

1. What are your three main problems or concerns with the NDIS?

Inconsistent decisions.

- i) Each planner or LAC that is dealt with will give you a different answer to a question. One planner could be helpful and knowledgeable, the next could be having a bad day and refute the first planner's decision.
- ii) There is no consistency or relationship with planners or LAC's.
- iii) A planner or LAC from one State does not understand the needs of a participant in another State. Eastern States have a multitude of services compared to Regional Western Australians.
- iv) Decisions take too long to be decided upon, and Elevations in decisions are not good for the participant.
This results in the participant doing an Internal Review.... then another lengthy wait for a decision....and off to an External Review.

Planners have no disabilities, or knowledge of disabilities.

- i) Some planners do have an understanding, or a disability themselves but when it comes to Complex Needs, only a person or professional will understand the needs of the participant.
- ii) Complex Needs requests are denied (when requested) which results in the participant doing an Internal Review.... then another lengthy wait for a decision....and off to an External Review.
- iii) A Specialist will request treatments for the participant, and a planner or LAC, will decline to consider what has been requested. Maybe a form of regulation or capping of services requested by a Specialist could be put forward. Instead, it is a straight 'No' from the planner or LAC.
This results in the participant doing an Internal Review.... then another lengthy wait for a decision....and off to an External Review.
- iv) A planner or LAC could go away and do some homework on the participants disability, or ask someone who has prior knowledge. Instead, they are making decisions which add tension and elevate the request.
- v) So much time could be saved by a planner or LAC having a "check-in" with the participant about their "Plan". Simple tweaks or changes can be made at this time, which would save the participant having to do a "light touch" to their plan, or eventually an Internal/External Review.

Lawyers holding participants and their families to ransom.

- i) We are currently at AAT for our third time in less than 6 years. We have the same lawyer, with the same disrespectful attitude. He likes to take his time when a Section 42D is requested. This puts the participant and their family (us) under unnecessary pressure. A week without funds to pay providers has cost us over \$7500. The lawyer knows this and does not care. Their job is to be mean, but cruel is different.
- ii) There is a lack of Advocates to help participants through the AAT process. All the paperwork and help can be sent to a person going through AAT but

it is stressful as hell. Someone with a heart, a lot of patience and unlimited funds can help a family but it takes a toll on the Advocate, the participant and the participants support network.

iii) The amount of money paid to lawyers, who purposely drag the process out, is more than the amount that could have supported the participant.

iv) Lawyers like to threaten participants and their families.
We have a Specialist Support Coordinator, who's job it is to support us and watch our funding also. I am great with numbers but having that extra support stops some of the below from happening.

In our case, the lawyers' threats started small like:

Do you know what you're doing?

Do you need more support to learn how to do that?

Why did you do that?

to.... If you don't accept this offer now, we'll:

Make you Plan Managed

Reduce your funding

Audit you for misappropriation of funds

Do you realise we have to call Specialists to Court, you'll lose them

Have you deported because you are not an Australian Citizen

Remove your son from your care and let the State take care of him.

2. How do these three main problems affect you and/or others?

i) Every second year I have to mentally prepare myself to fight NDIS/NDIA. I don't want to do this at all.

When I hear the words NDIS, I get tense and prepare for a fight.

When I hear NDIA, I know I have to fight for my son.

When I hear NDIA Lawyers – Sparke Helmore Lawyers – I am in full fight mode.

I know NDIS is an Insurance Scheme. I understand that they are there to save money, not just help the participant. But it wouldn't hurt them to treat a participant, and their family as a person, not a dollar amount they must reduce.

ii) When I have to do a Plan Meeting, I am asked for more evidence to prove my son requires the amount of funds that he is appropriated. Every single time we go near a Specialist, my son gets a new diagnosis.

This year alone, he has 8 new diagnoses. Each of these diagnoses justifies each allotment of funding but NDIS/NDIA wants to reduce the funds. For some reason they think Autism can be cured. When a Specialist writes "...a LIFELONG disability..." NDIS should understand that it's for LIFE.

iii) When we first fought via AAT, the process took a little over 2.5 years (with a Legal Aid lawyer). The second time was over 18 months (with the support of the same Legal Aid Lawyer), this third time has been less because I've had major surgery and a paid Advocate (because there are no lawyers available to help).

- iv) The toll this has taken on my mental and physical health has been horrendous.
- v) I have applied to NDIS for therapy aids for my son. I had a full hysterectomy due to pelvic floor issues. These issues came about by having to manually lift my son; who is 70kgs in weight.

-I have applied for Occupation Therapy hours, so that we can do Assessments for Home Modifications and Assistive Technology, all have been declined.

-I have applied for Assistive Technology to help him get stronger core and legs, so he can lift/hold himself (reduce falls). Aides to help him get up when he's down, and been declined.

-I have applied for Home Modifications so that he can get in and out of the shower, reduce falls getting into/out of the recess. No answer because we require an Assessment to be done first.

- vi) NDIS has to remember that Therapists, or anyone engaged by a participant is NOT their friend. They are utilised to provide a service. Therefore, an hour of therapy really means 45 minutes of 'hands-on' and 15 minutes in 'administration'. Nothing is done for free. A phone call, a text, a call or an email...it all costs.
i.e., when at an Internal review, it takes time to access the therapist or specialist, and it costs money to get these reports ready.
When at an External review, unless stated, the costs are not borne by NDIA, they are paid for by the participant, to prove their case.

-In our case, NDIA and their lawyers have our current Statement of Issues on the 13th of Oct 22.

-On the 20th of Oct 22, we had to provide quotes for our requests. This didn't take money, but it sure as hell took up a lot of time to compile. Only to have them get the costs, and refute them.

-So, on the 1st of Dec 22, we will reply with our Contentions. And on and on the fight will go until we can agree on something, or not.

- vii) The toll this has taken on my marriage has been my biggest struggle. Especially since my husband has just been diagnosed with Autism himself. He has also been grieving and processing his diagnosis. I do not get that luxury; I have to care for him and our son. Because he is high-functioning and older, he has less support. The attitude from his planner is 'He needs a lot more evidence to provide his disabilities, and he's gotten this far, what's a few more years until he's 65, and then the State's problem!'.

My husband accesses NDIS, and I am trying to help him, as well as fight for our son. I have no informal support; We have to pay for formal support. Paying requires funds. Funds withheld, or reduced by NDIA lawyers makes a struggling family more miserable. It's a circle that doesn't need to exist.

- viii) There are Carer Gateway's to help participants or families. If the family is not an Australian Citizen, these pathways are even more limited. I do not want a handout, but some help that would benefit me would be very appreciated.

-Courses offered: I do not wish to learn how to be a carer. I am a carer already. Why would I want a formal qualification when it's not a job I would do if I didn't have to already.

-I cannot access a carer allowance. I am not a Citizen. If our bills are \$1000 per day, what use is \$16?

-If we are homeless, which is applicable with the rate costs are increasing, where will therapists go to help us? where will my son be cared for?

3. What do you think are possible solutions to those problems?

- i) Hire planners or LAC's who know what disabilities they are dealing with. What works for one, is not the same for another.
- ii) Make sure everyone has the same information, the same rules and if they are unsure, elevate the issue to someone who does know.
- iii) Consult with Specialists. Real ones, not the ones that are paid to say 'No'.
- iv) Each participant is different. Treat them with respect.
- v) Do a light review of each Plan before it is implemented. Simple changes could help.
- vi) Get rid of restrictive wording in each plan. There is something wrong if you have to give funding and then put restrictive wording in that plan.
- vii) Get rid of the reminders (be polite/courteous, Covid vaccination, etc.) on the NDIS contact line. You're dealing with people who have disabilities. They might not be respectful because they're struggling to communicate.
Make it clear that the people at the NDIS call-centre know that our anger is not personal. We are already stressed when we have to phone that number.
- viii) Reduce the Internal and External process by dealing with participants like they matter.
- ix) Trial a department who can do all of the above and compare the cost of 'Hands on attending' to 'AAT' costs.
- x) Get rid of Sparke Helmore Lawyers. Only use lawyers if you have to. \$41 million dollars a year could have gone back to the participants rather than into lawyers' pockets.
- xi) Make the AAT process easier.
- xii) If a person works for AAT, they should not be allowed to consult for NDIA or a participant. They should always remain neutral, even when no longer working for NDIA.
- xiii) Pay Advocates if they're necessary. Take their costs out of the Lawyer's pocket, so the lawyers settle quicker and cost less for the Govt.
- xiv) Hire participants or their families to help tidy up the NDIS system. We could have scholars, lawyers and accountants until the cows come home. If they are not a NDIS participant, they will not know our struggles.

4. What parts of the NDIS are working well for you?

- i) Funding to access therapies is a great amount. I am forever thankful that there is funding there to help us get this far. Being told my son would never walk or talk properly, to what he is today is a credit to NDIS. I am not always angry, I am just sick of fighting for help.