

Submission
No 176

**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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Partially
Confidential

NDIS submission

Background

- I am my 20 year old sons' nominee on his NDIS plan. He has very high needs and likely fitting the criteria for 'complex needs'. He has a number of health conditions, severe physical and intellectual disabilities and requires 24/7 support. He drives a power wheelchair and requires a hoist to transfer between wheelchair and bed and bed to shower chair/commode.
- I fundamentally believe in the NDIS and had my son received this support when he was younger, I believe his capabilities would be greater and he would have needed less orthopaedic surgery.
- I am concerned that in making a submission, this information may be used for political purposes to dismantle the NDIS but I am sharing our experiences in the hope that the hearing will identify areas where the scheme can be improved and where there is not a good partnership or transition between the state services and the NDIS.
- My son was 18 years old and in year 12 when the full scheme rolled out in Sydney in 2016 and he was transitioning from school and from Children's' Health Services to Adult Services.

Positives

- My son has much more support in the home than he had previously
- The initial LAC was very good as was the second NDIS Planner who reviewed my son's first very poor NDIS plan
- Much more choice under the NDIS about when support can be accessed over the week therefore can access a greater range of activities particularly mainstream social and recreational activities
- Choice and flexibility in how the funds are used due to flexibility within the Core budget. Therefore, as needs change over the year, funds from one category can be used to cover a shortfall in another area
- Because the NDIS has stimulated a growth in Service Providers offering services that may not have been provided in the past, there is now a choice over which Support Workers are engaged to provide support. This allows for better aligning of personalities and interests and consistency of Workers resulting in higher quality support. This is particularly important due to son's health needs which includes the need to observe changes in son's behaviours which can indicate a deterioration in health. This has been particularly important this year and has allowed son repeatedly to get to the local Emergency Department in a timely manner. Choosing our own Support Workers who believe in my son's goals and will willingly support him to achieve those goals has ensured good carryover between the communication and physical tasks he is practicing in therapy and implementing those skills in real life
- The consistency of Workers has meant that less time is spent training and familiarizing SW with my son's needs and routines which has reduced some of the demand on my time and energy.
- The choice and flexibility in how core funds are used has allowed Workers to support him with speech and physical therapy home programs and hydrotherapy which promote his health and well-being, assists with pain relief from chronic pain associated with his disability, built capacity to assist with dressing and transfers and works on improving his social and communication skills.

- The NDIS does seem to be responding to problems in the system. The portal is more reliable and Short Term Accommodation rates for complex care have increased for example.
- My son is now living an interesting ordinary life of his choosing, getting out in the community rather than being segregated from the community full time in a group disability service doing activities just to fill in the time. He is doing activities that engage him, challenge him intellectually, improve and maintain his health and build his skills to improve his independence. He goes to group activities of his choice twice per week, which at the moment is music and drama and then. Support Workers help him get out in the community such as going to the local church, sailing at Sailability in the warmer months and exploring both the local community in his wheelchair and Sydney wide via public transport which he loves. With Support Workers, he also contributes to the household with cooking and some vacuuming.

Negative

1. Poor Implementation of the NDIS in our Case with Difficulty in Enacting NDIS Plan

- Poor transition from School: The first NDIS planner did not fully read the plan submitted by my son's LAC and so did not realise that my son was a school leaver. Therefore the plan was appalling, leaving him with no funding for post school options. The plan was also completed late in the last year of school, much later than had been the case pre NDIS, with Service Providers unsure of how the NDIS was going to work in Sydney so it was very difficult to plan for my sons first year out of school particularly as I was working and needed to continue working when my son finished school.
- It took 5 plans in 9 months for the plan to contain adequate funding for post school activities and for AT equipment. This was extremely stressful and time consuming.
- The most stressful event in the poor execution of my sons plan was when the plan was commenced without forewarning of the date and his existing supports were immediately ceased without notice. I actually found out that this had occurred about 2 days after it had happened. The stress and anxiety that this caused, in combination with a completely inadequate plan, cannot be overestimated. My son was due to go in to Hospital a week later for orthopaedic surgery for operations on both feet. I had hoped to organize what could be doing when finishing school before his surgery as I knew I would be stressed and tied up supporting his hospitalization and post op care. We were already under stress as this surgery had been due to take place two weeks earlier. I had taken a week off work for the first surgery. After waiting all day at the hospital on this first occasion, the surgery had been cancelled and postponed so I had to organize more time off work which was difficult.

What little in-home respite support we had at that time had been organized to provide assistance with showering my son as it was to require 2 people as he would have two legs in plaster for about 8 weeks. When the surgery was cancelled, this support had to be rescheduled and then when the NDIS plan commenced, this existing support was cancelled. Our Service Provider said that they could provide support under the NDIS but this would take time to

organize as a number of actions needed to be taken including a meeting with them and the writing up of a Service Agreement. My son also attended Respite with another Provider 1 night per week on an evening that I worked. This was also cancelled without notice severely affecting my ability to continue working. A service agreement was also need for the Respite house. I had no idea how to activate plan, a code which was later provided, did not work, there was little information on the NDIS website and NDIS call centre staff had no knowledge about the scheme and could only take messages. These messages would take 3-4 days for the NDIS to return initially and as time went on, even longer. It was an extremely stressful time and the stress has continued for a number of reasons.

- So to summarize, this therefore meant that during the time my son's rescheduled surgery which was stressful in itself, as my son went into the NDIS, and without assistance from the NDIS, I was trying to
 - remain working despite a loss, without warning, of the meagre existing care for my son,
 - trying to enact an appalling plan that completely failed to adequately support him,
 - continually advocate for my son to obtain a satisfactory NDIS plan
 - deal with the loss of his planned post op therapy (discussed later) and find NDIS registered therapists without huge waiting lists
 - meet with Service Providers who provided Life Skill programs and Support Workers to draw up Service Agreements once we managed to get a plan review which took into account that my son was a school leaver
 - we then, despite my son being unwell recovering from surgery, had to organize or attend the various assessments the Service Providers required to compile current Transfer, Mealtime Assistance and Behaviour Management plans.
 - The NDIS should not have been rolled out without a capable IT system, an adequate number of trained frontline and planning staff and resources and information for participants on the processes involved.
- 2. The process of obtaining equipment (Assistive Technology) was much faster and more transparent under Enable.** We waited 12 months for an essential replacement shower chair /commode. This was a combination of an unreasonable and excessive delay in the NDIS approving the chair and a delay in the supplier providing the chair.

3. A lack of Information for Participants

- This is improving but having this information at the time the NDIS was rolling out would have prevented a lot of stress.
- Having said that there is still a lack of detail in the information provided by the NDIS, including the criteria the NDIA use to assess if a participant is eligible for SIL and the precise information that the NDIA require to be submitted in order to assess this eligibility. For self-managers, the recently published Self- Management Guide also does not provide enough detail about what supports can be claimed in different categories and will result, I expect in participants claiming

for items that are not eligible under the scheme or participants missing out on supports that they did not know they could claim.

- As the scheme evolves and changes I do not believe that the NDIA has kept existing participants up to date on changes. I have only just become aware that my son would be eligible for transport funding under his Core supports. This was not the case when he went onto the scheme. One of my son's NDIS goals is to find long term accommodation. When he went onto the scheme I was told to locate a place in a suitable accommodation and provide a quote for the care to the NDIS. Now that we have explored my son's housing options, located a vacancy in a high quality suitable group home, and I wanted to organize a quote, I was recently advised by a new NDIS Planner that my son needed assessments completed to determine if he was eligible for support before a quote could be assessed. Participants should be kept informed as to changes in processes. This assessment has taken a lot of time to organize and complete and could have been done much earlier while we were searching for accommodation. My concern is that he may lose this place due to the time taken to get SIL approved. If he is not approved, I do not know how we will continue to provide the level of support he requires.

4. **Insufficient Oversight of the Scheme**, leaving the scheme very open to fraud.

The newly created NDIS Quality and Safeguards Commission should help address this, however currently, participants who are self- managing their NDIS budget do not need to present invoices or receipts in order to claim back money from the scheme. Participants can potentially claim large amounts of money from the NDIS with only the threat of a possible random audit to deter them. I wish to continue self- management and am concerned that in future this option may cease if others abuse the system. I am also concerned about unscrupulous Service Providers, some who may migrate from other government schemes such as children's' Family Day Care and provide either no service or a very poor service to vulnerable people.

5. **Insufficient Numbers of NDIA Staff to run the NDIS given the Speed of the Rollout**

– As mentioned previously, it is very difficult to access information about the scheme from NDIS staff and they have been poorly trained. I understand the NDIS has taken steps to address this and I cannot comment on the changes. However, I believe the pace of the roll out has also not allowed the staff to perform their jobs at the level that is required to smoothly transition and support participants, who may already be suffering stress and other difficulties, onto the scheme.

6. **Inability to Contact Specific NDIS staff**- when there has been a conversation with a particular staff member and you wish to go back to that person directly to have further discussion about that issue, no direct contact phone numbers are supplied and emails go unanswered.

7. **Long Waiting Lists for quality NDIS registered Speech, Occupational and Physiotherapists**- this has meant that therapy funds in my son's NDIS plan were not used and once we had commenced therapy these funds were lost when his plan was extended for 3 months.

8. No transport for Participants with Severe Disability- this would currently be our biggest difficulty. My son requires transport supported by trained disability staff. I currently provide most of the transport which is preventing me from returning to work. On other days when my son is supported 1:1 by a Support Worker, the Worker transports my son in our wheelchair accessible van. When my son was at school, on the days that I worked the Assisted School Travel Scheme would transport my son either to an After School Care Program or home to a carer or Grandparent so that I could work part time. I understand that prior to the NDIS, typically people with my sons' level of need, would transition from school to day programs and transport would be provided when necessary by many Service Providers. Transport is no longer funded and our experience in our area is that Service Providers who do have transport are tending to provide it only to those who were already clients prior to the roll out of the NDIS.

- Taxis have not worked for my son as his power wheelchair does not fit in all wheelchair accessible taxis making for long waits for a suitable one to be available plus they are not interested in turning up for the short trips he tends to need in our local area. On one occasion our own wheelchair accessible van was at the mechanics. After an evening Church group and a 1 ½ hour wait for a taxi, the Support Worker rang as she had gone well over her booking time and needed to get home to her children. My husband and I had to drive up to pick her up and drop her back to her car while the one of us walked our son home 2 km in the dark making for a very late night and much anxiety for our son as he does not cope well with changes to the routine. When I booked a taxi early on to get my son home from a Day program it again was a 1.5 hour wait and despite notifying Wheelchair Taxis of my son's requirements, the taxi that turned up was not suitable. The driver tried to make the chair fit and jammed my sons feet causing pain. Thankfully I had booked a Support Worker to accompany my son who otherwise would have had no support while he waited and would have had to make the trip in pain and in an unsafe manner. On another occasion, the driver of a wheelchair accessible Taxi told me in earshot of my son that he had a disabled nephew and that 'they', motioning to my son, should not be allowed to live.

- My son would like to live independently with his peers and as mentioned, we are looking into a Group Home. As transport is also not provided by the NDIS for Group Homes, will my son and others like him, be left at home all week socially isolated?

9. Poor Transition of Participants from an Acute Hospital Setting after surgery to the NDIS

- In my son's case, in late 2016 his post- operative outpatient care was provided by a local Community Health Team. Pre- NDIS this therapy team would have provided care for as long as was needed, however once clients commenced an NDIS plan they were only permitted to provide a care for 6 weeks then the NDIS should have taken over. In reality, this took months to. This is an appalling situation and could jeopardize the success of expensive surgery.

10. Initially a Poor Understanding of the Need to Support Families and Carers

- Initially poor funding for Short Term Accommodation Services. My son needed to transition from a Children's Respite Centre to an Adult Centre. After much searching we found a Service who had a vacancy but after commencing some orientation stays, the Service would not take my son on, saying that with the existing funding, they could not support his needs. So while my son had funding for Short Term Accommodation, my husband and I could not get a break when we required it, from this very stressful situation. Other services have closed as participants have not received enough Short Term Accommodation funding in their NDIS plans.

11. **Support Staff not permitted in Hospital** – my son has had multiple hospital admissions since late last year and required support from my husband and myself for much of that time which was exhausting, due to his intellectual disability and severe communication delay. We were unable to get a break as we were advised the NDIS cannot provide Support Workers in hospital. With some support my husband would not have needed to take so much sick leave and I may not have needed to leave my job. Multiple errors were made by hospital staff, some very serious and my son was unable to detect these errors. He needed support from people who were familiar with him. This is an important and overlooked issue as those with intellectual disability have much higher complication rates in hospital.

12. **Inadequate Number of Support Workers skilled in Complex Care so a number of shifts go unfilled**- this is despite that fact that we use 3 different Agencies and live in the Sydney Metro area.

13. A Great Toll has been Taken on my Health and Well Being and on my Job

- For all of the reasons above, dealing with the NDIS has been very stressful and time consuming. English is my first language and I have a high level of education. I was also, I believe, very prepared for supporting my son developing and implementing an NDIS plan having been researching and preparing for the 6 months prior. I was not prepared however, for how poorly the NDIA performed in rolling out the NDIS. I fear for those who due to their personal circumstances, such as English being a second language, being isolated or in poor health, do not have the resources to continually advocate for their need. I believe that the performance of the NDIS will result or has resulted in an inequitable distribution of funding which rather than based on need, may in many circumstances be based on how well participants or their carers can advocate for their needs.

14. **28 days insufficient time to appeal to the AAT**- the NDIS rejected a request to supply my son with a manual wheelchair so that he can access the houses of friends and family, which he cannot do in his power-chair. We had 28 days to appeal to the AAT which my husband intended to do, as I no longer had the resources mentally and physically to do so. However, our son has been repeatedly in hospital and has had multiple surgeries since late last year so my husband missed the deadline. 28 days is insufficient time to apply to the AAT when you are dealing with continuous complex needs and trying to keep someone alive. I had planned to try to stretch our finances to purchase the manual wheelchair for him which we believe is essential but am

unable to do so since I have now had to give up work. I understand that the AAT may be able to extend this deadline in some cases but that is yet another process that we have to go through.

15. We have been waiting since April for a review of NDIS plan- my son has been given a three month extension however, he has run out of AT funds which may be urgently required in case any of his vital equipment breaks down. He was also not given any funds for Short Term Accommodation which we desperately require and we are running out of therapy funds. My son's Support Coordinator has not received answers to his emails from the new NDIS Planner regarding these issues.

16. Lack of Support for Carers

- There is a severe lack of NDIS staff to answer questions and do plan reviews. Trying to save costs on employing more staff is counterproductive due to other costs rising as a result such as:
- poorer health of stressed carers with higher health care costs to the public
- Loss of income for Carers as reduced ability to work- I have now had to give up work to support my son
- Loss of income to employers as Carers will need to take more time off work due to the health plus needing to care for their person with a disability

Summary

- My son is very happy and is living a good 'ordinary' life with much choice but dealing with the NDIA has taken a great toll on my health, my family and my finances.
- In order for my son to keep doing so and for his 'informal supports' to continue to function, a number of changes to the NDIS are needed
- For our son with complex needs, the most immediate priorities are assisted transport, an extremely overdue review of his plan, more detailed written resources, better access to knowledgeable NDIS staff and an approval for SIL.