

## NDIS PUBLIC REVIEW July 2018 Submission

I have been managing my daughters NDIS funding for the last eighteen months. It has caused me severe stress and anxiety but we are now starting to see the benefits from it. This has been a huge battle, an extremely difficult path to navigate and thousands of dollars have been spent because either NDIS or their providers were unclear in their policies and procedures.

At the cost to the client of approximately \$100 an hour coordinators have spent hours trying to work at procedures to help participants receive funding and the services they require. Upon ringing NDIS services you are told up to five different things for the same question, from five different operators within the same week. This has not been a "user friendly service" for the needy within our society.

A complex web of knowing the right words and procedures, being disillusioned, exhausted, fed up and desperate would be some of the words to describe the transition for participants, carers, providers and NDIS staff (as can be seen in the high turnover of staff that I have observed).

Carers are losing group Carer supports that they have used over the years to help each other, share information and come together as families, easing that sense of isolation for parents and siblings. Apparently an individual with NDIS funding no longer needs to have their Carer supported by Carers Support where they can feel part of a community. This will have a huge impact on the mental health of carers especially as group activities for disabled are lost or costs are too high.

Different providers of the NDIS service, Intereach and the Brotherhood of St Laurence have both been working from different set procedures. Intereach in the Bendigo region use an area coordinator who makes contact with the participant and then relays that information to the planner, therefore there is no face to face contact with the person whose life they have in their hands. This process is completely dehumanised due to the person deciding on the plan not having to be confronted with the reality of people in severe stress.

Once the participant gives the request for services to the area coordinator they then will put it forward to the planner. The participant is left unable to make a personal request to the planner or to even know what is going to go into the plan, you are just sent a lump sum figure broken down into a few categories and left to work out if you have the funding for the hours you requested.

In January this year I spent a week trying to budget in the hours I had requested with the funds that I had received for my daughter, when I could not do this I assumed that I had not been given travel funds and proceeded to put the form in for a review. Through this process I find that the funds have just been indexed to the price rise in July of 2017 and that I now have enough funds, I would have thought that NDIS would have calculated the plan on the prices they had increased six months prior. I am currently in the position of signing service agreements where the providers are charging the July 2018 prices but the participants funds have not been indexed.....this is unnerving.

The original procedure in the leaflets given to us was that the planner would work out the plan and then present it to you for your approval. When I advised our first planner of the procedure I was advised that I was not able to view the plan despite me quoting the page number of the instructions on preparing a plan. The Brother Hood of St Laurence allows participants to see the planner and have a personal contact with the person making the decision.

In a legal contract for planning you are normally given a start date and end date which you can successfully budget against, NDIS gives you dates when your plan starts and finishes but the next plan does not start until the planner puts it in the computer which can take up to two months.

My daughter did not get her services running properly for the first six months of 2017 due to the total chaos of the system and the lack of knowledge of the system. Over the summer break I organised activities well over our normal budget to make up for the previous loss of services.

Our planner failed to make contact with me and then terminated her employment a week before Christmas, a new planner hurriedly put a new plan in place, I was of the understanding that it would start on the day after the end date of the old plan therefore I sent my daughter out on her holiday activities only to find that I had blown our budget for 2018 because the new plan had started as soon as it was put into place without advising me.

I then asked for a review of this to be told "don't worry" because the next plan would come through a month early as well, what if it did not start early as stated and I had delays with planners as I had two years in a row. I would be left having to cut hours from support workers a few weeks before Christmas. How are we supposed to plan a proper budget if the finish date is in a random state? Relying on when we can see a planner which has proven to be very unreliable and extremely stressful to organise when we are being asked to sign service agreements and to conduct everything in a businesslike manner. How are we to plan a cohesive program that works in with educational establishments and day services.

I love the fact that the NDIS is supposed to provide services to enable the participant to be more independent but there are two main problems:

1. Trying to get the therapies to enable improvement in a plan is extremely difficult and many therapies that have proven to be successful are being ignored. My daughter needs therapies to prevent her situation getting worse yet when asking for these services I am told that even though I have been funded for assessments this year I will not receive the recommended therapy funding this year because you were supposed to get less the second year.
2. Many people's lives are not going to improve and will only deenerate due to the closed minds of some, we need more support/funding, not less. Therefore how do you respond to a planner that tells you that you will not receive any more funding than last year because your special needs daughter is supposed to be getting better?

The absurdities of the system are overwhelming, such as the request for my daughter to receive an iPad to support her speech therapy that was in her first plan with a recommendation letter from her speech therapist that would be very beneficial for her development. The problem was that NDIS were managing the funds and that I could not find a registered provider who sold iPads under the NDIS and the funding was lost. The next year when I have control of the funds I am still unable to purchase an iPad despite it being an invaluable tool for speech. There is funding for apps but not for an iPad. Currently I am using my personal iPad which means that if I need to use my iPad my daughter and her support worker are unable to work on her speech progression.

Many people have lost more than they have gained through the introduction of the NDIS and I do not think that people realise how much until all group funded activities are gone and all the Carers Supports. It is hard for many to realise that all of the wonderful group programs that we have taken for granted will be lost and we will be left alone fighting for individual supports. Many will be isolated and unable to work through a complicated system that is trying to cut costs.

A camp that once cost you \$70 for a weekend now has to be budgeted out of NDIS funding for \$1800 for a weekend which means no money for a supported weekend with people of similar abilities. I have a University degree but this system has left me on my knees trying to get the support my daughter needs to thrive on.

I am relieved that this review is being held as there are many aspects that need to be looked at. I have been part of providers reviews which are quite stringent in their queries. I was told that NDIS were only going to have internal reviews which seemed quite absurd when they were the main ones causing the huge problems. In the future I would hope that this type of external review was on a regular occurrence so that problems can be exposed and corrected.

How are the vulnerable going to navigate this broken system?

Also perhaps one would have more confidence in a system that could at least get the calendar correct on the portal for funds requests!!!!