

Hello.

You have asked for people to have their say and to share feedback on their experiences within the NDIA to help you with streamlining the NDIS for all concerned.

I have a couple thoughts that I would like to share from a support's coordinators point of view.

My first point to consider would be that the national disability insurance scheme was created to enable individuals with a lifelong and challenging disability the opportunity to add value to their lives, by way of offering them a chance to create a meaningful life that the majority of NDIS participants had previously been denied due to their disabilities.

A chance to choose, to be heard and to be seen, to experience the sheer joy and warm fuzzies of following their own unique path, complete with following their dreams and achieving goals, things that most able bodied and neural typical individuals regularly take for granted.

The collective voice speaking up for the disabled community had finally been heard and someone was listening, and the NDIS was created, they now have something solid to believe in and are encouraged to build capacity and offered the same opportunities as the rest of Australia's population to build and lead an independent life of THEIR choosing.

As exciting and beautiful as the intention in this sounds, the process to achieve it for many has created big challenges, which in turn has increased stress and anxiety related issues for the people involved, and not just within the participants.

With any grand project this large and new there are always going to be teething problems and hiccups,

some can be addressed and ironed out, while others just need to develop and work themselves out organically.

I have three areas I would like to touch on and share with you, these are areas that I have had experience in over the last few years and feel there is a need to address.

1. PRACTICE WHAT YOU PREACH.

My two favourite things written in the majority of NDIS reading material that constantly pop up which I believe need to be re-visited, overhauled and honoured to help secure a solid NDIA/NDIS foundation are,

To be Open, Honest and Transparent

and that each participant would ideally have **ONE** person inside the NDIA (The black and white framework) to deal with when it comes to doing their plan reviews etc, offering them familiarity and consistency so they wouldn't have to keep repeating their story.

They are both important and worth some serious attention so they can add value to the NDIS experience for all concerned.

Most people I have met that have a disability be it friends, family or participants, don't like having to go over and over the specifics of their disabilities or the personal nature of the challenges that their disability creates for them.

Most participants have had different supports with no connection coming and going from their lives, in their personal space and have had very little privacy their whole entire lives, with little to no say in the matter.

It takes time to build trust and confidence in new people so we can feel safe, so jumping from person to person based on availability is a breeding ground for creating anxiety.

The second half to this dilemma is that I am constantly told that the planners don't have time to read all the reports that the participants and supports coordinators collect up for reviews.

I believe that here in lies one of the biggest triggers for stress, anxiety and confusion and a WHOLE lot of unnecessary wasted time and funding for all concerned.

If the participants have a different planner for every meeting and the planners have no idea who the participant is, and all they have to go on, is what is written in the reports, and they **don't** read them, how are they supposed to evaluate the correct needs of the participant and respect their unique situation and perspective?

- A. When the reports come in, we (supports coordinators) read the reports from the specialists and put their professional recommendations into our reports before submitting the review documents, which are usually sent a couple months in advance.

The planner is then supposed to read the participants notes, and reports, and refer to the specialists reports and assessments for the relevant evidence needed prior to the meeting so they are up to speed and on the same page before starting the meeting with the participant, it is very rare that this ever happens, in nearly every review I have had the two consistent things I get are that they can't seem to find the reports been submitted through enquiries, and that they haven't had time to read through them.

I now just have an email with the reports attached to send through on the day, just in case.

- B. The NDIA NEED to be clear and transparent about what they are looking for in reports and put as much effort into reading and understanding them as goes into collecting the evidence and writing them.**

I have had numerous reports from professional therapists and OT's dismissed because the planner has said it hasn't contained the correct evidence needed to prove that requested supports and therapies was reasonable or necessary or specifically related to their disability. But when discussed with the specialist, the evidence required is all contained in the report under the individual category being assessed.

The planners have then added thousands of dollars in extra funding to capacity building in the participants plan to REDO the reports and FCA's with ANOTHER therapist or OT that has had absolutely no previous contact with the participant, and then at the end of repeating the whole process with a different planner, the reports are dismissed again????

which in my book does not make any sense at all?

They are doubling up services, creating extreme clinical over stimulation, putting the participant, therapists and supports coordinator through hell to get something they already have, not to mention wasting the hours and hours that go into writing the reports and then re-funding an extremely considerable amount of money that a fraction of which would have been hugely beneficial in covering the supports the participant actually needed in core??????

- C. Paperwork, organizing, maintaining and attending all the associated tasks and appointments to achieve the requested assessments and reports does not come naturally or easy to most participants, so they are presented with all manner of confronting barriers and challenges that they face in their day-to-day life to achieve this, and will usually require support, but they do what it takes to get what is needed, because that is what has been asked of them, so that they can have a chance at obtaining this amazing opportunity offered to them to lead an 'as normal as possible' life of their own choosing.

But isn't that your job? You may ask, (which brings me to my next suggestion.)

This is a two-sided coin amongst the lengthy list of what my job description covers, it is both yes and no.

Part of my role is to teach my participants how to understand their plans and the NDIS so they can navigate and maintain it on their own with minimal guidance.

(Which can be challenging as it still has myself scratching my head at times).

As it stands currently, this goal is getting harder and harder to achieve as the rules, guidelines and what is expectable keeps changing from one minute to the next, the information passed on through enquiries and planners is inconsistent and is subject to their own understanding and individual interpretation at any given time, which is confusing as all hell for all concerned when trying to get a straight informative answer to questions, this is where the **Open, Honest and Transparent** philosophy comes into play again,

something needs to be designed to outline all the specifics without all the confusing maybes, some straight yes and no guidelines that are easy for all concerned to understand and abide by, I think too much cautious red tape has gone into constructing the guidelines, so they are able to be creative to each unique disability situation and participants individual needs, which is great, but it is flimsy.

It is so vague and non-descript that the variables for interpretation is completely in the hands and perspective of the person looking into it at the time, so the majority of the average participants needs are getting overlooked or dismissed because they are not worded or interpreted correctly in the eyes of the planners, and not one person can give a straight answer, the usual go to is refer to section 34, which goes without saying, so it just goes around in circles, as what is reasonable and necessary for one person may not be reasonable and necessary for another person.

As a supports coordinator that LOVES my job and watching the exciting outcomes from helping my participants achieve what the NDIS has offered them, please believe me when I say that the following is not just for my own benefit, it is beneficial for all Participants AND support coordinators and the important part we play in the process.

We get to connect with our participants on a much deeper level as they share their lives, situations, dreams and daily challenges with us, the time spent doing that builds a connection based on trust, understanding and compassion, giving us the opportunity to be the ones to add some colour to the black and white framework, to help put all the collective pieces that each participant needs to create and live their best life together and to stay on track to achieving their goals and potential.

But we are still only able to do so much or in most cases so little, as in my case.

The participants I have are lucky if they get 2 hours a month funded for supports coordination to help them navigate not only the NDIS, but to source and structure the support needs that they require to link them to the opportunities that help them to create their unique individual story, that is not reasonable for the work it takes to get everything up and running, it is fine for maintaining it in the future,

but it takes at least a good 24 months to solidify a sustainable support network and team and to build the confidence for the participant to manage it themselves.

The hours needed and the hours put in to maximise the participants chances of a successful transition to an independent life far exceed the billable hours that they have funded in their plans, which leads to a big problem, when the supports coordination funding runs out,

a lot of supports coordinators will not support the participant without it and is why a lot of participants regress back to square one undoing all the hard work with building confidence with supports and attending necessary therapies, accessing AT's, following through on home mods, and sourcing local community and mainstream connections to name a few.

For supports coordinators like myself (and I am not the only one) who care and are not just focussed on KPI's, who trust in the process and can see the huge difference that it is making to the participants lives, It leaves me in a frustrating cycle where I am over worked, under paid and get into trouble for over servicing my participants and accused of making it harder for other supports coordinators to prove more SC funding is needed and for making them look bad because I continue to honour the service agreement that I signed for the duration of the plan so my participants have the consistency that I promised, and to also make sure the hard work and long hours of their support team are not wasted and their progress derailed.

These are also the reasons why there is a high level of burnout within the supports coordinator's role.

There needs to be a realistic assessment of the hours and the time frame required for each participants supports coordination funding to maintain consistency with the supports coordinators so capacity can continue to be built to a comfortable level for the participant to manage their own plans and supports.

Summary: If each participant had a regular planner or case manager, that was more actively engaged in processing the participants information and maintained contact with them during the review process, all our hard work would count for something and we could all be on the same page meaning the stress and anxiety would be lessened, plans would be more efficient and relevant, and funding for repeated assessments and reports would decrease or be put to better use in the plan.

And with a good 24 months of higher funding for support coordination hours, to build a solid foundation for participants, the overall outcome would be more chance for them to self-manage with the help of a plan manager, less funding used over a longer period of time, less stress and anxiety related issues and less burnout for support coordinators.

2. FAMILYS WITH DISABILITIES.

Another area I have had come up against walls with, is when working with large families where each member has a disability, including Mum and Dad.

There is no consideration given to the collective needs of the family unit or procedures in place to access and work with how the individual supports required can be incorporated into strengthening the whole family.

Instead, it is segregated to uphold the hard work gone into achieving individual plans.

While this is admirable, it is unreasonable and absolutely no help at all to the informal supports, usually the mother,

(And in this case also with disabilities) who is trying to involve all her children in sports, community, school, personal tasks, eating, therapies, social interaction outside of the home, managing escalations, housework, driving them everywhere, appointments, the list goes on, and Mum gets no time at all to work on her issues or return to the workforce.

It is **necessary** to be **reasonable** about the limits of parental responsibility in a family dynamic like this to be able to maintain those supports by allowing a look at the whole family picture to be able to apply the most effective supports that will help harmonise the whole family balance but still fill the individual requirements to access capacity building supports and social and community inclusion independently, to allow them to maintain a loving supportive family experience and insure each the best chance at building independent lives outside the family unit.

Summary: Stronger family connections and informal support, stronger social and community involvement, stronger chances of valuable therapies been accessed and applied, greater chance of progressive development with age-appropriate milestones, greater over all lifelong capacity building likelihood for future relationships, employment, living out of home, and opportunities to lead an independent life, again decreasing the need for as much funding in the future.

3. MENTORS & RECOVERY COACHES VS SUPPORT WORKERS & PSYCHOLOGY.

I also see a lot of wasted funding within my Psychosocial participants for therapies they don't want or engage in,

I see a huge grey area that has the potential to be extremely successful and beneficial by developing mentor and Recovery coach type supports who have lived life experiences that the participant can relate to, so they connect with one mentor and one trusted "go to" to talk with, who guides them through experiences and situations, walks beside them while they are learning to navigate their new path, through both good and bad challenges, someone to share options and a difference of perspective based on their own life experiences, and helps the participant to actively engage and attend the specific outings, groups and events that they are interested in trying, work through job interests and build confidence in social engagement and relationship prospects.

Summary: Having this type of mentor and Recovery coach team will take a considerable amount of weight off the mental health system and regulate escalations, without the need for extra funding from either department.

It will also increase the likelihood of the participant engaging in important specialist type therapies such as psychology and counselling by helping them process their fear, anxieties, and concerns about attending.

Again, over time lessening the amount of future funding needed as they build capacity and create the independent life that they choose.

When I first started my journey with the NDIS I was in ore of the potential it had to change lives, the opportunity it offered those with disabilities to find their voice and be heard was powerful and exciting and long overdue.

I have seen so many amazing transformations and lives changed for the better already and that is with all the teething problems.

I 100% believe that if we all come together under the one umbrella, using the gifts we are uniquely strong in, some common sense and forward thinking, with the same goal in mind, and clear, honest and transparent guidelines, then the whole NDIS experience will be a life changer for all concerned, Participants, planners, plan managers, supports coordinators, providers, recovery coaches, support workers, mentors, Mental health, Allied health, therapists, enquiries staff, LAC's.

Even though our job description and roles are different and require different skill sets, we are still all just a small piece in the picture that will make up a complete life experience for every person we are able to help.

I am really looking forward to seeing what your team comes up with to making this amazing scheme even better and I hope my experiences and suggestions are of some help in the process.

Good luck...

Kindest regards

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Supports Coordinator

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