment, and it is giving you the opportunity to actually control what you want to do. You might nibble a little bit from this budget to help you with something over here on a different budget, or you might have a grand plan about going on a long holiday or something that might need a bit of support in place. So learning how to forecast that to make it really work is really important, and it’s not a natural skill and I don’t think it is something that is taught a lot as part of NDIA, but something that Able does in its support coordination team is budget training. So if you’ve got somebody that can do that for you, I really encourage you to learn a strategy that works for you to manage the funds, even if you are agency managed or plan managed. It doesn’t matter. Just having that skill is important to have to give you the control over what you are doing with your funds.

MICHELLE: Thank you. Meredith?

MEREDITH: Yes, I have a question for Jessica and Justin.

I’m just aware, I have heard often, or sometimes, what is discussed in the planning meeting isn’t what comes back in the plan and I’m just curious to know, I guess, first Jessica and then Justin, if you have had that experience where you agreed on everything that would go in the plan but then that’s not what was in the plan when you read it and what you did and how you went through the plan and checked if what you talked about in the meeting was in the plan. Could you talk about that Jessica and then Justin?

JESSICA: Did you want me to go first or Justin, would you like to go first? I’ll go first? Okay.

Well, my experience with that, when I received my plan after going through everything and having issues with the ‑ sorry, I will just go back. When I first had my meeting, I sat down and I explained everything that I wanted, I laid out my goals, it looked like the meeting went really well. They send that off to NDIA and then when I received approval and I got my plan, I thought, “Hang on, it doesn’t seem to actually match what I had outlaid in that meeting”. I felt a bit frustrated to be honest. I got in contact with the Mission Australia and am working with Mission Australia under the NDIS.

So Mission Australia, I met with them to discuss my plan and I said I never said, you know, this, this and this, and I had some proof with regards to some of the things that were in my plan, but I actually ‑ I got all the nod and everything was fine and I was really quite excited and I thought the NDIS would have covered everything and they said they had looked back over our previous discussion, so I was quite excited, but with regards to my daughter and my husband and things like that ‑

INTERPRETER: Sorry, I’m just a little bit lost with Jessica. I think we’re having some problems. Sorry. Jessica can we go back again. I’m so sorry. I will try to pin you and make you a bit bigger.

JESSICA: NDIS had said it was fine for having CCTV and things like that. They said there was no problems with that. Then when I went back they said I wasn’t allowed. So I had to think about how I was going to advocate for that. They said they updated things and my family and daughter in the house and these are essential things that I’m going to need. I then actually received a letter saying that it was impossible for me to receive this particular piece of technology. I thought why am I getting this back and forth no when I had obviously originally had a yes. So this kind of went around in circles. So I contacted mission Australia and got them in on the negotiations and they actually wrote an apology letter and we continued to advocate quite heavily. We did want the door bell, the flashing door bell, and we did have the budgeting for that, but at that time my plan wasn’t covering the things I needed, but it has since improved, which is fantastic.

CAROL: My husband has had a very similar experience where we wanted to have CCTV because we have had problems with theft and things like that over the years and we actually approached the Tribunal to say that this is something that we actually needed, CCTV, because of our needs, and they said it was absolutely possible. So we worked it out going through that way getting that support, but I’m in Sydney.

JESSICA: Thank you for explaining that, Carol. I definitely got a no at first and I had to keep advocating quite heavily to get them to realise my needs. We do have an alleyway next to the house and we have a dog. We needed to feel safe in our environment. We had to advocate heavily. We kept getting “no” over and over again, and then ‑ and over again, and then after a lot of work we were able to install CCTVs on our own, but thank you for explaining your experiences, Carol, and how you achieved that.

MICHELLE: Do we have any more questions?

MEREDITH: I did just want to hear from Justin as well if he has had a similar experience and what he did if the plan did not match what the client had discussed in the session, the planning session.

JUSTIN: Yes, absolutely. I think when NDIA was more in its infancy there was a lot more problems of matching to need and expectations. In general, there shouldn’t be any issues about me and how you describe your supports. That should be verbatim. That’s your story. The planner or the LAC who is doing that section should be following very clearly what you say and how you say it. It is your life.

In terms of funding in a plan, I think sometimes there’s confusion about why some things are not written into the plan, so, for example, if you say that you might need a CCTV, it may not be clearly stipulated there, but it may be a component where it is under improved daily living for an OT assessment to match you with the right CCTV device. It might not mean they don’t fund it, but they want clarity around what is the best device for you so it matches your need as you currently need it, but it is going to support you going forward.

Sometimes people think that they will get support, it could be commguide hours and interpreting hours, and we have heard a lot of speech around reasonable and necessary, and I don’t like that wording because it’s not something that actually is really relatable to everyday life for lots and lots of people. I think planners struggle with it as well, what is reasonable and what is necessary. I think everything is reasonable and everything is necessary.

I think it’s more about matching your life to the goals that you want to achieve and how you think that fits. So if you need 150 hours funding for interpreters interpreting, fine, then give some direction to the planner and some context as to how that gets used and what that actually looks like. Put some supporting evidence around what you’re asking for and how that would improve your quality of life, and how that would actually offset cost elsewhere and what that looks like, and that can be coached and taught in language around that for a person to understand.

The other thing that I think participants sometimes miss is ‑ and Ryan can answer directly for me, I don’t want to answer directly on behalf of NDIA, but if they are just a planner, they may not have delegate authority, so in theory you’re telling a story to a planner and your needs to a planner who then in turn writes a plan who is going to pass it on to a delegate, who is technically doing the advocacy for you about signing it off on how they’re justifying the funds in a plan, and sometimes that story can get missed. I think I have had planning meetings where I’ve had a delegate as part of aged care in that complex system and getting things signed off really, really quickly right down to a quite new LAC doing a planning meeting and that process can be very, very different.

So I think really understanding who you’re meeting and respecting their position in the whole world of NDIA and giving as much resources you can to the planner to understand what you’re asking for.

The other thing too to remember is certain parts of your NDIA plan are actually regulated by other areas. For example, complex technology, braille devices, complex communication systems and so forth may be controlled by the assistive technology section within the NDIA. So the maker might put in a budget to have those things actually looked at and researched, but they’re not going to approve it. It will be another department that will be based off reports from professionals and others to fund that process. That can be a bit time consuming and also worrying. You would never meet that AT department, you never meet the person who makes that decision, but all of a sudden you get your funds to purchase your braille device.

So I think sometimes there’s a bit of confusion about how the NDIA actually works and I think take a step back and see how somebody else might try to understand your story and how you’re describing things that you need. I think you’ve got to ‑ it’s all very well to explain it to somebody like me as a support coordinator, I understand it, but I really encourage my clients who have family close by or with them to explain it, somebody who doesn’t live with you potentially, because you’re trying to sell your experience of what you need and trying to convince somebody that this is important, so linking that in and understanding, getting feedback from them “Did you understand what I meant by that when I said that? Can you see how it link with this?”, and having a cohesive process is important as well.

If you don’t agree with anything that is in your NDIS plan, you have the opportunity to ask for a review of that decision and you also have a right to access freedom of information, which is how the decision was actually made. It is a bit of a drawn‑out process, but it is possible to get the actual detail of how a decision was made by the NDIA.

Sorry, there was a lot in there.

MICHELLE: Thank you, Justin. Do we have any more questions for any of other speakers?

No. Thank you to Jessica for sharing your experience, thank you for Justin for giving your support coordination experience and Ryan for the NDIA’s view.

We Thank you everybody for your time informed for attending this webinar and if you do have any more questions going forward, please let us know.

We do have another webinar next month.

Sorry, Carol, do you have a question?

CAROL: Last year I went to the NDIS, my LAC, and we typed up our whole conversation. We had two interpreters in the room and we finished the original negotiations and then the virus spread and I thought how was I going to get interpreters. I asked for NDIS for technology for VRI. I was given a hard no. I asked about using my iPad so I could get an interpreter.

Long story short, discussions kept going until May. I kept saying that I needed a deaf interpreter. I kept explaining my situation and reiterating how different it is to be deafblind as opposed to being deaf. The second person I spoke with, which was after six months of my funding drastically reducing, the second person I spoke with was a lot better. It was a drawn‑out process to get the plan approved, and when it was approved, it was great, but it was a drawn‑out process and it was better with the second person.

MICHELLE: Thank you for your experience, Carol.

Certainly from working with the clients I have, there is a process, but the NDIS have responded well and tried to help in those situations. Thank you.

Any more questions? Thank you to everybody for attending.

CARMELA: Hi, I’m from Adelaide. I work for a deafblind ability program: I’m a project officer. I’ve had deafblind clients within the organisation who have had negotiations with the NDIS saying they wanted specific things included in their plan and different interpreting organisations looking through the plan as well. So I just really want to know, I feel like some of their questions aren’t really relatable. I feel like the meetings don’t go well because a lot of deafblind people feel quite intimidated and they don’t want to express themselves. The questions can be invasive or not understood in an appropriate way by the deafblind person. Later when they’ve received the actual plan, they’ve looked at it and they’ve not been happy with what they have gotten, so they have to go through the interview process again and explain why they’re not happy and go through the negotiations again and it can draw things out and the deafblind person can decide to just leave it. They decide they’re not happy with the service and you don’t understand my language and the communication isn’t going well. That has a really strong impact on the deafblind person. They might leave that particular person and go to an LAC that might be deaf in a hearing organisation so they can have that more relatable conversation and shared language so they understand their experiences better and that process has actually worked and they’ve received their plan and looked through it and they’ve been quite happy with the results and it has been a smoother process. So this is what I’ve been told by a deafblind person, that sometimes they don’t ‑ the LAC might not understand the experiences, depending on where they are from and who they are, and they might not be able to give them the things that they want and need, whether it might be a community, getting into the community and having an interpreter or whatever. I’m wondering if this is something that just happens regularly or does this happens with any of you guys, do you think? I’m curious to ask. Jessica, what are why you are experiences? What do you think and what are your thoughts?

JESSICA: That’s really great, looking at what you were saying there. I understand that perspective from the deafblind person and maybe a hearing person may have some previous experience and maybe they’ve met many deafblind people over the years. They’re not deaf themself potentially, or deafblind, but they may have a lot of experiences. Maybe they have studied things at TAFE or whatever it might be, so they have the experience needed. In a deaf organisation maybe it’s quite different. Maybe they don’t have the knowledge of deafblindness. Adelaide is quite small, so it is difficult for me to say. I was deafblind and I was born here in Adelaide. It is my matrimonial home town, so I’ve been living here for many, many years. I grew up knowing the deafblind community in Adelaide, which is very small and there are a lot of issues with there being a lack of knowledge and understanding within the deaf community over deafblindness and they tend to hide and get involved in the community and not get the support they need.

I think Melbourne is different. Ryan has been working for many years in the deafblind community and so he has had a lot of experience, but Adelaide, there is only a few people around. To be able to find the right person with the right experience makes a huge difference, that have that deafblind perspective. I mean, Ryan, obviously, has a lot of that in his background. That is right, isn’t it, you’ve been a deafblind guide, you’ve had experience in that realm as well in different situations, but to find that person in Adelaide is really quite limited. That is why it was great to bring in a support person like Karen who could help with me, so I don’t know, Ryan, do you have anything to add on that?

CAROL: I couldn’t keep up there. I didn’t know who was talking.

INTERPRETER: Me too.

JESSICA: Maybe put your hand up and it gives the interpreter time to pin the person because if we’re all darting around it gets confusing.

CAROL: I do want to add some talk. I’ve just got so many experiences. There’s not many deafblind people here also. The blind community is quite different. Victoria has a much larger community that you can connect with this Victoria and there’s also Able Australia, so deafblind organisation, so there’s a lot of support. Really it’s been fantastic having that kind of support available.

JESSICA: I’m just trying to find the name and make sure I’ve got the spelling right. It’s Carmela. I was responding to what you said before.

CARMELA: Yes, you covered that, thank you.

MICHELLE: Would anyone else like to add anything? Thank you for your time and thank you to the speakers. We appreciate your time today. We will upload a copy of the webinar and the captions and we have another webinar next month which we will email you to let you know about, but thank you for your time for today.

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