

Submission to the Joint Standing Committee on the NDIS

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To: Joint Standing Committee on the National Disability Insurance Scheme
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Summary of Document

This is a letter detailing some of my difficulties in dealing with the NDIS, as primary carer of my daughter. The points covered are as follows.

- Personal details
- Experience with reviews
- Communication failures within the NDIS
- Need for staff training
- Sharing of records

4 Pages

I am the mother of a daughter, who is on the Autism spectrum with some intellectual disability. I am also her primary carer. I have recently abdicated my role of administration of her estate due to ill health and was starting to be assured that when I die she will be adequately looked after. The NDIS held a promise of this which is now unfortunately being eroded year by year as funds are cut and very inept decisions are made during review. I wish to address the issue of the whole application and review system.

As a result of being missed from the initial rollout of the scheme there was a great flurry to get her onto the NDIS before the next group were processed. There was very little time to prepare and very little knowledge available. No one can sit down and inside an hour come up with a detailed monetary value for what the disabled person needs. Particularly when as a carer you are submerged in the daily emotional and life needs of the person concerned.

An agreement was made that because of the rush we could apply for a review after a trial period, if we found important items missed.

A request for a review was made when it became clear that her needs to live independently were not being met. Her health and mental abilities deteriorated during that time and she ceased taking her medication.. Two hours a day (one hour morning and evening) were instigated so that medication could be administered and recorded for the doctor, and personal hygiene and meals could be supervised. A 3hour recreation time was set so carers could encourage her to join in social activities.

My constant and regular requests for the date of the review were answered with a promise to notify me when it was set ,which was to be April the following year(2021). At the end of April my request for the date were met with “Oh it’s been rolled over.” NO contact No answers as to why. Not even the courtesy of informing me. And the hours and funds had been cut without consultation.

After a lot of hours spent trying to manoeuvre within the system I applied for another review. By then, after constant requests over 2 years, or more, for a support co-ordinator, I had found some-one from ELPE to act for my daughter. I became nominee and through from ELPE we applied for a review. All the supporting material and assessments requested were supplied and sent off. Naively, I expected to have the granted review. Instead I received a phone call on September 21st 2021 from someone who finally refused the review on the basis of “lack of evidence”.

There is a current complaint regarding that particular phone call which is being dealt with in the appropriate way and is presented here only to highlight some of the difficulties.

The results of the 2nd review came through a few weeks ago and the money had once again been cut, but this time to the point of denying my daughter the support she really needs in order to live independently. Her carer hours which are necessary for shopping, personal hygiene and most important ,medication supervision have been slashed to an unusable level. It has taken me 45 years of trying different services to find a psychologist or even a counsellor who is able to succeed in helping anxiety and depression. Now having at last found some-one who can help her, this essential service has been summarily dropped from the plan – once again without consultation or full knowledge. Money and time for any social activity has been ruled out as “unnecessary”.

The argument seems to be that “the money wasn’t used” and the attitude that because it wasn’t used she doesn’t need it. At no time in talking this out with the local area co-ordinator was the fact that all such activity had ceased due to Covid lockdown and extended isolation, as [redacted] is a vulnerable person. She also lost her employment in 2020 due to Covid.

In all the above it should become apparent that communication is not a strong factor in dealing with the NDIS. I cannot begin to name the horrors of the government speakinese language which puts carers at a total disadvantage when trying to get the required help. If you don’t speak in Acronyms you don’t succeed in communicating. I would probably cope better if it was in French as I have at least a little knowledge of that language. I do not know appropriate form numbers therefore at times complaints or requests are ignored because they “should be on a form such and such”. Or worse still I am directed to a website and told to look for form XYZ which appears nowhere on the website to which I am directed. I consider my time to be just as valuable as those at the other end of the line and, in amongst the time spent dealing with government departments, I would like a little time left for sleeping and, if I’m lucky, eating.

I believe that the people making life impact decisions have very little or no knowledge of what any disability involves. I believe they are office staff who look only at the dollars and cents involved and never enquire into the realities of living with any disability requiring constant help or aids. Those making the decisions should be better aware of the difficulties and needs of the person, no matter what the disability. It is apparent to me in the reviews that in [redacted] case the people making these decisions have no idea of what autism is about or what is important to maintain in the person with autism. A clerk at a desk should not be making such decisions without training.

I believe that there is a great waste of money and resources in the duplication of examinations, proofs involving the same forms or medical certificate or letter. The government departments could well do to have access to each others records thus saving time, energy and unnecessary duplication of both resources and services. If the Taxation department can access Centrelink records and earnings why can’t health, NDIS and Centrelink talk to each other. In 6 months [redacted] had 3 identical medical surveys, 3 forms or more to be filled in by the doctor, a diagnosis by 2 specialists, and numerous repetitive letters. When I said “But you have all that information” the department concerned insisted that it had to be done again for them. For heavens sake isn’t this the age of communication or is each department a little box each with its own working rules and isolated from each other.

If the Government cannot afford to run the NDIS then please don’t promise what you can’t maintain. The scheme was rushed into without adequate research or thought and now the very people it was meant to help are being punished by withdrawal of services. Once again the government has promised help and a chance at life to those less fortunate and are now withdrawing it.

Some of my suggestions for improvement of the NDIS would be:

- Adequate explanation of the scheme for both the person and the carer in simple terms so that a realistic idea of what the person needs can be assessed without duress. Please keep in mind that carers are usually running on overload at the best of times. To put the person into total care would cost far more than disability funds.
- High level training for those decision makers within the NDIS so that informed decisions can be made when reviews are requested and are based on the actual disability needs.
- Better communication with the client and carer. Communication to be carried out in clear terms with no acronyms, and spoken in plain English.
- Sharing of documents between the concerned departments. E.g. health, Centrelink and NDIS to avoid duplication of proofs where possible.
- That when assessing the amount of money allocated to an individual a 2 or 3 year period of assessment be enabled before a decision is made to lower it. The unused portion need not be rolled over but the same amount should be allocated the following year.