Submission
No 255

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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8 August 2018

Submission to the Inquiry into the implementation of the National Disability Insurance Scheme (NDIS) and the provision of disability services in NSW

NSW Parliament

To whom it may concern,

I make this submission as the mother of a 9 year old boy with a diagnosis of Autistic Disorder (under the previous diagnostic manual). Under the current diagnostic manual, would be Autism - Level 3 (or quite severe for want of a better description). is partially verbal, communicating verbally using echolalia (scripting), or otherwise gesturing, using visual prompts, or using a speech device. He requires prompting and physical assistance to ensure hygiene is maintained, and is also an absconder with absolutely no regard or appreciation for his own personal safety, or the safety of those around him. equires 1:1 assistance and supervision 24 hours per day, and will do so for the foreseeable future. My husband and I expect that will be in our care for the duration of our lives, and that our youngest two children will continue his care when we have passed.

ttends Aspect South Coast School in Wollongong (a specialist school for children on the Autism Spectrum). It is a wonderful school whose Principal is passionate about ensuring his team of teachers and therapists have the best training and resources available in order to help our children grow and assimilate with their mainstream peers. Through this school which we privately fund at around $7,000 annually, we have access to exceptional Occupational Therapists, Speech Therapists and Child Psychologists, and thus I have not requested funding from the NDIS for these therapies for .

Our personal experience with the NDIS began in July 2017 when the NDIS rolled out in Wollongong. We were lucky enough to be contacted early on, and had our first plan implemented from 7 July 2017. Until this point, we had not received any support services, though we had been a waiting list for over 2 years with local disability support services provider, Interchange Illawarra, for a fortnightly Saturday respite program. We had also been on a wait list for a support worker who would be able to pick up from school and assist him with after school activities and personal care.

We didn't touch our available funding until was finally allocated a place at Saturplay (fortnightly respite), run by Interchange. was allocated this place in November 2017 after **two and a half years on a waiting list**, such was the demand for this brilliant service in the Illawarra. At this point, this was the only funding from our plan that we had accessed.

In February 2018, we were allocated a support worker who could assist us after school, although we were only able to afford one day per week with our funding. She was able to pic up from school, and take him to appointments, or out to community events, working 1:1 with him so that he could involve himself in activities. When the time came for our review, we intended on requesting an increase to this support to 4 afternoons per week, as we had been relying too heavily on my mother for the other 3 days. She is nearing 70, working 2 days per week herself, and already caring for my 31 year old brother who has a diagnosis of schizophrenia.

Having been through what I now know is the standard review process, I feel I am in a position to make some very important points about *who* is making the final decisions for our loved ones. It is not us.

The review process begins with an appointment with a Local Area Co-ordinator (LAC), during which you discuss the successes of the previous plan, changes to your life that may result in changes to your needs for your new plan, and generally what you would like included in your new plan to meet your goals, and to ensure you live your best life. We ensured that we were prepared for our LAC meeting and brought with us a letter of support from Interchange which confirmed the supports we were receiving, and we also provided costings for the supports we were requesting for the coming year.

The LAC then pulls this information together and provides the base for the plan to an NDIA Planner. The planner will take this base, look at the information the LAC has collected from the client, and put together the final plan. The NDIA/Planner then approve the plan, which immediately cancels the previous plan.

It is only at this point, ***after*** the plan approval/cancellation of previous plan, that the client is advised of the outcome of the review. Their new plan is effective immediately whether it meets their needs or not. The client is not given any opportunity to review the plan, or give feedback prior to approval.

I have been told on three separate occasions with NDIS phone operators, that I am unable to access the draft plan, with no legitimate reason forthcoming. There may well be a legitimate reason, though NDIS staff aren't well versed in articulating it, only advising that draft plans can't be forwarded to clients. I did learn of a case where a client was told she would need to lodge a Freedom of Information request to gain access to the draft plan sent by the LAC. This seems like a fairly extreme process to go through, to gain access to your own information. It is certainly not a timely solution either, as I imagine it would be more than likely that a plan was approved by the NDIA, *before* an FOI request was granted and completed.

As a result of this process, our current situation is as follows:

- our previous funding of approx. $17,000 (2017/2018), has been overridden by the new plan funding of approx. $9,000 (2018/2019).
    - We had requested approx. $30,000 funding in total for 2018/2019.

- Our new plan allocation meant that we had enough funding for 2.5 Saturday respite sessions
    - We requested 26 (fortnightly)
    - We have obviously already exhausted this funding, and also privately funded ½ of one session.
    - We have had to relinquish our place at Saturplay, which we waited 2.5 years for, and which absolutely loved.

- Our funding for afternoon support has been significantly reduced and allocated to a different funding category, which increases the hourly rate and changes the role of the support worker due to the reporting requirements on the support worker.
    - We requested 2.5 hours, 4 afternoons per week
    - The planner actually allocated all of this time to my aging mother. I was stunned that a planner feels it is within their power to allocate my mother's time for her when we specifically stated that she is aging, works 2 days per week and also cares full time for my 31 year old brother with a diagnosis of schizophrenia.
    - We have enough funding for a support worker 2 afternoons per week, to keep us going for approx. 2 months.
    - I have had to reduce my work hours which has been detrimental to my financial planning business, and I must now consider winding up my business in order to manage our afternoons. At this point with a very new business, I cannot afford to hire another person to manage my workload.

Saturplay was an incredibly positive experience for . He received 1:1 support, went on outings with the support workers, was assisted to play games with his peers and was developing beautifully with this program. *If* our appeal for funding is successful, we will need to re-join the waiting list, which seems futile, given the previous wait. I am however, led to believe that the wait has reduced somewhat as the NDIA has withheld funding for other clients who requested this service. This situation has been devastating for us, and would be devastating for so many young autistic children and their families locally if the NDIA/NDIS fails to support these sorts of programs.

In terms of afternoon support after school, I have called every local provider of after school care services. None are secure enough to accommodate a high needs child with the tendency to abscond. All are able to apply for funding for extra support for a special needs child however every single one was at pains to explain to me that this does not provide 1:1 support for a high needs child. The extra staff member is there purely to reduce staff:child ratios. There is no assurance that eyes will be on him at all times. There is one provider who provides secure support for children from age 12. They are unable to accept as he is too young. With no reliable family support locally, I may be put in a position where I need to wind up a business which currently employs three people (with genuine growth plans), in order to manage our afternoons. The government subsidises after school care for school children Australia wide so their parents can continue to work. Though parents with children with disability are isolated yet again, by a lack of support for high needs children once their school day is complete. I would have hoped the NDIA/NDIS would be far more flexible in assisting us in this regard.

I hear so many wonderful stories coming out of the NDIS, and our initial year opened up a world we hadn't tapped into before. has been on the receiving end of amazing experiences with support workers who adore him. He has flourished this year with all the extra external input in his world. He laughs, and has found the most beautiful sense of humour, he plays *with* his brother and sister, laughing with them, which has been tear jerking to watch. His experiences at Saturplay and with his support worker after school have penetrated a world that we were having trouble trying to access.

And then one NDIA Planner, who seems to have completely overlooked the requests we made, has swiftly taken that away from us, and literally relegated us to the back of the Saturplay queue. We are holding on to our support worker by the skin of our teeth, hoping that our appeal will be completed before we run out of funding for her. We know that is unlikely. Apparently there is such a backlog, appeals are taking 3 – 6 months to get through.

Processes need to change to allow the client far more oversight during the planning process, or at the very least, some degree of sign off prior to approval.

I also firmly believe there needs to be some greater consideration by the planner, as to who it is actually funding the NDIS. That I need to consider closing down a tax paying business, which employs three taxpayers, whose monetary contribution to the government would essentially fund many, many plans, seems very silly.

I very much welcome the opportunity to contribute to this inquiry, and look forward to hearing the submissions and outcomes.

With kind regards