Submission
No 205

INQUIRY INTO IMPLEMENTATION OF THE NATIONAL DISABILITY INSURANCE SCHEME AND THE PROVISION OF DISABILITY SERVICES IN NEW SOUTH WALES

Name: Name suppressed

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I am writing this letter to express my disappointment and my frustration towards the NDIS.

I am speaking on behalf of my 10 years old daughter, , diagnosed with global developmental delay and autism spectrum disorder Level 3.

’s first plan was approved on the 26 July 2017 and I was happy with the outcome of the funds, but not with the denied option of managing the plan . With this option I could not pay one of my daughters therapist which is not a NDIS provider. Short after I logged a complaint to review the managing options and it took 8 months for NDIS to reject my request with no reasonable explanation. So for 12 months I was not able to pay this therapist with NDIS funds .

Few months ago started the ordeal of the “review”. A very, extremely stressful process.

I was expecting NDIS to cut my daughter’s funds. We were all expecting that and not because my daughter is better, but because of the experiences of many family I knew; with the second plan the funds have been cut to all of them, no exceptions.

First of all my daughter’s new plan was put in place 2 days earlier that should have been, without my knowledge, and for this reason a certain amount of money was frozen, becoming inaccessible and unable to be used.

Why the person, so called “the planner”, did this….we don’t know! I spent an hour talking to NDIS costumers service line, without having an answer; my believe is that there was no answer but the easiest explanation it would be that this person with the authority to sign the plan, shouldn’t have this authority and probably should not have been chosen for this job.

This person, whose name was not disclosed to me, also decided to dramatically cut my daughter’s funds.

These below are the reasons for the cut:

- Funding for CORE SUPPORT was cut from $ 20,801.00 to $ 3,494.20. This funds are used to assist with daily activities and community participation, to enable maximum independence in personal activities. The funds is intended to help my daughter to build relationships with her peers and others, engaging in different activities in the community, to develop and built a network of social skills outside the family environment.
  The planner concluded , my daughter, should have never been given money for the Core support category in the first plan. What was given in the previous plan was a mistake, because has 2 parents; so the planner indicates that in the case of a child with disability, with 2 parents, there is no need for support in accessing the community. Why is that??

- Funding for IMPROVED RELATIONSHIPS used to access specialist behaviour intervention therapies, helping to develop skills in building positive relationships ,to require less support in the future, has been dramatically cut as well ,from $ 5,893.5 to $ 1,827.40 because at this point , the planner concludes again, should not be in need of anymore behaviour therapy , instead strategies should be implemented.
  My daughter has big behavioural issues, her frustration becomes uncontrollable anger, and her outbursts can occur unpredictably, from breaking windows with her head to trowing

object around the room, smashing ipads, computers, screaming, hitting and biting others. We, as a family ,cannot go out in public places with her, we cannot go on holiday or just a simple cinema… But according to the planner, doesn't need therapy anymore, doesn't she???

- Funding for last category IMPROVED DAILY LIVING has been cut as well , from $ 9,129.64 to $ 6,991.14, used to support in reaching her goals of communicating her wants and needs. Reason given by the planner is: can add 20 session of any therapy using Medicare rebate, which is correct, but what the planner may doesn't know is that these 20 session are claimable once in a life time and used them already when she was 3 years old. For general knowledge is now 10 years old, almost not verbal, she can hardly read or hold a pen.

I found the planner to be an very ignorant person , a person with no respect and knowledge of the few points given to me as an excuse for the cutting. A person that should not dare give an opinion or make decisions .This person did not consider any of my daughter's GOALS; this person did not consider, probably not even read , all the reports, pages and pages of reports, VERY EXPENSIVE reports, that NDIS FORCES me to present, stating the conditions of my daughter. None of this has been taken in consideration, because the "so called planner" came to the conclusion that my daughter is suddenly cured.

Well, let me tell you something: NDIS came to life to help people with disability so they could have a better future in the society.

NDIS is not doing that. The only thing NDIS is doing is cutting, and cutting, and more, with no reasons or explanations. There is no one of the family I know that have been spared; their plans have all being cut like my daughter's.

NDIS brought just misery, huge level of stressed and unhappiness to my family. I did everything I have been asked from my local coordinator, to PLEASE the "planner" and to PLEASE NDIS. I have been under a lot of stress and all for nothing, just more misery.

When there was no NDIS , I did not have to ask , or should I say convince people of my daughter disabilities; she was having therapies every week , going to Vacation care every school holiday and all of this was coming from Government's funding.

My daughter has been deprived of $23,511.40.

Personally I am disgusted the way we have been treated by NDIS and especially by a person /planner which should be better off working in an ice cream shop, instead of having the power of signing documents.

Regards