

21 August 2018

Dear Commissioner

Submission to the National Disability Agreement Review July 2018

My personal experience with the NDIS has not been a positive one from the beginning. In fact, it appears that the more difficult the process is made, the more likely people are to be intimidated, give up and not go through with all the bureaucratic red tape to achieve their goal.

In the first planning meeting, I specifically set out how I wanted my daughter's plan to be managed and nominated a Plan Manager to manage the funds. When the plan was received, it was not set up as I had requested thus triggering a review to rectify the Planner's error. I was advised by staff from the NDIS that in applying for a review, there was the risk of losing some of the funding that had just been allocated. I found this statement rather intimidating but I was willing to take the risk of this happening because I was unable to implement the plan the way it had been set up.

The review took 4 months to complete and during the review process, service providers were not being paid and as a result, I lost several providers. During this 4 month process, I was unable to utilise my daughter's plan to the maximum because of the possibility that a review could jeopardise the funding that had just been allocated.

When the review was finally completed, my daughter was then able to start various activities. As a result of having to wait 4 months for a review to take place, my daughter's plan had a large surplus of funds at the end date which were lost.

From the outset, nobody from the NDIS advised that I had to apply to become a nominee for my daughter's plan which resulted in further delays. Therefore, it was 5 months into the year before my daughter's plan was up and running.

I continuously found the NDIS staff were not familiar with procedures, regulations, etc., and when making a call to ask a question, I often found it difficult to obtain a clear and concise answer most of the time receiving a response along the lines of 'pretty sure that is the procedure' or being given several different answers to the same question. Some service providers that I had tried to engage, were also experiencing difficulties with the NDIS staff resulting in their unwillingness to register as a provider.

I have been told by many service providers that the NDIS portal has been problematic and the Mygov website registered to me does not represent real time expenditure of funds thus giving a false indication of funding available/spent.

Aside from the usual time consuming tasks a care giver undertakes, I now spend countless unpaid hours doing paperwork or following up on some query. The NDIS process is not an easy one to navigate and is time consuming, intimidating and overwhelming.

SWEP is another major problem in the system. I have waited for over 12 months for an essential ramp to be built. After many hours of work by the Occupational Therapist trying to navigate the NDIS process in preparing an application, it took SWEP 5 months to acknowledge receipt of the application for a ramp and a further 5 months before the application was considered. I am still waiting for the ramp to be built because it appears there are not many organisations that specialise in disability renovations that are registered under the NDIS. In the meantime, my daughter is at risk of falling every time she leaves the house and must be guided carefully by someone to do so.

I have another application with SWEP for some essential railings. The application was acknowledged in March 2018 and 5 months later, I still have not had any response. It does not matter now whether the application is approved or not because this year's plan has not allowed any funding whatsoever for home modifications and assistive technology.

The organisation of the plan review was poorly executed expecting me to be ready for a review meeting with one or two days notice. I managed to put off the review meeting for a week in order to be able to prepare a reasonably comprehensive submission.

At the plan review meeting, I was advised from the outset that funds were going to be cut and I should expect a reduction of funding in the new plan compared to the previous year. How can a comment like this be made prior to any information gathered or discussion. I was also advised that the planner herself was leaving and would not be the one to prepare the plan. Why spend 1.5 hours of intense discussion/scrutiny with someone who is not going to see the plan review through.

It appears that the NDIS expects people with permanent disabilities to improve and to have achieved or partly achieved their goals. People with permanent disabilities unfortunately rarely improve, in fact, they either deteriorate as time goes on requiring more assistance or they plateau requiring the same assistance to maintain the level they have reached.

My daughter's plan this year was cut by 50% with no justification whatsoever. Her brain injury is permanent and therefore she will not miraculously improve, requiring as much assistance as she had been receiving with the first plan.

My daughter has an Acquired Brain Injury, is classed as high needs, is high risk for falls among other problems and has psychosis and paranoia and cannot be left alone. As her sole care giver, I spend many hours attending medical appointments and ensuring that all her needs are met often neglecting my own medical needs because there is insufficient funding in the new plan to allow extra time for me.

There is a 9 day gap between the end date of the 2017/2018 plan and the start date of the 2018/2019 plan. How is this possible and what happens to expenditure incurred during this period – nobody can provide an answer.

This 50% reduction in plans appears to be happening to many people with disabilities again with no justification. In arbitrarily cutting funds, the government is not taking into account the effects this has on the person with the disability and the family caring for that person.

My daughter's new reduced plan is not allowing her to continue with activities that have become important in her ability to access the community and to further learn independent living skills. I have had to cancel access to some programs that my daughter has been benefitting from due to lack of funding.

In drastically reducing the funding for plans, the government is not taking into account the effects on those care givers that provide the bulk of the required support and who are ultimately on call 24/7. Nobody is taking into account the relationship breakdowns or the stress of being a sole carer with no family support or funding to be able to engage in activities to have some personal time and respite. Health professionals continuously stress the need to care for oneself when you are a full-time care giver. How is this possible when funding is not available to support the person you care for while you engage in something other than providing care for the person with a disability. The lack of extra support means more pressure is being put on the care giver resulting in increased mental and physical health problems for that care giver. This in turn, puts more pressure on the public health system because private health insurance is not affordable.

My daughter was in supported accommodation for a period of nearly 4 years prior to the NDIS being introduced. I took the advice that I should place my daughter in care because I was getting older and she should learn to live independently from me. After 3 injuries and continuous issues with lack of nutritious food, lack of hygiene in the house and many, many other problems, I pleaded with DHHS, the Minister and Premier to step in and see what was going on, to no avail. Following another injury, I decided to bring her back home to live with me before any further damage could be done to her mental and physical wellbeing.

The fact that no government department, having been provided with undisputable proof of what was going on in this particular house, was willing to take the appropriate action was another example of the government not caring about the effects of their decisions on persons with disabilities or their families.

Prior to the NDIS, there were many free programs for persons with disabilities. With the introduction of the NDIS, organisations are now charging exorbitant fees, albeit within the NDIS price range, disadvantaging persons with disabilities if there is insufficient funding in their plans from the NDIS for them to continue to participate.

The NDIS has the potential to be a beneficial program for persons with disabilities and their families but until such time as the government shows some compassion and understanding of what people endure on a day to day basis, this initiative will not fully benefit those in desperate need, particularly if funds are arbitrarily reduced thus taking away much needed supports and if the process is difficult to navigate.

There is one factor that the government continuously overlooks and that is, it is the families who provide ongoing, unpaid care for their loved ones in their own homes. In caring for

their loved ones at home they are ultimately saving millions of dollars of tax payer money compared to what it would cost the government to subsidise them in group homes. If these families received proper funding, support and an easy to navigate system, it would make life a little less stressful for those involved.

When the NDIS was introduced, it was said that nobody with a disability would be disadvantaged. This has not proven to be the case in my personal experience.

Yours sincerely,

Marie Mills