Webinar#1: Autism and the NDIS

Nicole:
“So my name is Kylie and I feel like I've taken a scattergun approach to having my son diagnosed. Basically the doctor gave me a piece of paper and said "Okay, goodbye!" and I was left on my own. I've had separate assessments with the OT, with the speechies, and it's all over the place, and I have to deal with the NDIS negotiating, planning, and I feel completely overwhelmed.”

If some of this resonates with you, well then you're definitely in the right place today. My name is Nicole Gamerov and I'm the founder of MyCareSpace, an online platform that creates meaningful connections for people with a disability so they can build an extraordinary life.

This is our first in a series of webinars and we're delighted that you can join us. We've been swamped by the response and the number of questions. So to that point we will try and answer as many questions during the webinar today and both Charmaine and Randa will be answering questions, but we have limited time so we will not be able to answer all 200 questions.

So, over to the panelists, so I'd like to just make a brief introduction. So we've had sitting with me here is Randa Habelrih who is an international and award-winning speaker, autism activist and author. Randa has also been a marketing executive and she has worked with some of the largest global brands, luxury brands. Randa has also written a book called Dealing with Autism, and Randa has also created a program called SCHOOL MATES to prevent bullying in school. Randa holds a Bachelor of Commerce and is a mother of two children, one of which is on the autism spectrum.

Something quirky about Randa. Randa says she is allergic to wine but she loves a good scotch.

Randa can be found on www.randahabelrih.com and she also has a Facebook group called…

Randa:
Autism Connection on the Spectrum. Come and join us.

Nicole:
We will provide links for all this relevant information afterwards, so over to Charmaine.

Charmaine is a support coordinator and a peer mentor for people in the NDIS. Charmaine is also a trainer for parents and professionals dealing with autism. Charmaine has a Bachelor of Behavioral Studies and in Psychology, and also happens to be a mother of two children, the older of which is on the autism spectrum.

Something quirky about Charmaine is that she actually was a ballroom dancer.

Randa:
I didn't know that, Charmaine. [chuckle]

Charmaine:
I keep it a secret. [laugh]

Nicole:
Not anymore. So in terms of Charmaine's Facebook profile which is private, but she has been very generous in providing a long list of useful links which we will email to everybody after the webinar, so no need to write all those useful links down.

So on to the meaty part of our discussion today. We have split the webinar into three key sections based on the number and the nature of the questions that have been sent through.

The first one is ‘**NDIS eligibility and Access**’. The second section is ‘**Planning for the NDIS**’, and the third section is ‘**How do I get the most out of my NDIS plan**’.

We're going to kick off the first discussion which is NDIS eligibility and access with the question that we received from a mother, and this is - I'm going to pose this to you Charmaine –

A mum says "I've been using **HCWA** funding for my three-year-old daughter. Will she automatically register for NDIS, and **what happens if my HCWA funding runs out before I get NDIS approved**?"

Charmaine:
Okay, so all the acronyms are already starting off, so I'm going to do my best to try and explain those. So HCWA stands for ‘**Helping Children with Autism**’ and it's the prevailing funding that has been in since 2008. So for anybody who's got a child that's under the age of seven or might have received it in the past, Helping Children With Autism funding will transition to NDIS.

So the simple answer to this person is -- will she automatically register for the NDIS? The answer is yes. The Australian government is aware of people who are receiving current funding and it will then trigger the NDIS to contact her to transition.

What happens if your NDIS or your HCWA funding runs out before your NDIS gets approved?

Well, this is the nature of individualised funding. There will be a gap but the NDIS will take over, and I guess -- and I know you're going to keep me to time here, but really there is another broader point here, which is the Helping Children With Autism funding signifies and represents the old style of funding. The funding that will be used up, it's rationed in some way, time-limited, dollar-limited up to a certain age, and really when you transition to the NDIS it's a new style of individualized funding. The NDIS funds what's ‘**reasonable and necessary**’, and they are two words that you'll probably hear me say a few times during this webinar, and therefore as long as required.

So I hope that kind of starts to answer, to reassure this parent that yes, the funding will transition across, and actually I got a great link where the Department of Social Services kind of steps through every question that you could ask about that transition, so I'll make sure that's in my notes for you.

Nicole:
Right, thanks Charmaine. So I guess in terms of NDIS eligibility and access, where do people start? Because a lot of people who actually registered for our webinar, I'd say about most of them, probably 90 percent don't have their NDIS plan yet. So a lot of people are in that sort of early stages of trying to find that about the access and eligibility.

Charmaine:
Alright, so what would Randa and I going to say? It's really like when everybody is in the swimming pool going "Come on in, it's lovely!" and you're kinda standing there going "I don't know!" I mean, I was incredibly anxious about getting into the NDIS, the application form sat on my sideboard, but I really do believe that you're better in than out.

So let's just talk a little bit about the pathways, and again I've given you links to these documents.

There are essentially two pathways into the NDIS (for Autism):
There is for those who have a **child under the age of six** and that's called the **Early Childhood Early Intervention** pathway. That's **ECEI**.

So you will noticed some of my resources specifically used that acronym ECEI, and it was developed in response to the fact that people with very young children often don't have all of that -- the documents, they don't have all of the reports. So they created a pathway into the NDIS that has wider gateways. It's a softer entry, and there is currently an early childhood access partner just waiting to pick you up and kind of smooth your entry into the scheme.

For those who are already over the age of seven, then you go through the standard pathway, and I've given you a link to the NDIS - My Pathway document, and essentially the eligibility is that you meet the age requirements, and the only age requirement is that you're under the age of 65, because before over the age of 65 you're captured by the aged care system. So the NDIS is under the age of 65, that you meet residency requirements. That is either that you are an Australian citizen or a permanent resident, and that you meet the disability criteria, and I think that's the one that perhaps hits home the most for either people with autism or somebody who loves and cares for somebody with autism.

So we might talk a little bit about that, about the diagnostic criteria. So the first thing I can share with you is that you probably need to know at what level your loved one - what level of autism -your loved one has, and that's really going to come from the latest diagnostic criteria.

So **autism is diagnosed i**n accordance with the criteria set down in what they call the **DSM-5**, and that's the **Diagnostic and Statistical Manual 5th Edition**, and that sets out the various features of autism under two broad categories of social communication and behavior, and there is a number of different diagnostic tools that might be used including things like the **ADOS** or the **GARS**. Back in the day my son did the autism diagnostic interview.

And they can then say your -- you or your loved one has an **autism level of 1, 2 or 3**, and they can be described as:

- **autism level 1**: requires support,
- **autism level 2:** requires substantial support and
- **autism level 3**: requires very substantial support,

and these levels are important because the NDIS provides automatic access, no more assessments required, to people who are autism level 2 or level 3.

Now, it doesn't slam the door in the face for those with autism 1, but by the time - I've given you a few links to these, I don't expect people to remember it but it's in my useful links - but if you have autism or you or your loved one have autism level 1, then we'll really go down a little bit deeper into a few more of the kind of underpinning principles of the NDIS which is it's not just diagnosis, it's **functional capacity**.

So if you have autism level 1 you need to be looking at the areas of functional capacity, that what they'll be looking at is mobility, communication, social interaction, learning, self-care and self-management.

So I've given people some links to understanding the diagnostic criteria and then understanding the eligibility criteria for the NDIS as it relates to autism diagnosis. Does that help?

Nicole:
Definitely. Randa I mean you've been through that process, so would you relate to that?

Randa:
We've just been through it because we had our planning meeting, and we were given the heads-up that we really do need a **DSM-5 diagnosis**. Now he is 21 and didn't have a DSM-5 diagnosis, so we then had to go and get one.

So don't wait until you're given the planning date to organize this because when I started ringing around I was given three-month waiting periods to be seen. Luckily we were able to be seen and to get a report tabled, but get that DSM-5 diagnosis as soon as possible, and that way you will know.

If your child is diagnosed with level 1 you will need further reporting and further substantiation, but definitely go and do that as soon as possible.

Also, if you do have a diagnosis of level 2 or 3, again that doesn't mean a carte blanche of everything you want. You still need the supporting documentation. It's very important to know what you want to ask for. Document that in NDIS speak or terminology so that it relates to your goals, and then have the supporting documentation whether it's from the allied healthcare professionals, your OTs, your 'sppechies', your psychologists.

And also **if your child is post-school, have some sort of connection with the employment service that you're after now**. We were caught out with that. We had to do some backtracking and now we have the report required or some statement from the service that we're working with a quote with what Richard needs and what his supports will be.

So everything must be supported. Yes, ask for everything, make a big wish list, but use your NDIS speak and have every supporting documentation ready. They do not accept any document that is over two years old.
I went in with a mountain of paperwork and it was just pushed aside if it was more than two years old, so that's also very important to remember. They don't care about the initial diagnosis. They want two years and under.

Charmaine:
Alright, and can I conclude access requirements, with the first time I'm going to mention, that **every decision that the NDIS makes, almost every decision is a reviewable decision.** So if you apply - you or a loved one - apply to be a participant of the NDIS and they say no or they say "We don't have enough information," that decision can be reviewed.

And in the links, I've given you the **link to a reviewable decision**, and actually some people have taken it all the way to the Administrative Appeals Tribunal about either they'll be accepted as a participant or not, so it's not even the last say just because the NDIS says no. If you feel that you or your loved one should be a participant of the NDIS then you can review that.

Nicole:
And Charmaine, in terms of having a review, I've heard some people say “well, it's better to just wait until your next plan”. What's your view on that? Do you go for a review or don't you, and how demanding is it to go through that process?

Charmaine:
Alright, so I'm going to talk about reviews as they relate to funded supports a little bit later in our getting a new plan. This is purely about getting in the front door, this is purely about whether you meet eligibility criteria or not, and if you're not backed at the first swing then that decision can be reviewed.

For all the discussion about reviews, we'll talk about that when we talk about funded support steps, okay?

Nicole:
But really, to wrap all that for a lot of people, the question was "I have ASD-1 or I have a child with an ASD-1." It's not automatic. You have to then go through those extra hoops in functional assessments.

Charmaine:
Yes, so I've kind of - I've put in the links - just exactly what the wording is that the NDIS used.

They say "Permanent impairment and functional capacity - no further assessment required for ASD level 1 or level 2."

Then they say "If your condition is not on the list of permanent impairment functional capacity you must provide evidence of the impact of your condition on your life, including those six domains of functional capacity, communication, self-care, self-management."

So for whom that is the most important deal, I've given you some useful links.

Nicole:
Right, okay, wonderful. Now, any questions that you think we received that might be relevant in this section around eligibility and access?

Charmaine:
No, but I think we got another question that might segue on to the next section, which was about respite. Did you want to ask that one?

Nicole:
Yes, yes. So we received a question from a parent saying “**why is respite for carers not recognised as a need?**".

Charmaine:
Right. So I’ve got good news in that is that **respite is in the NDIS**. It’s just couched in a different way.

So firstly my good news is it comes in the NDIS in the form of what they call ‘**short-term accommodation**’, and actually this - the prices in respite and short-term accommodation - really came to a head in October, and new prices were released.

It's unprecedented, as there is usually a price guide every financial year, but they had to rush out a change in prices to prop up respite providers because the pricing was completely inadequate.

So this is in the price guide (and I'm going to give you the links to the price guide) on page 42 and 43. It talks about this short-term accommodation which is the new word for respite.

And Randa really nailed it when she said it's this ‘**NDIS speak**’, it's this language, and that really cuts back to the philosophy that underpins the scheme. So we used to talk about respite and that was really centered around the fact that it's hard to be a parent, that there is a lot of stress, and the parents need a break from their caring responsibilities. That's where ‘respite’ kind of came from.

But actually, the NDIS is person-centered. It puts a person with a disability at the center of their planning conversation, so rather than saying parents need respite, it will frame it that the person who has the disability can have an opportunity to live independently with the support that they need. The by product of that might be that the parents get a break but the intention of it is actually something that is good for the participant.

Does that make sense?

Nicole:
Yeah, I mean it might not be what people want to hear, but really we're not here to change the policy or to change these things. We're here to understand them and how do you work with them. So if parents understand that -- say, Randa, what about your experience?

Randa:
We're accessing the respite service that we used to access pre-NDIS, under the NDIS, and how we framed it was that "our son would like to go out, without his parents present all the time". He's over going out with Mom and Dad. He's a young man. He's 21, and he wants to go out with his peers, with friends, with other people.

So while we're still accessing a 'respite service', under the plan it's 'community participation' or 'socialisation skills'. So it's back to becoming aware of the language you use when you're sitting down with your planner and really, not a lot has changed in that regard. They used to be called the respite service, and now they've dropped that part of their name but they're still operating and as I said, nothing has changed, only the words in how we apply for this particular funding.

Nicole:
Great. So Randa, one of the questions we got from a parent was about "their **first experience with the NDIS funding and what to do**", so you've answered that to some extent.

Is there anything else that you'd like to add to that? So you've spoke about - I think it's very important to know - that your assessments and your health professional's input can not be older than two years, and we've spoken about the DSM-5.

Are there any other learnings from your transitioning of Richard in that first sort of 'eligibility and access' phase that might help other parents going through it?

Randa:
Well, just in terms of appeals, we have started, we have activated our NDIS plan, but there is a part that we want reviewed, and that's ongoing as we have already activated our plan. So it's not the be-all and end-all if you don't get every part of what you've asked for. We're reviewing that particular part of it.

So just keep going, and just remember. **It is a one-year plan and you'll get another go in a year's time**, but in the meantime you can still appeal for a particular decision, which is what we're currently doing.

And we can shift funds around, particularly since we're self-managed. Now, if it is an option for you to self-manage, that will certainly stretch the dollars further, and it also gives you the flexibility in employing your own support workers, and really picking and choosing who you wish to be a part of your child's development rather than being tied to certain service providers who have to stick by the NDIS price guide.

This way, you can employ them under your terms, and they pretty much work for you and your child.

[Note: Our next webinar is **April 12th @ 12.30pm** and is titled '**Getting the Most out of my NDIS: Plan Manage or Self Manage?**']

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Nicole:
Okay, we'll probably talk about that in more detail in ‘Getting the most of your plan’. Charmaine, would you like to add something?

Charmaine:
I'll always jump in. Look, I probably didn't prepare well for Jack's first planning meeting, so I've learned deductively. There are providers - again, I have links - to some fabulous planning tools. The work that you do in **preparation can really help you to understand what the NDIS can offer**, to bring in the things that you need to discuss, because it's quite a different way of determining what will go into the plan, and you kind of fill your whole life story, and then that falls into different funding categories.

So I've given links to - probably the best one for young children is by the **Association for Children with a Disability**. There is also a good link to the one by **Every Australian Counts.** I actually Googled - you probably still can go to pre-planning courses in places like Jaegar Institute, and this is like a 48-page planning document. So I've given you links to those.

So imagine that you've got this document, you've got all the assessments that Randa spoke about, you might even have quotes or a wish list. **You will need to develop ‘goals and aspirations’.**

I think that I really got caught. Yeah, they said "What are your goals and aspirations?" and I was really thinking "Well, I don't know."

I mean, I've been very much in the therapy environment. We have targets and drills, but as for the kind of the broader life goals and aspirations so I was a bit lost. It took me a while to kind of work out what that was and that funded supports are about helping you reach your goals and aspirations.

So use those planning documents that I've given you links to, to help you to write good goals.

Because I think everything kind of hangs on that. Be ready for the planning meeting.

Nicole:
We've jumped in. So we've started the ‘**Planning for the NDIS meeting**’.

Right, okay, so just so that everyone is with us. If any new people have joined, we're now talking about planning for the NDIS.

So we're at the stage now, just to revisit that we're eligible and we've confirmed access. **How do we actually find out that we're eligible and that we have access?** Just when do we receive that confirmation? Is it in email or is it in a letter in the post?

Charmaine:
I'm not sure. Randa would know. I mean I've literally joined the scheme four years ago in trial phase. We dropped the form in and somehow magically must have got some kind of word back. What happened, Randa?

Randa:
You will receive a letter.

Nicole:
Okay, snail mail, normal like the old-fashioned --

Randa:
Yes, that's right. If you're already accessing services and you're in the system, there is - there are - many for whom participation is automatic, but you will still get a letter confirming whether you apply or whether you don't apply. You will still get that letter telling you. And then it gives you the phone numbers to phone if you disagree with the letter. If you're rejected then you'll be given the details on how to follow up.

Nicole:
Okay, and presumably a lot of the feedback we get is "We haven't heard", "We haven't heard", "We are still waiting". So I think there is an element of - you do need to be patient, but at some point you also need to follow up. Letters go missing and - let's work by step.

Randa:
Absolutely. I was on the phone daily for about three months - I am not exaggerating - daily, and they document every phone call particularly if you insist that they do and you ask them to read it out to you. So you must if you think you've fallen through the cracks or if you think they're dragging the chain. The reason I did this is because in my area, everybody I knew was well and truly on their way.

If your area hasn't rolled out, there is no point phoning, but if it's rolled out and everybody that you know is already involved, it's time to start. And I don't know what happened, but we did fall through the cracks and it was from persistence that we finally got some attention and we were told that they've tried to call but I didn't answer which was a load of nonsense.

But you do need to follow up if you think that you should be at this particular stage.

Nicole:
Okay, alright, great.

Charmaine:
So if the people are not sure whether the NDIS is in their area, there is a couple of links that

I've given you. You can go on to the main NDIS website and you can click down under, I think it's participants, and you can go into state by state about where it has rolled out and where it hasn't.

And I've also given you links to the New South Wales NDIS website and the Victorian one and the Queensland one. You can almost put your postcode in and see when it will come to your area.

So - and look, the only other thing is just remember is that this is a numbers game. 460,000 Australians will become participants in the NDIS, and while there was a slow start during trial phase, those jaws have opened and there's loads of people coming in.

So if you meet the eligibility requirements, there is a place for you in the NDIS. It's a bit like kind of squeezing into a packed peak-hour train. You just got to kind of grapple with that. It's quite a very tight time frame at the moment for rollout.

Nicole:
And we do need to remind people that this is the single largest policy change that Australia has ever undertaken aside from Medicare. So we're taking all our state-based schemes and we're combining them into one national scheme. It has never happened before anywhere else in the world. It's the first time so there are teething problems but we do believe that they will be overcome.

So let's hop into the second part of our webinar which is planning for the NDIS. Now, a lot of people are terrified about that first planned meeting. They understand that it's potentially a make-or-break. I've spoken to local area coordinators and they say "Look, remind people, autism is a lifetime and your plan is for one year, 12 months."

That's fine, but Charmaine, share with us a little bit about planning. How can we plan for the NDIS meeting and that first plan?

Charmaine:
Yeah, well, do what I say, not what I did. I really wasn't prepared.

Really, I guess that's why I feel so passionate talking about the NDIS, because I feel very much that I was in the same shoes as everyone who is watching this. It was daunting, I didn't know what the scheme could pay for, I didn't know what to ask for.

I've use this analogy: It's like going into a restaurant where there is no menu. You know they sell food but they won't tell you what you can order. You just have to kind of tell them your whole life story and then they'll magically create this plan and you're gotta eat it.

So I feel like now that I've walked that path I can say "Hey, by the way, this is the process."

So yeah, definitely **do some pre-planning, complete some of those pre-planning documents, understand that the planning meeting is likely to be based on one or two questionnaires**. **If**

you got a child they'll probably be asking you questions in accordance with what's called the PEDICAT. That's P-E-D-I-C-A-T. It's an **assessment that helps to determine functional capacity**, and perhaps then deduce towards **what funded supports you might be eligible for.** Or, **if you are an adult it will be the WHODAS**, World Health Organization Disability Assessment Scale.

I've given you links to those in my notes. They will just help you to understand why you can ask these questions, that you have to write on a Likert scale and -- I don't know, I get very confused by those things.

I have also given you a link to my story of going in for the planning meeting with Jack so you can click on that link.

Actually one of the other links that I've given you is some 'T**op 10 tips for planning**' that were prepared by '**Every Australian Counts**', so of them, things like 'write a list', 'think big', 'be specific', 'learn the language' (which Randa has already mentioned), 'do research', 'take paperwork'. And then the other one, the last one of theirs, is 'take someone with you'.

If there was one thing that I would say, **as a parent of a child with autism is that, any meeting you go to, take someone with you**. I think that people react very differently when they've got you alone in a room as they do when there is somebody watching them.

So there are my tips, and I've also given a couple of my big heavy-duty links to some heavy-duty documents, and heavy-duty documents are the 'ASD evidence-based and informed good practice'. It is, I'm not kidding, an 80-page document, but buried within it on page 11 it talks about what's the best practice for autism.

So for those who might be watching this webinar who are very interested in getting intensity in their early intervention funded, there is a specific wording in there that starts to land on the programs that have been evaluated, what's effective for treating autism, and intensity in hours. So that's in the links.

And the other one is the '**Interface of COAG**' which is the Cooperation of Australian Governments if I've got my acronyms right. Way before the NDIS was born, all the different areas of government sat down and had a little card game to determine who would be responsible for it.

So people think that the NDIS is coming to be and it's just going to solve all the problems you could possible have with disability, but there are very clear borders to the NDIS and they're called the 'interface', and the most common interface that we bump into when we've got young kids with autism is the interface with the school system.

And now, the school system may be treating our children well or not, but **there is a really clear set of rules about what the NDIS will pay for and what the school system has to pay for**.

The other one that we have a common interface with is health - how much should we expect the health system to do and what the NDIS will do, and actually, lots of people get caught up spinning their wheels expecting the NDIS to pay for something and then finding that it doesn't. They get really disenchanted. But actually, there is a document that sets out who is meant to pay for what.

So if you can follow the link, get into that, find out the interface that impacts on your family, your loved one the most. I reckon it'll kind of help you to avoid some of those conversations where the NDIS might say "I wouldn't pay for that" or "We don't fund that. That is the responsibility of another service system."

Nicole:
So is it similar with health? A lot of the questions we've been asked are, “I need to get all these assessments, and some of these assessments are really expensive.”

Who pays for those sorts of assessments when you are in the planning process?

Charmaine:
That's a really good question. At this stage, the **NDIS don't fund diagnoses**. Diagnosis is definitively in the health system. **Assessments to prepare for the NDIS planning (the NDIS only pays for things once you're in) would still either be, out of pocket** or somehow covered within perhaps Medicare item codes, perhaps private health funds. I mean this autism is an expensive business, and Randa I think just mentioned a waiting list. It can even be that you have to wait to get into the pediatrician. But also, I think one of the things that I have provided in the links is, who can do this, who can provide an autism diagnosis, and it comes down to that under a multidisciplinary team, so sometimes you could get those through local councils or the government or the health system, pediatricians (they're always going to be covered by the health system), psychiatrists, the health system, clinical psychologists, And that's where you might need to get things like better outcomes for a mental health plan, or an arrangement by your GP to give you referrals on how to get the assessments done before you get into the NDIS.

It's a tricky thing and actually, you really pointed out a gap. There is a gap, and there are many gaps.

Randa:
Yes, and unfortunately you have to pay for that gap.

Nicole:
Okay, out of pocket?

Randa:
Out of pocket.

Nicole:
So that was your experience?

Randa:
Yes. It has always been our experience, especially if you don't want to join an 8-month waiting

list, and that's hardly an exaggeration. So the 3-month waiting list I was referring to was for private practitioners.

Nicole:
Okay.

Charmaine:
Yeah, I have heard one more story which is, if you really do go into the NDIS with nothing, no assessments, no recommendations that can help a planner, well then your first plan might be funding your assessments. But then that's your first plan. Really, what you've done is you deferred your entry until the assessments come through.

So I have heard of that as well, but yeah, I'm not sure.

Nicole:
Okay, so one of the questions that we've had, and that's probably relevant to this planning phase, because we know you gotta go in there and you gotta think about your goals, and you gotta think about your supports for an ordinary life, but what happens - and Charmaine, this is for you -

Does the NDIS acknowledge the difficulty of having more than one child with ASD?

How do you manage that where you've got maybe two or three children that are on the spectrum? How does the NDIS face that issue?

Charmaine:
Look, they do acknowledge it and what we would know is that having more than one child with an autism spectrum disorder - I look after participants as a support coordinator and I've got some participants who have two children with autism, I've got one that's got three, I've got one that's got four, and the most I know is a participant that's got six children with autism spectrum disorder, so yes, think about that for a moment - So the NDIS really do acknowledge that, and the way that they acknowledge that is on the **sustainability of informal supports**.

So what do those words mean? Sustainability means that it is tricky. Informal supports are friends and family so the NDIS really does have a bit of a thought process in what's reasonable to expect parents to do for their child up to a certain age, and then beyond that what might be captured by funding supports.

So really, you know, **for ages 0 to 6, parents are expected to do a lot.** So for instance, bathing and personal care is largely the responsibility of the parent. By the time an individual is 16, the NDIS starts to acknowledge that you know that usually parents have stopped providing personal care for a teenager, certainly by the time an individual is 26, and **they don't expect aging parents to be providing personal care for this 16-year old adult child**.

So they do come to this: If you've got two children with autism, do you get double the funding? The answer is it's not quite that clear, but being able to speak of your daily life and what goes on in your house helps them to build that part of the plan and then deductively fund ‘reasonable and necessary funded supports’ to sustain informal supports, because trust me, everybody costs a lot more once they're out of the family situation.

I do have participants who are out of home care and much more expensive, so sustaining the family unit is actually an economical thing. It has been an economic reality to keep families together.

Nicole:
Great, thanks, and I remember one of the presentations you did with Randa, where you spoke about this and people talk about the lack of consistency in plans. I think the analogy that you made was that your plan is a combination of the requirements for formal supports and informal supports, and that's the part that differs, so the end outcome is going to look different.

Do people hold back in their planning meeting about the level of informal supports? How do you manage that for formal and informal supports?

Charmaine:
Alright, so it's the story of the three Jacks. So my Jack is 15, he's got autism and he's got another friend called Jack, and another friend called Jack. There was a stage where almost every kid we knew with autism was called Jack.

So my Jack lives with both parents, and his plan reflects the amount of support that we give. Then we've got another friend Jack whose parents are separated, and his plan reflects the fact there is a bit of back and forth between those parents. There is some extra complexity in the way that his informal supports manifest in his life. Then we've got another dear friend Jack whose mum was widowed when he was three, and her plan really acknowledges the fact that she's not a single parent. She's a solo parent.

And you know, you could sit there and say these Jacks literally almost have identical diagnoses, but their lives are really different, and in some ways even though I've got the Jack with the least funding I actually like the fact that the NDIS acknowledged that the different families that surround the different Jacks need a different plan to help them to have an ordinary life.

Now that did prompt a question once when I said that to. Somebody said "Well, should my husband and I separate?" The answer is no, definitely not. That would not allow you to get more funding, but you should be honest about the supports that you've got.

One more point that I would make about informal supports, is that they can really change even if all the characters remain the same. As we get older there may be times in our lives where grandparents were an invaluable source of support, but in lots of instances as we get a bit older that relationship can change, and some of us find ourselves actually looking after aging parents. So as those plans [NDIS plans] evolve, it's being able to just speak up so that the planner can understand exactly what's going on and where the supports might be coming to.

Nicole:
Right, so **informal supports are really important, and really the bottom line is that it's often the reason for the inconsistency in planned values**. I got a question for Randa now. This is another parent who has asked this question.

So the parent says "How do we word our goals so that our child has a support worker for community access and independent skills?"

So given that Richard is probably at that stage where he probably wants to participate in the community and have independent living skills, what is your advice?

Randa:
Well again, **I used the NDIS speak and tied in with the goals**. I'll just read out to you the wording we used, and we'll speak as if Richard is writing this:

"I would like support to source and skill, skills developed to be in supported employment through allied health professionals and individual daily skill development. This will allow me to be financially independent so I can live out of home."

Now they're his goals, and that gives us access to allied health and gives us access to support workers, because what we're doing is tying it into his goal of achieving employment. That's his immediate goal, and then his long-term goal of moving out of home. Now, in order to move out of home, he needs to learn how to navigate the public transport system, how to go shopping, how to cook. So that gives you scope to employ different types of services.

So again, the key is using their terminology and tying it into the goals.

Also, remember that the great thing about the **NDIS is that it has shifted the power to the person with the disability or the carer**. Previously, we had to literally go and beg for services, "Please take my child", fill out the paperwork, fill out the application form, and every year we would fill out the same paperwork and you cross your fingers and hope to God that they would take your child on.

This has reversed that entirely. In fact, I was on the phone yesterday with our service providers, stating to them that now I would like to have a meeting, discuss outcomes particularly with the social groups. He would meet the social groups - and I used the word groups plural because it wasn't just one organization. They all did this. They meet, they get herded onto a bus or onto a train as a group, they travel somewhere, they go and have lunch somewhere, and as a group they get herded back onto the train and back and then they make their way home. That's not good enough.

Now I have asked for outcomes. Are they teaching him to use the same system? Are they expecting him to go and get his lunch independently? Are they expecting him to create social connections while being herded around?

And this may sound harsh but if **I have to make a decision where to put the dollars that I've been allocated to achieve his goals, I want outcomes**. In fact, I need outcomes to justify requesting these services again for my next plan. So it has shifted the power entirely.

So use the terminology to support your goals and remember: when you are engaging services you hold the power.

Nicole:
That's right, and that's really valuable. I think some people actually forget that they do have choice, and I mean in terms of MyCareSpace what we try to do is demonstrate just how vast that choice is, and yes it's not necessarily always easy to make that choice, but get connected and have a support group around you. Speak to people like Randa, reach out to a peer support group, because at the end of the day you need to demand the service that you believe you're entitled to.

Now, we've all paid good taxpayer money for the NDIS. If you've not getting any outcomes then it sounds like in this instance it's really not good enough, and you are entitled to say, well, "What social outcomes are we getting?" Or "What independence skills is he learning?"

So have you had any feedback?

Randa:
Well, they've putting together a document and it's as simple as when they offer cooking classes. Previously, they were taught to make gnocchi. I don't expect my son to go home and make gnocchi from scratch. I expect him to be able to function in a kitchen whether he needs to defrost a meal or warm up a microwaved meal or scramble eggs or make toast or cook a really basic -- just grill a chicken breast and make a salad.

They are the outcomes I want. I don't want a gourmet cooking class, and I've made that really clear, and they've taken that on board.

Nicole:
Great, fantastic. So Randa, one more question for you from the parents in Victoria:

"**How do I start putting it all together?** What do I provide? Do I do a spreadsheet? Basically I have no idea where to start. There is so much information out there."

So that is more about --we're going to have Charmaine's useful links. That's great - but really for someone who is feeling overwhelmed, they know that there is the NDIS website but how do they actually get started? And having gone through the process and successfully, what is your best advice - two or three kind of top tips for someone who is feeling overwhelmed?

Randa:
Yeah, the **top tips** are to **make sure your reports are less than two years old.** That's really important. The second one is **there are workbooks available**. The NDIS has a workbook available, and various other support services or services providers have their own version.

Now, these workshops are really, really useful. I filled them out and as I filled them out I thought oh gosh this is so repetitive, and they're literally asking you to document almost every hour of the day. In fact I think the NDIS one breaks it down into three parts of the day: morning, afternoon and evening, and what they're trying to gauge is how much support you as a carer have to give for basic tasks such as waking up, personal care such as showering, shaving, making breakfast, feeding.

They want the nitty-gritty, and I don't think that any task is too minute or irrelevant to mention. We're so used too as parents thinking positively, trying to empower our child and trying to maintain a positive mindset. Now with this, you have to go in with a deficit model, as painful as that can be.

So if you have to wake your child up every day? Write that down. How many times do you have to police him? Write that down. Do you have to tell him what to do, how to get ready in the morning? Write down the details, and write it down for every single day.

It does get repetitive when you start from Monday and you're on Friday and you think "Oh, as above, as above." No, don't write "As above." Just write them, because I took that workbook in with me. In the planning meeting they don't want papers. So if you hand that to them they're not going to take it. But what that enabled me to do is read it out, because when you're in that meeting, as well-intentioned and as well-prepared as you may be, you forget things, and this reminds you that oh yes, he can't tie his shoe laces, oh yes, I do have to put this opal card in his pocket in his wallet, oh yes I do have to walk him to the bus stop, whatever situation that you're in. It reminds you to talk about every detail, so that's the best way.

Okay so that’s the best way to prepare: the documents two years old, and fill out the workbook.

Nicole:
Okay, thanks Randa. So don't expect it to be an easy process. It will be emotionally draining if you focus on all the negative issues, but it really is important. This planning, understanding, connecting with people who have been through the process and find the support that you need whether it's before or during the meeting.

So that wraps up our planning for the NDIS, and with only ten minutes or less than ten minutes to go, nearly every single person asked the question about "How do I get the most from my NDIS plan?"

Now, we could do a separate webinar just on that and we potentially will, but for the moment and for people who want to understand what are the resources out there, Charmaine, a lot of people ask things around "Should I self-manage things?", "Should I get support coordination?" So can you just walk us through some of the **top tips to get the most of your plan**?

Charmaine:
Okay. So the first thing is, if you are going shopping at the shopping centre and you only got

$100 to spend or if you've got $1000 to spend, you're going to look at the prices so that you know how much it's going to be when you get to the checkout.

I didn't realise it, but **there is this NDIS price guide**. Well, I didn't know it at the start until I went to get a one-day vacation care, and they said "That would be $270", and I went "What?" like it's crazy. A vacation care would be like $30. That was cost-subsidized by all these other things.

And then this lovely woman said "Dear, it's the price in the price guide." I was like "In the what guide?" and so she gave me her copy of the price guide. In those days it was just 90 pages long. Now it's just 50 pages, but I've given you to the link to both the price guides, and they're different in different states, it's like the Eastern Seaboard and then the rest, and also the link to the Assistive Technology Price Guide because that's one we probably not going to have a lot of time to cover today, but there is a price guide. You can have a look to see what things cost and how far your budget might go.

But you really touched on perhaps one of the significant points that influences how you can get the most out of your plan, and that is how your funds are managed.

There are **essentially four choices**. The first one is you **self-manage**. Both Randa and I self-managed, we'll sing its praises until the cows come home. We'll come back to that.

The next one is you’re **agency managed**. That means that the NDIA keeps the funds, you're quite restricted to only use registered providers of supports, and they claim directly off the portal. There's nothing wrong with it but you don't get the most amount of choice or control or innovation or flexibility.

Then you can be **plan-managed**. That opens up the opportunity to use non-registered providers of support, and the money to pay the plan manager is included on top. So you don't have to pay to be plan-managed. It just gives you more options.

And the fourth option is some kind of a **combination of that**. So you could self-manage your core supports - and we haven't touched on that, but it's in my notes, the different categories that funding can fall into - and you might just decide that your therapy's budget which would come under ‘improved daily living’ - there is all these codewords and they correspond with support categories, and as I said, I could and would talk about it all day if you let me but I won't - so how you manage your funds, then determines how you can engage supports.

If you're agency-managed then the only way that you can engage supports is to use registered providers of support, and they are literally going to be your old-style disability service providers. There are some few innovators coming up, but pretty much.

If you self-manage, then you could choose to use independent contractors, or you could choose to directly engage supports, and the last thing I'm going to just touch on is innovation. So there are innovative service providers that have popped up.

The NDIS stands for National Disability Insurance Scheme but really it stands for change, and actually right now it's disruption. So if you feel anxious about it, it's because this is disruption, but it's for the best. This change is going to create a better future for our kids, make no mistake. I believe that with all my heart.

So the innovators that are popping up, I think like you might have heard of them - Hire Up, Better Caring, Care Seekers, Home Heroes, MyCareSpace. There is a whole range of them, and it just makes it easier to engage the supports.

But perhaps the one that we might come back to, which is choosing to be a self-manager. I was really daunted. The only reason why I did it was because I went and saw another person talking about self-management and I thought “if she can do it, maybe I can do it”, and that was the catalyst for me going "I'll do it!" It has been the best thing we ever did.

But right now, I thought Randa, you might talk a little bit about that.

Nicole:
Well Randa, we’ve got 4 minutes to go, so now Randa, one of the things you said was that maybe employing someone directly yourself… In two minutes, do you want to give us your experience there and how that has helped you get the most out of Richard's plan?

Randa:
Well, that's for daily living skills we are in the process of employing our own people. That way, **we don't even have to refer to the price guide**, because a lot of people complained about the prices that are being charged. Well, there is no point complaining because this is what they are allowed to charge and they will charge that, so that's the going rate.

Now, **when you employ someone directly, you can negotiate your own rate**, still offering a fair return, but what you're not doing is paying providers in layers. So you're bypassing one or two middlemen and paying the support worker directly. That's why it's more reasonable. So that's appealing to us. It stretches the funds further.

And so by self-managing, employing some people directly, asking for outcomes, you really do stretch the dollar further.

Nicole:
Right. So I mean we have only got two minutes to go now, and in terms of getting the most out of one's plan, I think it's pretty obvious you should consider to self-manage. There are other options. Find out what they are, understand what skills and resources do you need to self-manage. Maybe you can do a combination if you're afraid of going straight to self-managing.

And as Charmaine said, **get the NDIS price guide, keep it in your handbag**, keep it in your wallet, and make sure you know what it's all about because once you know what a unit of physiotherapy costs or a unit of occupational therapy, you can then start working backwards as to how many you can actually fit into your plan.

Look at innovative ways of engaging people. As Randa said, you can employ people directly and you should consider it. In that way you have more choice and control. I have to say MyCaseSpace is really about demonstrating to people just how much choice they have. We seek peer reviews of providers so that you can see what your peers think of different providers.

So unfortunately, we've now run out of time, but I would like say a huge thank you to Randa who is here with me in Sydney and Charmaine for being so enthusiastic for giving generously of your time and your insights. A huge thank you.

A lot of the information will be on the MyCareSpace website, all of Charmaine's useful links will be emailed to everyone, and please go on to www.mycarespace.com.au and join us at Randa's Facebook group. All of this will be shared generously on our forums.

Thank you everyone and goodbye.

Randa:
Thank you. Bye.

Nicole:
Bye.

===== Finish ====