

We have been receiving support for 2 years for our son Yawan who is on the Autistic Spectrum. Although Yaz is quite high functioning, he struggles with social pragmatics and theory of mind, resulting in a number of distressing social situations.

One of the issues with NDIs was the lack of flexibility in changing the plan, as in the first year he required a psychologist quite urgently as he was stating he was not going to school and he should kill himself. The school were so overloaded the access to a psychologist would have been months. As a mental health trainer and a Mum, not something I take lightly. In the end we gave up as apparently this had to be a long winding process of “proof” on our part that he really needed support.

Adding to this, in developing this first plan, the planner who was very lovely in nature, suggested she could include funding for the school YMCA program to increase Yaz’s social connections. Unfortunately this demonstrated a lack of understanding of the anxiety experience for Yaz’s and the inappropriateness of one off social events. These types of situations guarantee anxiety /panic attacks.

I then proactively assisted the Laboratory (a weekly computer activities groups for children on the spectrum) to start up in Torquay. This group is fabulous and specific to the need of children on the spectrum with like interests and harnessing specialised skills. I had to fight for NDIS to fund this. There is no more relevant and beneficial program for a child on the spectrum!

Coming from the community services arena as a case manager and now trainer, I am very happy to say I have a good deal of insight for what our son requires, but I cannot predict a year ahead what services he may require. The onus on the carer to “prove” a changed plan, even with paediatrician recommendation was ridiculously strenuous for us. So much so we gave up.

The following year the plan was re evaluated? At the time the Speech pathologist and OT were not required (Please note they were both very beneficial for the period of time utilised. The OT was largely for a sensory assessments (so short term) the speech- as required. The speech pathologist said she felt she was not instrumental towards the end, so we were happy to leave services for a while.) In the last few months of this year, Yaz has experienced an increase in social issues at school, so we all, including Yaz, thought a speech pathologist was beneficial to revisit some of his social communication fears. I was told upon request of this that I would have to provide all the past paper work from the OT and the Speech pathologist, for NDIS to consider. Again, why was the onus of specialist responsibility, placed on the carer? I then saw his paediatrician who wrote a very assertive letter to NDIS, who “suddenly” reconsidered the flexibility, especially given that he/we have not been using respite dollars for a number of months. Again – we were not to predict that the services staff provided through respite, would not be a good match as in Yawan’s words, “Why was grandma who smokes, which he has an intense sensory dislike to, sitting on the couch watching tv?”

During this last year I engaged in the survey on NDIS from I think, Flinders University. Both telephone interviews and the focus of the questions, gave us no chance to articulate any of the issues we were having and do have. The survey was designed in a way that the issues could be clearly avoided by not asking any questions relevant to the following.

- Was the current plan working **and if so why not?** NO
- Does the planning process provide for flexibility for unforeseen life events? NO

- Does the use of the portal work for you as a carer? NO
- How did you feel about having to chase specialist reports to prove need? NOT GOOD
- Do you think the planner understands Autism? NO

Two days ago, I received a phone call from NDIS for a reassessment over the phone of Yaz's case plan. The planner suggested we can possibly lock this in for 2 years. I cannot believe that a service for a child/adult would think they can predict a two year plan. My fear is the lack of people contact as any expectation to change, will be placed on my ability to access a portal I don't ever use, and to chase specialist recommendations with no guarantee that the service will be provided.

I am more than happy to talk personally on these occurrences if required. I would also like to add that, these issues appear to be now an embedded protocol and practice of NDIS, which I am very concerned over. Human beings needs are unpredictable and in particular vulnerable citizen's needs. My son, like many clients, will not be a square peg fitting into a round hole for two years.

Thanks for the opportunity to feed this back

Regards

Jules Haddock