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First published on NDIS Plan Management Blog, avers.com.au

Demystifying *Reasonable and Necessary* and Discussing Communication Supports for Children with Autism Spectrum

Reasonable and necessary. You've heard the phrase in NDIS meetings, therapists have frequently used it and you've seen it written on NDIS material.

But what does it mean?

Let's look at it.

- Reasonable = fair, sensible, appropriate, rational
- Necessary = obligatory, required, mandatory, essential

When you consider accessing a service or purchasing an aid or device for your child, question whether it is *really* necessary.

Quite simply, the NDIS only funds ***reasonable and necessary supports that relate directly to a person's disability.***

- Do you want/need the service or item *because* of the disability? It must assist the NDIS participant to do something their disability *prevents* them from doing.
- Will it assist the participant to achieve goals and live 'an ordinary life'?
- When it comes to expensive tools, think about what you want the device to do for the person. Is it the right device for his/her specific needs?
- The same applies to all aids and services. Will they meet immediate needs?
- Will the aid, service, or device be beneficial to the participant in the future?
- What does the person need on a day-to-day basis? How can the funding bridge the gap between disability and ability?
- Shop around—seek value for money.

A good way to discern whether something is likely to be funded is to ask yourself: -

- Would a person without a disability be expected to pay for 'this'?
- If the answer is 'yes', then it is unlikely that the NDIS will fund it.

Imagine for a moment... a dream planning meeting!

It would be great to take a professional with you, but the truth is families are not encouraged to take therapists to their planning meeting - yet these are the people who know the participant's specific needs as well as, and in some respects, better than parents.

NDIA says they have staff who can advocate on behalf of families regarding the making of significant decisions in the planning sessions. I've never come across an advocate and we certainly weren't offered one. Even if you locate an advocate, they really need to know each individual participant and his/her specific needs.

Errors as easy to make as not seeing (or perhaps not knowing the meanings of) words such as paraplegia or hydrocephalus have been made by NDIA staff resulting in plans being rejected. Parents are frustrated and dejected when they have to begin the process again.

Planning staff might not know that paraplegia means a child's condition may never improve or that microcephaly and Down's Syndrome (and pretty much any other disability you can name) can be accompanied by other medical conditions, each requiring different supports. You as parents *must* document all of this.

- How this information is conveyed can mean the difference between rejection of a plan, acquiring some funding or receiving adequate or abundant funding.

I recognise now that I wasn't specific enough in my planning. Even though the NDIS planner I met with had a child with a disability, she didn't have *my* child.

By now you'll be realising that this is not an easy exercise.

You've got to get it right, or you'll be compelled to have a review—that means going through the whole process all over again; and probably with a second NDIA planning officer *who doesn't know your child*.

Believe me, you don't want to do a review before it's required. The issues that arise from writing multiple plans in a year create a different headache. I won't concentrate on those issues here—that's a whole separate article

So, parents, you're it—odds are you're exhausted—the things you have to consider and undertake on your child's behalf in any one day are endless, (more than for a child who doesn't have a disability, right?) but it is imperative to be ready for your planning meeting.

The only people in your corner are you and your child's therapists (who NDIA insists must stay in the background). But you *can* go to the meeting armed with their words of advice.

The speech pathologist and/or occupational therapist are invaluable because they understand the disability and how it manifests in *your* child. Therapists can put forward points that won't necessarily come to the minds of parents—and in a way that only a professional can convey them—so have them written down.

Consider this: -

- A participant with ASD may benefit from an augmentative communication device now—but might not need that same device in the teen years when the ability to engage in reciprocal conversation (based on current progress) has greatly improved.
- A less expensive device, or an app for an iPad could be adequate now. A speech pathologist will explain why an expensive device isn't always necessary.
- It could be costly if the participant can't or won't work with a device because of sensory challenges.
- There is a lot of hype around devices, but the benefits can be limiting.
- Effectively using devices takes practice.

Another example of where it is good to be guided by the child's therapist regarding devices is when considering apps for the iPad.

- General apps are not necessarily the best option for children with autism.
- They may be too noisy, too fast or have small icons.
- The iPad must have sufficient memory to support software to enable its use as a communication device.
- Finger pressure, (not the incidental pressure,) must be built in—this is not available on an ordinary iPad.
- Key guards and a non-reflective surface increase the cost of the iPad.

If communication is an issue—and it is generally a big one with autism, think about interaction at home. How do you communicate with your child?

- How can you optimise the child's ability to engage in reciprocal conversation?
- Here's the point! *You may not need or benefit in the long term from purchasing an expensive device at all.*

Our son was a child of the nineties. Over time we used Makaton, a basic communication system devised by speech pathologists in Britain.

<https://www.deafblindinformation.org.au/>

Though it was created for the deaf, it was beneficial to anyone experiencing communication difficulties. Officially, the word Makaton is no longer used in Australia. Here the concept is called Key Word Sign.

Key Word Sign uses manual signs and gestures to communicate. It utilises a core vocabulary of words to communicate concepts and ideas and each word or concept is matched to an Auslan hand sign (with Auslan's endorsement, of course.) <https://www.scopeaust.org.au/services-for-individuals/specialised-communication-services/key-word-sign-australia/>

http://shop.scopeaust.org.au/shop/getting-started-key-word-sign-auslan-edition/?_ga=2.239579011.1061704473.1598586701-17960416.1598586701

We also used Social Stories with our son. This is a concept devised by Carol Gray in the USA. <https://carolgraysocialstories.com/>

Gray would say that to understand an idea we need to look at the trends surrounding it. These days we see toddlers in strollers and supermarket trolleys viewing mobile phones and iPads. We can see the trend is to avail oneself of devices as entertainment and teaching tools. They are wonderful—and they're accessible. But being accessible only means they are the obvious and easiest option—not that they're the only or best choice available.

And here's the thing. Those old ways of the last century still work. 😊 There are modern versions of the stick figure symbols/drawings that we used. And these days they're coloured. I know, exciting, right?

Arguably the most popular system in Australia is PODD (Pragmatic Organisation Dynamic Display). PODD is a way of organising whole word and symbol vocabulary in a communication book or speech generating device which can be carried everywhere with the child. Every person supporting the child can (and should) use the system to communicate with him/her. (This is called immersion support.)

The advantages of PODD are: -

- Communication with multiple people and in any setting—continuous interaction
- A family can begin with the printed version to teach the method to the child and, if it proves successful, they may later upgrade to the more expensive electronic device if necessary

- Written language is used to augment the pictures with PODD the same way we used it when creating our social stories back in the nineties

<https://www.spectronics.com.au/>

<https://novitatech.com.au/equipment/podd-communication-books/>

Have a look at <https://www.assistiveware.com/> for Proloquo2go communication boards as well.

To sum up: -

- Prepare well.
- Talk amongst your friends to find out what was and was not approved for them.
- Have high aspirations—but realistic goals. Don't, for instance, consider team sports for a child who can't follow instructions or understand the importance of engaging with and being an integral part of the team.
- Be cautious—ask for a discount for the first lesson to find out if it's a good match.
- Don't go for the most expensive option (but don't settle for students to conduct therapy sessions when your child has complex needs either).
- Have your MyGov, Bank Account details (if you are self-managing) any specialist's letters and a plan of the participant's week with you.

Go for it and good luck.

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