**Transcript – Deafblind Hub Webinar #7**

MEREDITH PRAIN: Welcome, everybody. It looks like we’ve got 20 people online which is a really great number and good to see the interest in this topic.

I just wanted to start checking in on the technology and making sure everybody can see the interpreter that needs the interpreter. So if you are using an interpreter, you will need to pin the screen, and you pin the screen by going to the video where the interpreter is and there’s a blue box with three dots and click on that and then you click on “Pin Screen”.

I can see Rodney is online. Rodney and Carla, can you let us know if you can see the interpreters okay? Just type in the chat. So the chat is down the bottom.

Could I just have Carla ‑ yes, hello. Carla can see the interpreters. All good. That’s great.

MEREDITH PRAIN: We will make a start. This is our 7th webinar on working with people with congenital deafblindness in the NDIS.

I will start by acknowledging the traditional owners of the land on which we’re meeting, all around Australia. I’m aware we’ve got people from a few different States, so we pay our respect to their Elders past, present and emerging, of wherever you are based at the moment.

We have got four great presenters this evening to speak to you, Emily Shepard, who is a parent and founding member of Usher Kids. We have Melanie Robartson, who is a senior speech pathologist and deafblind consultant with Senses Australia; Emily McDonald, who is also with Senses Australia; and Ryan Malonda who works with the NDIA.

We will get started right away. Please do type in the chat if you’ve got a technology issue. We will try and help you to make sure you hear and see everything, and I will hand over to Emily Shepard to give her perspective of the parent journey in the NDIS process.

EMILY SHEPARD: Thank you, Meredith.

Welcome, everyone. Thank you for so much for having me, Meredith, and Michelle. I appreciate being part of this webinar tonight. I have a ten‑year‑old son who has type 1 Usher Syndrome. He was born with a profound hearing loss and wears cochlear implants. He has some vestibular dysfunction as well as the degenerative eye disease. He currently has night blindness and a peripheral vision loss and we can see that that is gradually degenerating each year.

NDIS‑wise, we have just finished our second year on the NDIS. Before this he didn’t have any funding for supports other than those that were provided through the Medicare care plans. He did receive when he was a child, a young child, access to the Better Start funding for children with a disability, but this ceased when he turned six.

So the NDIS came to us as a real welcome relief financially for our family. We were able to receive funding for his therapies and he sees a range of different therapists. He sees a physiotherapy ‑ he has physiotherapy, speech therapy, occupational therapy, orientation and mobility therapy and sees a psychologist on top of a wide range of medical specialists as well.

The NDIS are able to help us financially with seeing all those therapists, but another benefit is that we’re able to receive this therapy in a really flexible way. Therapists are able to visit us in the home rather than in a clinic. They’re able to visit us at school and this makes a really huge difference for our family.

My son doesn’t moan and groan about sitting in a waiting room. Instead he is able to play in his own environment where it feels more on his terms. This helps build the relationship between himself and the therapist. I think that that has made the therapy more successful as well.

That is the benefits and rewards for our NDIS therapy.

We also use some of our funding for therapy assistance, so a support worker works under the guidance of our occupational therapies or physiotherapists. We work on our goals for the plan in the year and we work towards the goals with the therapy assistance and they can incorporate that into fun activities. What my son thinks is rock climbing or stand‑up paddle boarding or football with the support worker is really a dedicated plan to build his core balance, for example, coordination skills to help him with his vestibular stuff. So he is really able to engage in his community, make meaningful relationships without the term “therapy”, really. So it has been an engaging and wonderful experience for our family.

We are also able to use the NDIS for community participation. We have used funds to work with his local sporting clubs, with his coach we’re able to let them know his specific needs and challenges, and this is has allowed us to make us that all the environments are firstly safe for him, but he is able to participate the same way other kids his age are.

This has been life changing because sports in the past had been challenging for him and because of his disability he would have had to have stopped, but with the support from the NDIS, we’re able to really broaden the wider community’s understanding of disability and deafblindness and make that a more accepting place for him and others.

My work at Usher Kids Australia, we have about 40 kids across Australia now who are all on NDIS plans, and some of the positive experiences we have heard from them really are around giving kids the chance to participate in things that they wouldn’t have had the opportunity beforehand. Again, this comes down to things just being too difficult. They don’t understand the hearing loss, they don’t understand the vision loss, they’re not willing to put in the work, but now with the NDIS funds the children are allowed to work on their goals, find what really interests them and work with their NDIS specialist to be able to incorporate that into groups being really accepting and accommodating to our children with a disability.

In regards to some key services for participants to consider, and this is really for children up to 18 years old, it might be early intervention, orientation and mobility services, community participation, so assisting our kids and our teams to really develop those social skills that will be really important to them going into the workforce later on, getting them job skilled ready, mentoring programs, but it really depends on the individual goals of the child and making the right accommodations to making this all happen.

Equipment, there’s lots of equipment that might be able to help children and teens in regards to particularly safety, and this is really about flashing or vibrating smoke alarms or recreational things which is very popular in our house, which is our TV streamer. So my son is able to stream the TV through his cochlear implants without disturbing noise levels for the rest of the family.

One last point I just wanted to make before I finish up and pass back to Meredith, I think it is really important for participants to ensure on their NDIS plan that their primary disability is stated as deafblindness rather than either hearing loss or vision loss with sub-disabilities, and not all of our participants have been successful in doing this, but I think this is really important to ensure that our participants have less complications with the various services that they might be requiring, but I’m sure that our NDIS team member will be able to elaborate a little bit more on that and just how important it is to get that primary disability correct in the first place. That’s all from me. I will pass back to Meredith now, but if anyone has questions, I will be here at the end when we open it up to question time, or you can email me at Emily@usherkids.com.

MEREDITH PRAIN: Thank you. That was fantastic. It is great to hear what a positive experience it has been for you and your son.

We will ‑ I should have said at the start that we will have just some questions after each speaker if anyone has got questions, but then we will come back at the end as well for a broader discussion.

So if you do have a question for Emily, we want you to use the raise hand function if you want to voice or sign your question, or you can type it into the chat and Michelle will read it out. So if you have a question for Emily, just raise your hand and Michelle will unmute you, or you can type it in the chat. So the raise hand is usually at the bottom. If you open up the chat or the participants area.

MICHELLE SCHOFIELD: We have one from Wilma.

WILMA: I just wanted to know how old is Emily’s son with the Usher’s.

MEREDITH PRAIN: I think Emily said 10 years.

WILMA: Right. That’s all from me.

MEREDITH PRAIN: Thanks, Wilma. We need to keep Emily unmuted to answer questions.

I hope I heard and remembered correctly that he is 10.

EMILY SHEPARD: Yes, my son is 10. We didn’t have a senior planner. We had a local area coordinator work with us on our plan. One of the benefits was that she actually has Usher Syndrome, so she had a really good understanding of the conditions and the needs for a child of my son’s age, but I would absolutely recommend that people ask for a senior planner, so that there is someone with really good understanding of the needs of the deafblind community.

MEREDITH PRAIN: I think that is a really good point.

Are there any other questions for Emily at this point, just remembering we have time at the end if you think of something later.

RYAN MALONDA: That is wonderful you had a great experience. I missed you were from or based.

EMILY SHEPARD: I’m based in Bayside area in Melbourne and we go to the Brother of St Laurence for our planning reviews.

MEREDITH PRAIN: We will see if there’s any more hands up or typed questions.

Thank you, Emily. I’m sure we will hear from you a bit more at the end.

We will hand now over to Melanie Robartson.

MELANIE ROBARTSON: Thank you, Meredith, and thank you Emily Shepard for those interesting insights into your planning experience and I’m really glad that on the whole they’re positive outcomes for you.

I’m going to be talking about what it is, what we mean by “goals”, and what goals might look like in an NDIS plan for a child with congenital deafblindness or a person who is grown‑up now and was born with deafblindness.

For simplicity sake, I’m going to assume that it’s a family that is listening and they’re listening in terms of planning for their child, but I understand the situations will be different and we see different therapists on board as well, and so there will be a segment for questions after this.

I’m a speech pathologist and deafblind consultant at Senses Australia, and I’m going to start with when we talk NDIS, people start immediately using the word “goals”, and assuming everybody knows what they mean, but that’s not always the case. It is not a word we use in everyday life. When we think about growing up and being in part of our community, and when the NDIS planner writes your goals on the plan, they’re not referring to kicking a ball between two poles or throwing it into the net. So I wanted to break this idea of what a goal is down a little bit more.

What are the services and equipment you can fund using your NDIS plan will be determined by what it is that you want for your child, what they want for themselves, what theirs or your concerns are and what you and professional assessment can tell the NDIA about your child’s development, sensory status, involvement in life experiences and as part of their family, their child care, their school or other part of the community.

So the NDIS uses the term “goals”, when talking about these ideas and they discuss goals right now that you want right now and also for what you might want in the longer term, and aspirations that you might have in the longer term as well.

When you think about what are your goals, it might help if you ask yourself these questions: what skills does your child need to learn as they grow up? Do they need help to get better at doing some things? What places do they need to go? Can they get there? How will they get there? When they are there, can they see, hear, feel or understand what they need to? What groups do they want to belong to or activities do they want to participate in? What kind of relationships or connections to people do you want them to have or do they want? Do we as a family have the information and skills to understand the disability and help our child? Do we need guidance with this?

When you have your answer to these sort of questions, they can be made into general goals about independence, doing things with your child doing things for themselves, communicating, participating in life in the community, or broad enough to encompass all the services and supports around equipment you might need to work towards those goals.

So I have pulled out some examples of these broad goals, and when you’re working with your service providers, they may actually narrow them down to what that might look like in regard to what exact service that provider is going to provide you, but at the NDIS stage they’re quite broad, and that’s probably a good thing because they ask you to be quite flexible and pull in all the services and equipment access that you might need to get there.

So some examples. I might want to participate in activities that I enjoy; I might want to improve movement skills to increase confidence and participate safely in activities; I might want to develop independence skills to do things for myself and communicate and socialise with others; I might want to be safe in the community or at home; I might want to meet new people and be supported with my communication when doing this; I might want physical, emotional and mental well‑being, which certainly brings challenges in all these areas. Your NDIS planner might also want to talk about some shorter‑term goals or more specific goals as well, but definitely your service providers will.

If you would like, as we go along, you might put in some examples in the chat of maybe some examples of goals that you have put in your plan, and that would be, perhaps, useful for our audience.

The funding to help you achieve your goals falls under several different areas in the plan because sometimes you will need different people, services and equipment to achieve them. Take a goal about communicating and socialising, we come across very unique communication styles and methods in deafblindness. You can use a therapy team and deafblind consultants to find out about these and learn new ways of communicating with your child. You may need the service of someone proficient in signing, for example, to help the family learn Auslan, for example. You might also need to learn how to modify the sign language so your child can see it better, if the sensory status of the child changes then those communication methods might have to adapt as they grow and change. If your child is signing or learning to sign, they might need a person to be the bridge to a non‑signing person in situations. You might get core supports to help your child to communicate in the community. Your child’s diagnosis may mean help to prepare ... and therapy can include equipment, the equipment that a specialist needs to sign or help you choose, and you will get funding under daily living category and capital supports to pay for the equipment. They may need other equipment as vision aids.

Supports learnings, new skills ... for a person with deafblindness this might including hearing device, thickeners to make drinks safe for swallowing, continence products, magnifiers.

Core supports are also needed to fund a communication guide and interpreting and note taking services.

Up next is Emily McDonald who will explain the services I’ve mentioned in more detail, but now we will pause for questions about NDIS goals.

MEREDITH PRAIN: Thank you for that, Melanie. That was fantastic and I’m sure has given people a lot to think about.

Rodney has just noted that the background of the interpreting is very bright, so I do apologise. We did look into doing what we could there and hopefully, perhaps, you can follow the captions.

Does anybody have any questions for Emily? Again, you can raise your hand or type your question in the chat.

I can see Erika has typed that peer support is important and that mixing with other people who are deafblind and understand the support is very important. That is definitely, I think, for people to mix and have that peer support, if that’s something that they’re wanting, then, yes, definitely looking at how you would facilitate that.

MELANIE ROBARTSON: I think the NDIS gives you the flexibility to personalise, and if that’s important to you, you can put that in your plan. I think Emily mentioned mentoring and also the communication guide, and Emily McDonald will talk about core supports and getting that sort of service in accessing that sort of service.

MEREDITH PRAIN: I see Ryan has typed a question: what would you say is the most challenging in terms of goal writing? How can planners, LACs support participants better in goal setting and plan writing?

MELANIE ROBARTSON: That is a really good question and I’m not sure it has an easy answer. I guess that those sort of questions that I kind of give people as homework, that I sort of went through, to help them define what is important, where do they want to be, they don’t necessarily know how to get there, but the planner can help, or if they don’t know how to link in with the supports they need, they can get a support coordinator, specialist support coordinator, to help them to link up with services, but you will often find if people are unsure, then maybe that might be part of the process of their services, is starting with some really broad goals, but narrowing it down in the therapy process or whatever services they are accessing.

So I think from an NDIS point of view, if we get a nice broad overarching goal and until you know sort of some is a generous package, because deafblindness comes with high, uncomplicated need and requires quite specialised supports, so a broad goal, a generous package, and people will find their way.

MICHELLE SCHOFIELD: Carla stated she is wondering about the preplanning process. Is there a time limit for this and how many meetings can be held prior to the actual planning meeting?

MELANIE ROBARTSON: This might potentially be a question for Ryan in his segment. I’m not too sure. He is happy to take that. It will depend also whether you’re already in services or whether you’re new to services in general and who is going to help you with that pre‑planning process, whether it’s your existing services or you’re actually given a package to help plan and then get another package sort of a short while later for the actual services for goals, yeah.

Does that sound kind of accurate, Ryan, or are you happy to look at that question more?

MEREDITH PRAIN: I think we will move on to Emily and it will be good if that’s the first question we ask Ryan when we get to Ryan.

So thank you so much for your time, Melanie. We will have you back on at the end to answer any questions that come through once we’ve heard from anybody. So thank you.

We will hear now from Emily McDonald who is going to talk about potential therapy supports and equipment that are particularly relevant for people with congenital deafblindness.

EMILY McDONALD: I am a deafblind consultant and occupational therapist in Senses in Perth. I will discuss the supports you can access using your NDIS fundings specifically for people who are deafblind.

Under capacity building supports you may receive funding for a few different titles, either called improved daily living or improved relationships and there’s a few others, but they’re the kind of two key ones, which can be used to fund therapy intervention.

The therapy team for an individual who is deafblind might be slightly different to other people accessing the NDIS due to the complex nature of the disability and the need for a specialised team. When you’re looking for a provider of therapy services, it is important to think about whether the provider you are considering can meet your needs or whether it will be more appropriate to engage multiple agencies with the support of a specialist support coordinator to make sure that you get what you need. A specialist support coordinator is funded when there are additional high or complex needs and will be a qualified and experienced practitioner such as an occupational therapist, a psychologist or a social worker.

A deafblind therapy team may include generic therapy supports; that is therapy supports that are easy to find and more generalist in nature. These professionals includes a physiotherapist who can help the individual to understand the physical world around them which may involve stretches, strengthening and gaining early physical milestones, also inner ear abnormalities are common in diagnosis such as CHARGE and Usher Syndrome, including nausea and dizziness. Physiotherapists can provide treatment and exercise to improve these symptoms.

An occupational therapist or OT whose role is to help people to do all the things they want to do or need to do in their daily lives but can’t because of illness, injury or disability, this can include completing a functional assessment of daily life to identify strength and challenges, recommending helpful pieces of equipment that may make life easier and safer which can include things like wheelchairs, alerting devices like the Bellman system, video magnifiers or detection devices, depending on the individual needs, and developing new skills and compensatory strategies. An OT can also have valuable input into a positive behaviour support plan if this is needed.

A speech pathologist can assess communication skills and determine best modalities for communication. A speech pathologist with specialist training in dysphagia can help with good eating practices. This may be using modified food and using equipment at meal times. A speech pathologist is a key member of the team for a behaviour support plan. A social worker can work with individuals, families and with the community to address inequalities and empower individuals and address systematic barriers faced with individuals with deafblindness and their families. A psychologist can support the emotional needs of the individual. A psychologist can assess, diagnose and treat the psychological problems and behavioural dysfunctions resulting from or related to physical and mental health. They can also provide valuable input into a positive behaviour support plan and they play a key role in the improving the individual’s quality of life.

For individuals who require nutritional support or concerns around their eating and drinking, a dietician might be involved.

They’re the generalist health professionals that are easy to find and more specific supports provided by allied health professionals with skills working in the field of sensory disability which might be more specific to somebody who is deafblind. These include an orthoptist, who can undertake a functional vision assessment. This is not an eye‑health test which may be conducted by other professionals. This is an assessment of visual function which is what you’re able to see and under what conditions. This typically involves assessing all aspects of visual function such as distance and near vision, whether your eyes are aligned, whether you require things in high contrast, if you have troubles with depth perception and colour vision. The they can then recommend low vision aids which can assist the person to maximise their vision and give them access to visual information which may otherwise be outside their field of vision.

The results of a functional vision assessment conducted by an orthoptist can be helpful to other professionals such as an OT who may be helping with other tasks such as cooking which is important to know the person’s visual function to make sure they’re safe.

An audiologist is somebody who is not typically part of a community‑based therapy team, but they’re still a very important member of the support team. Audiologists can provide diagnostic tests to understand hearing and auditory function. They can also provide rehabilitation and habilitation, which may include fitting of hearing aids and other devices such as FM receivers and TV listeners. An orientation and mobility specialist may also be involved. They’re known as O & M specialists. They can work with people to develop skills and strategies they can use to know where they are, both inside and outside, and to move from one place to another safely, confidently and independently. O & Ms work with people throughout all stages of their lives and goals they want to work on. This can teach using a cane, apps or technology that may assist with mobility. If you require an Auslan interpreter, they should be present throughout all of your therapy sessions. If your therapists have not worked with an Auslan interpreter before you may need to provide them with guidance throughout the sessions. Auslan interpreting is funded through your core budget in your NDIS plan, so separate to therapy. An Auslan interprets spoken English to Auslan and Auslan to spoken English for the deaf and deafblind community. An Auslan interpreter with experience working in the deafblind community will be familiar with modifications needed to ensure Auslan is accessible. This may include close range signing, visual framed signing, tactile signing and deafblind finger spelling. Social happen particular communication may also be used. This is aa way of communicating information in a tactile way into the body of another person. An Auslan interpreter should always be booked for formal appointments and meetings, including therapy sessions, where this level of communication support is required.

A communication guide is different to an Auslan interpreter. A communication guide can provide some level of communication support to people with deafblindness. However, they are not it typically trained and accredited as Auslan interpreters. A communication guide is funded through your core budget in your NDIS plan.

The last member of a deafblind team that I would like to discuss is a deafblind consultant. A deafblind consultant is an allied health professional or a teacher who has gone on to do additional study or work in the specialised area of deafblindness over a number of years. As a result of this additional training and skill development, deafblind consultants have a deep and broad knowledge of potential issues faced by people with deafblindness and some of the systems, strategies and supports available to address these issues. A deafblind consultant will assess the skills and needs of the individual with a particular focus on communication, mobility and the need for assistive technology. Following this assessment, deafblind consultants work with individuals and their networks to develop skills and strategies which will support their everyday life. This may include referrals to relevant allied health professionals as appropriate. Deafblind consultants have a role in linking people with deafblindness with relevant networks such as local deafblind social groups, diagnosis support groups like Usher Kids and wider national and international support groups. Deafblind consultants can provide support when accessing education, employment and the wider community by providing support to the individual and their support networks about how to access various places and events. They can also run training to build the skills of the service providers and wider community to meet the needs of the individual. A deafblind consultant helps to bridge the gap between people with deafblindness and the services and systems around them to make sure they can access services and supports as equally as everybody else.

I am going to hand back to Meredith now, but if you have any questions or if you would like to chat about anything from the presentation, please feel free to get in contact.

MEREDITH PRAIN: Thank you so much, Emily. That is a lot to give everyone to think about, I think.

Michelle, I see there’s a comment from Emily Shepard.

MICHELLE SCHOFIELD: She writes: “I think the compounding impact of a dual sensory loss is underestimated and providing supports for hearing loss plus support for vision loss are just not enough. Specialists such as deafblind consultants are integral to the process to allow a real understanding of the impact of deafblindness on young children and adults”.

MEREDITH PRAIN: Thank you. That’s great to hear a parent advocating for the neat for deafblind consultant input.

Are there any other questions or comments for Emily?

CARLA: I have been hearing the term therapy assistant. Can someone please explain that role? How is this different from a communication guide?

MEREDITH PRAIN: I will hand that question to Emily and then we will get Carol to share her screen to ask her question.

EMILY McDONALD: A therapy assistant is somebody who has gone to TAFE and done a certificate in therapy assistant or they might be an allied health student at university. They don’t necessarily have the same skill set as a commguide because they might not be Auslan proficient or undergone sighted dog training. So they have a different set of skills to a commguide.

MEREDITH PRAIN: Is Carol’s ‑ if the interpreter can see Carol to voice for Carol.

INTERPRETER: It’s a bit bright behind, yeah. She was talking about the background behind the interpreter being bright and the other room was better where it was darker.

MEREDITH PRAIN: Carol, we did try that but because of the social distancing, we needed to be in a different room and there wasn’t time to set up the dark background, but we apologise. We are aware it is a problem, so thank you for the feedback. It is not an issue that we can deal immediately with.

MICHELLE SCHOFIELD: Debra has her hand up as well.

DEBORAH: I recently got my video magnifier. Is it possible to have some training with the item?

MEREDITH PRAIN: Was there a question that came through?

NEW SPEAKER: I got my video magnifier. Is it possible to have training from my deafblind consultant or a worker to help learn how to use the buttons on the machine?

EMILY McDONALD: Absolutely. That would be something that your deafblind consultant or your OT could help you out with.

MEREDITH PRAIN: It’s something to follow‑up after this session.

Thank you very much for your time.

NEW SPEAKER: I will ask my OT those questions?

EMILY McDONALD: Yes.

NEW SPEAKER: Thank you. Stay safe and keep your social distancing.

MICHELLE SCHOFIELD: There is another question from Shayne. He asks how to identify and locate specialists in your region.

MEREDITH PRAIN: Did you want to answer that, Emily?

EMILY McDONALD: Can we do a team answer? Where do you live, Shayne? That’s a point to start with, I think.

NEW SPEAKER: We are in Brisbane, in Queensland. To be honest, we are attempting to engage with Meredith to help us overcome some of this, but it’s been something that we’ve been struggling with for a number of years up here trying to find the appropriate person with the skill set to work with, with the gentleman, because he doesn’t quite fit some of the descriptions we’re hearing, but it’s been a struggle and we’re a bit blessed to have found this group, but as a general approach, are you trying to put together like a nation‑wide registry of people who ‑ say if we’re looking for a psychologist who had the experience and the skill set to delve properly and support and help this man, trying to find one is a challenge in itself. It’s almost a full‑time job. I’m just wondering if there’s another resource that I haven’t seen yet that’s available.

MEREDITH PRAIN: Shayne, we are all well aware that it is a big issue across Australia, that the only two services that specialise in deafblindness are based in Melbourne and Perth. We are starting to put a list together, but there’s not many people, but I guess one of the things we’re doing is running sessions like this and trying to build capacity and trying to support therapists who are new and learning.

I’m just mindful of the time and we can, perhaps, pick this conversation up again, but I will just thank Emily again and thank you to everyone who is asking questions as well, it’s really great. There’s no webinar without participants, so thank you.

We will bring Ryan on now and I think Ryan, are you signing or voicing?

RYAN MALONDA: Voicing. Hello, everyone. For those who can see me, my same name is Ryan. I’m deaf myself. I work for the National Disability Insurance Agency, so NDIA. I’ve worked for the Agency for close to three years now. So I was a planner meeting participants, including those who are deafblind for about two and a half years, and now I am working as a team leader in a new team that’s looking after the quality of plans and checking that plans are suitable for people in making sure that the supports in their plans are meeting their needs. So that side of things, making sure we’re doing the right thing and supporting people where we can.

I want to say thank you to Michelle and Meredith for inviting me to be involved. I was involved in a webinar last year and that was a really great experience and I was glad to be involved again this time around.

I also want to say thank you to the previous speakers. There was Emily talking about her experience with her child, having their experiences with NDIS and it’s really good to hear that it was a positive experience and that you were able to have a LAC who themselves also has Ushers, so that’s a really fantastic situation to have where you have a mutual understanding and hopefully the best outcome possible. Of course, you mentioned to me in the chat before that, of course, there are some challenges and the agency is looking at what challenges participants are having, how can we address those and best support them through the planning pathway, so getting a plan, having a meeting and using the plan. It’s still a work in progress but we’re getting there.

Thank you to Melanie for an in depth presentation. It is one of the hardest things to do, especially goal setting, because you have to think about your life, what you want out of your life, what you would like to achieve and figure out how to put that into words, into writing on a plan. Most people if you ask them, “Okay, tell me five goals that you would like to achieve in the next few years”. Most people will go “I’m not too sure”. It is a similar experience for participants. Often we talked about goals at the end. That way we talked about what their needs were, talked about what supports they would like and then figuring out, okay, this is what you want, what goals do you need to be able to support those, so sometimes you can in a planning meeting ask if you would like to talk about goals at the end because that might help. Of course, you can tap into other resources such as Able Australia, Senses Australia, the two main ones for deafblindness, that can support you with your goal setting, your allied health professionals can support you as well, and I want to say thank you to Emily for talking about potential supports. It was very in depth and it is clear that you have learnt a lot given how complex the NDIS is and what can and can’t be funded by the NDIS. It is a really good touch on what can and can’t be included in a plan, including the different types of supports that can be included in a plan.

I was invited to talk about overview of NDIS, but the previous speakers covered so much, so I’m trying to think what would you like from me. There was a question before. Is someone able to remind me what that question was because it was quite a couple of minutes ago.

MEREDITH PRAIN: Carla asked how long does it take, how many meetings can you have for a preplanning period and is there a time limit?

RYAN MALONDA: Sure. That’s a great question. Usually this is your typical scenario, usually we look an hour and a half to two hours for a planning meeting, but, of course, we need to take into consideration that doesn’t always suit some people. For example, for some people who can’t tolerate sitting in a meeting for a long time, it doesn’t work for them, so you might split up the meeting into shorter meetings, although if you’re deafblind you have tactile interpreters, you might get fatigued throughout the meeting, it could be quite an exhausting environment and especially for a long time, same for those with vision frame signing, or tactile finger spelling. We do try to accommodate communication needs and other needs in the meeting. Depending on your circumstance, just is, say “I don’t think this meeting will be suitable for me. It’s too long”, or “too short”, and just flag that and we will be happy to accommodate. So we will do the best that we can with that. Of course, be mindful that maybe in advance you let the agency know. That way if you need Auslan interpreters and multiple meetings or commguides or tactile interpreters, we can get that arranged for you.

MEREDITH PRAIN: It would be great if you could touch on the recently‑announced hearing services with the NDIS and also if you could talk about early intervention and the very beginning with people newly diagnosed.

RYAN MALONDA: Yes, thanks, Meredith.

The first thing to talk about the hearing services program. This is a tricky area which has been developing over the last couple of years. So some background to that is many people would have been engaged with Australian Hearing who have now changed their name to Hearing Australia, which some people are still trying to get their heads around that. So they were previously or currently still are funded through the Commonwealth Government hearing services program. So this was typically funding from the Department of Health. However, when the NDIS came on board and started rolling out throughout Australia, there was the agreement between different areas of government, both Federal and State that certain disability supports will transition to the NDIS. So that included the hearing services program. That meant eventually the NDIS would be responsible for paying for the same stuff that historically the hearing services program paid for.

It’s a bit of a complicated space because there’s different transition arrangements depending on how old you are and what type of support you’re receiving from the hearing services program. So at this point in time, so information current as now, if you are a participant who is under 26 years old and you’re receiving supports from Hearing Australia, you will continue to receive those supports through Hearing Australia for the foreseeable future. So that won’t be changing at this point in time. However, if you are over 26 years old and you’re receiving support from Hearing Australia or through the hearing services program, because you might have been accessing that through a different audiologist, that support will then be funded in your NDIS plan from 1 July onwards this year.

So because right now the Commonwealth government hearing services program is paying for it, if you have a plan approved now, you might have that funding included in your plan from 1 July onwards, but you won’t be able to use it yet. That money is there to prepare you, give you that money that you need so that you can continue to see your audiologist, get your hearing aids checked up, have your maintenance and repairs and that sort of thing.

That’s a broad overview of what’s happening with that. So lots of people know that if they’ve been going to Hearing Australia, that they get a replacement hearing aid or hearing device every ‑ it’s a certain time period. From 1 July onwards for those who are 26 years old or above, if you need replacement hearing aid, money for repairs and maintenance, that will need to be in your plan and make sure you ask for that and flag that in your planning meeting.

Are there any questions?

MICHELLE SCHOFIELD: We have two questions. Firstly is Deborah.

RYAN MALONDA: She is talking about her meeting being split in half, to discuss her overall NDIS plan.

That is great that they were able to accommodate you.

MICHELLE SCHOFIELD: We have a question from Shayne: “For folks who are agency managed, could you confirm if it is possible to compartmentalise some services for a greater range of necessary services? If able to happen, what approach would you recommend to achieve this?”

RYAN MALONDA: What sort of supports are you asking about?

NEW SPEAKER: The gentleman is agency managed. We’re finding that we can access some supports. However they’re not actually agency registered. So that then means that we have got that gap between what’s possible and from either end, and I had heard that it may be possible now for an agency‑managed person to actually have a part of their plan, plan managed, but I’ve yet to see that in reality yet. So it’s only hearsay at this point.

RYAN MALONDA: That’s a really great question. That is possible. So for those who don’t know, when you have an NDIS plan, the funding in that plan, the way that you look after that money, there’s three different ways. So you can have it agency managed or NDIA managed, which means that the NDIA looks after your money and your services that you access, the providers of those services, will claim directly from your NDIS plan. The other option is plan management, which means you have a third party, think of it like a bookkeeper or accountant who just looks after that money, they don’t have much control other than you giving them an invoice and they pay it for you from your NDIS plan. That allows you to use providers that are both NDIS registered and nonregistered providers. Then there is the third option, self‑management, which is you are responsible for managing the funding, you have access to it on the NDIS portal, website, you can make claims and you get the money in your bank account and you are responsible for paying for your services. So Shayne you can have a combination of different ways that you look after that money. So you can have a combination of agency managed and plan managed, and depending on where that person’s plan is, I don’t know what the timeframe is, but if you’ve got a review coming up, you can definitely ask for different money to be arranged a different way and it’s definitely ‑ it’s the participant choice. So whatever is your choice in terms of how you want to manage your funding, that’s up to you. The only thing is for self‑management we do have to make a risk assessment, making sure you haven’t been bankrupt or insolvent in the past.

NEW SPEAKER: Is there any approach to that, that you would recommend or just raise it as we’ve raised now?

RYAN MALONDA: Yes. Just raise it as you have now. Say, for example, “I would like my capacity building funding to be self‑managed and others agency managed”.

NEW SPEAKER: I just recently had my hearing appointment. Can I use my NDIS to pay for my hearing services? Like, for my hearing aid repairs or when I get new hearing aids, et cetera, new batteries and stuff like that?

RYAN MALONDA: Sure. That’s a great question. Going back to that hearing services program discussion that we just had, at this point in time until 30 June this year, the hearing services program is responsible for paying for your hearing aids, your upgrades, your maintenance, your batteries, you might pay a little contribution, some people pay between $30 to $60 a year to Hearing Australia or the hearing services program and they get batteries and repairs and maintenance in return. That arrangement will continue until 30 June. However, 1 July onwards, then you can use your NDIS plan to access that.

NEW SPEAKER: Thank you. My next point with Australian Hearing, do I need to use my NDIS funding to attend my appointments?

RYAN MALONDA: It depends if your next appointment is before 30 June or after 30 June.

NEW SPEAKER: I had one in April recently, and one will be around about October/November, later in the year. My audiologist told me I had a choice, 12 months or six months.

RYAN MALONDA: Sure. So that sounds like it will be after 1 July, so I would encourage you to bring a copy of your NDIS plan. You don’t have to show your audiologist, but bring a copy with you just in case and your audiologist will be able to tell you if they need to claim from your NDIS plan and if necessary they will get you to sign what we call a service agreement. It’s basically a contract outlining that they can claim money from your NDIS plan and how they will get paid if they need to get paid.

NEW SPEAKER: I have to take my plan with me to my audiologist appointment next time?

RYAN MALONDA: Probably it is safe to do that. Whether it’s a physical copy or just a copy for yourself, what you really need is just a good idea or way to check how much money is in your capacity‑building budget and what your NDIS number is and your plan dates. That way if your audiologist needs to claim money from your plan, they will be able to help you arrange that.

NEW SPEAKER: Thank you. Have a nice day and stay safe.

RYAN MALONDA: You too.

MEREDITH PRAIN: I’m just mindful of the time. Ryan, if you could just talk briefly about the process of the family with a child who is newly diagnosed and their journey or the process and then we will open it up for questions to the whole panel after that.

RYAN MALONDA: Sure. The NDIS has various different ways that you can access the NDIS. We call these pathways. So we acknowledge that various different ages, disabilities, circumstances may require a different approach and we are constantly tweaking and adjusting and learning how we can do better to best support participants to get the supports they need. So at this point in time for children who are between ages of 0, from birth, up to six years old inclusive of six, we have a pathway called the early childhood early intervention pathway, so ECI pathway for short.

This is a pathway that has a tailored approach where participants, so children, they will receive multidisciplinary supports, meaning that they will get funding based on the level of disability or their condition because some children under six may not have a diagnosed condition as yet, but they still have needs. So they will get funding that they can see a wide variety of allied health professionals such as Emily talked about before, who can help identify that child’s needs, what their supports should be put in place to build their capacity and their ability to do everything else that everyone else does. So this approach is quite an intensive approach because the NDIA acknowledges that in terms of milestones and the crucial time periods for children to acquire skills, language, build their capacity, it’s important to get in as early as possible so that they can have the best opportunity to learn and develop and grow, so that’s why we have a specific pathway for it that is a little bit different to the general pathway for participants who are seven years old and up.

That’s a very broad overview. If anyone would like me to elaborate more, feel free to ask.

MEREDITH PRAIN: That was great. Thank you, Ryan.

I will hand over to Michelle to ask any questions that are coming through, and we will open it up to the panel. If anybody has a question for Emily Shepard or Melanie Robartson, Emily McDonald or Ryan, and each might have something to say about the questions, but I will hand to you, Michelle.

MICHELLE SCHOFIELD: Thank you. We have a question from Emily Shepard for Ryan which says can you talk more about the different service providers other than Hearing Australia providing audiological services for those over 26?

RYAN MALONDA: Yeah, I can definitely do that.

Prior to the NDIS coming in, you had the hearing services program, you had hearing Australia or back then Australian Hearing who provided what we call specialist hearing services, so those with complex needs, those who are children requiring early intervention, pretty intensive regular sports to make sure that they develop as best as they can. For anyone under 26 their main provider, the one that you would go to, is Hearing Australia because they’re set up for that and they’re able to provide a much higher level of support than other providers. However, for those who are over 26 years old, the hearing services program had about 280 hearing services program audiologists, not like Hearing Australia, but like Bloom, the private audiologists that when you go to the shops you see those hearing aid stores, those type of shops. Because hearing Australia was set up in certain areas but maybe some people don’t like hearing Australia, some people prefer a different audiologist, they have that choice to go to a different audiologist. They have 280 different options. However, after 1 July you might see even more audiologist organisations pop up as they won’t have to be registered with the hearing services program. Instead, they will be registered as potentially an NDIS provider.

MELANIE ROBARTSON: A question for Ryan. A lot of people born with deafblindness have fairly complex medical and care needs at various stages of their life, often when they’re very little and in the first couple of years of life before they stabilise and then as they age. I notice there’s a line for funding for nursing in the kind of funding line items and I’m wondering how this might apply to someone with general deafblindness when they have those really high medical needs.

RYAN MALONDA: This is a very big area. So historically, just for background, NDIS was very focused on funding supports that were strictly disability related. If it was something medical, in most cases at that point in time it was the responsibility of the health care system, hospitals, your usual Medicare to provide. However, as a result of the disability reform council, who meet together regularly, they talk about changes and the government, how NDIS can improve, what things need to be changed in various different government departments and systems.

So they came together and as a result of one of their discussions, on 1 October last year the NDIA introduced what we call disability‑related health supports. These are supports that alone you might look at and go that’s very medical, but the purpose of that is the NDIA acknowledges that some people might only have those health needs because of the specific disability that they have.

So one example that I can think of in relation to deafblindness is potentially someone who is deafblind and has diabetes. So maybe they have full dual sensory loss and they communicate in tactile Auslan. If they need to have regular insulin injections and they might not be able to do it themselves because they can’t see or access their blood sugar, the reader, they can’t do the injection themselves in a safe manner, then based on the person’s circumstances, NDIA may consider funding nursing supports to do that for the participant and help them administer their own insulin because that is the more safe alternative and it’s only required due to the fact that they are deafblind, because if they were not deafblind, in most cases people with diabetes can inject their own insulin. That’s one example off the top of my head.

MICHELLE SCHOFIELD: Are people who are deafblind getting enough supports and services granted in their NDIS plans or are they having to seek a review or an appeal?

MEREDITH PRAIN: It would be great to hear from each of the panel members with response to that question from Erika.

Emily Shepard, do you feel you have received enough for your son?

EMILY SHEPARD: Yes, definitely for my son we have had adequate support, but I think that that came down to the relationship that I had with the LAC who really understood the condition, but I know that that is few and far between. I do know that a lot of our families do struggle with the understanding of the dual sensory loss and many have had to go to reviews for more support.

It seems to be that those supports were around access to interpreters for those with Auslan as their first language who have struggled the most, but I do think that it is slowly improving. There is more and more awareness from the NDIS about the needs of our community, but, no, it’s not perfect and, yes, many do have reviews, but I think they are getting looked at and reviewed more quickly at the moment, so it’s not a perfect system, but we’re getting there slowly.

MEREDITH PRAIN: That’s great to hear, thanks. Melanie, what is your perspective on that question, the adequacy of plans generally for people with deafblindness?

MELANIE ROBARTSON: Again, I think it is very mixed. If a family is very involved with their services and that service has a good understanding of deafblindness, then they can help the family think about things that they might not have thought about already and the family can do likewise with the therapist, and they can prepare a nice report with lots of assessment information and rationale to get the supports they need.

Where there have been reviews, it’s over issues of congenital deafblindness, you have unique communication needs, and sometimes the families sort of struggle to support those communication needs, so we try and bring in people who already have those skills to support the family to support the child and also support the child in social situations as well in terms of their communication, their orientation, mobility skills, getting around from A to B. So we might use support workers to help build those skills as well and sometimes we might really not get an ideal amount of support work, perhaps, to support that need, but with review and advocacy we might get success there.

The other aspect is that it can be quite a difficult area for support workers to work in and they need a lot of skills to do it and to stay there and to stay in that role and feel confident in that role, so they need a lot of training support as well, and so sometimes we all try and work that into the individual’s funding package so that the people working around that child get specific upskilling to continue to support them. That’s probably my two bits worth there.

MEREDITH PRAIN: Thanks. I would echo exactly what you’ve said. It’s true for adults as well. I see a lot of adults with congenital deafblindness and that need for training support staff around the individual. There’s a really big need there and I think that hasn’t been well addressed in a lot of plans that I’m aware of, so, yeah, that need for ongoing training of staff working with the child or the adult.

Emily McDonald, what is your perspective on your clients that you’ve been working with and the adequacy of their plans?

EMILY McDONALD: Getting the plan in the first place and that being adequate is getting better. The thing that a lot of the people that I work with and struggle with, if you don’t use it you lose it model, where they might have had an issue finding the right fit or supports and then subsequently those supports not being repeated in another plan because they weren’t used in the previous plan.

MEREDITH PRAIN: Ryan, your perspective on that?

RYAN MALONDA: First addressing what Melanie said about making the most of the resources that you have. I do want to reiterate in a planning meeting you can always bring any support person that you feel that you want involved in that meeting, whatever you need in your planning meeting to support you through that process. You do what best fits you. So you can bring someone, like an advocate or family friend, who can help you through that process, I encourage it and so do the agency.

So the question was around reviews and whether or not deafblind people are getting the supports they need in their plans. I’m not too sure about what percentage of participants with deafblindness end up having a review of their plan. I can say, however, that deafblindness is a very unique disability type where there can be various different courses. As you know, you have Ushers and other different reasons, you have people who are impacted in different ways and have various different communication methods, and that’s very evident. You’ve got deafblind people who are oral, deafblind people who can hear, you’ve got a bit of both or full total sensory loss. You’ve got tactile Auslan, visual frame, finger spelling, you’ve got everything. So it is a very complex disability and it can be quite tricky to really understand it as a whole and that’s why I do really want to reiterate that it’s important and helpful to collect all the information you need, talk about how your disability impacts you individually, that’s the whole point with NDIS, that it’s an individual approach, you tell your story, and we will try and figure out how to best support you with the right funds in your plan.

Recently, I think it was last year, the agency did link in with varies different peak bodies that represent different disabilities, so I do know that we linked in with Deafblind Australia and there are resources now available in the agency for planners and LACs to refer to. These help, of course. They’re a good overview, because going back to the complexity of the deafblindness, but the resources that we have and that you have are growing and make the most of all of that.

MEREDITH PRAIN: We have probably got time for one more question, if all the speakers respond.

Are there any final questions? You can direct it to a particular speaker or the whole panel.

EMILY SHEPARD: I had a question for Ryan in regards to training for parents and carers. What is deemed reasonable and necessary? Lots of our parents are thrown into this world with zero understanding of the needs of hearing impaired and vision impaired or a combination.

RYAN MALONDA: That’s a fantastic question. It is hard to give a blanket question to that. Reasonable and necessary, it depends on the participant and the family’s circumstances, what needs does the family have, what needs does the participant have, my head is already thinking about what if the child uses tactile Auslan and the parents are struggling with that, so we may potentially find it reasonable and necessary to provide Auslan training or we might provide training for parents who understand how best to deliver and implement therapies and skill development in their home in a way that is accessible for their child. There’s so many different ways that we can approach this. All I can really say is that just with your therapist. They’re the ones who are qualified to identify what needs that ‑ what needs to be funded in the participant’s plan in relation to training and enabling the people around that participant to best support that participant taking into account the individual needs. That’s the key thing about the NDIS. If you’ve got the evidence for it to back you up, then that gives us the best information that we need to be able to determine if it is reasonable and necessary.

NEW SPEAKER: I have a comment this time to Meredith. Meredith, I just have a comment. It’s been very interesting. I really liked the way it worked today. I have to go soon because I have to go and have my dinner.

MEREDITH PRAIN: Thank you for that feedback. We really appreciate it. It’s good to know that it was valuable and useful for you, and good luck with your speech.

NEW SPEAKER: I have to have my tea shortly.

MEREDITH PRAIN: Thank you for joining us this evening.

We might wrap it up there. I just did have a couple of things to say, so one on your question, Shayne. I know Ryan spoke about people who use all those different communication methods, but I’m aware that the man that you’re working with has very limited ability and is very challenged with his communication and I think people with congenital deafblindness who are deafblind from birth, developing communication is a major challenge and there’s a lot of adults out there who do need more services, so I’m really pleased to let everybody know that this project that has funded this webinar this evening is finishing up. We have another two webinars to go, so we hope you will join us for those, but the project that is starting up is there’s a strong focus on congenital deafblindness because we do recognise this is an area that hasn’t been as well addressed, so there will be more training and resources being developed, so we are hoping that that will start to improve the services being provided for that group. We recognise there’s an unmet need out there, as you’ve identified, Shayne, so do keep an eye on the Deafblind Information Australia website and also on the deafblind information Facebook page, which is where we put information about new resources going on the website or training that is coming up.

So three minutes to go. If there’s any very last questions, otherwise I would just like to thank the speakers. It’s been a great session, a really good diversity of perspectives and a wealth of knowledge there, so thank you so much for your time this evening, Emily Shepard, Melanie Robartson, Emily McDonald and Ryan Malonda. We really appreciate having the NDIA perspective and someone who knows the tricky questions if we don’t know the answers.

So thanks again to everyone who has participated, thank you to the interpreters and the captioner, Lee, and thanks a lot Michelle for doing all that work in the background.

SHAYNE: Thanks Meredith.

MEREDITH PRAIN: If you have questions for the presenters, you can email Michelle or myself and you can forward them on, but, yes, have a good evening, everybody, and thanks for attending.

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