

**INQUIRY INTO IMPLEMENTATION OF THE NATIONAL  
DISABILITY INSURANCE SCHEME AND THE PROVISION  
OF DISABILITY SERVICES IN NEW SOUTH WALES**

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Partially  
Confidential

## NDIS CUTS AND LOSS OF ACCESS TO DISABILITY SUPPORT

Our family lives in \_\_\_\_\_, NSW, and we have a daughter – \_\_\_\_\_ – who is 18 years old and has Level 2 Autism (low function, moderate intellectual disability).

I am appealing to you to see the failings of the NDIS in ensuring that 'no families will be worse off under the NDIS' – and to also be aware of their ridiculously slow processes and lack of empathy towards carers.

Our plan was cut from \$30,000 in Year 1, to \$15000 in Year 2, with no explanation.

Pre-NDIS - for 10 years, we had accessed wonderful government-subsidised services in the form of:-

- 1) Free Short Term Accommodation (respite) – 1 weekend per month – with ADHC
- 2) Day Activities during school holidays (Samaritans)
- 3) One Saturday per month group activities, centre-based, also subsidised. (Samaritans)

However, we are now half way through our 2<sup>nd</sup> Year with the NDIS – and this is our new reality:-

- 1) Short Term Accommodation funding was slashed from 1 weekend per month, to 4 weekends in total for the year – because it wasn't deemed 'reasonable and necessary'. Try explaining that to your autistic daughter who thrives on routine and stares at the blank calendar, wondering why she can't go to her 'holiday house' with her friends;
- 2) School holiday Day Activities were abruptly cancelled in July 2018 by Samaritans, due to the lack of participants who could afford to attend under their existing NDIS Plans. The provider also cited 'lack of billable admin hours' under the NDIS. Many senior staff have left the disability sector in our region as they can't stand by and watch the families suffer under this failing system. This has left \_\_\_\_\_ with no activities or social interaction with peers during the school holidays, and this has in turn put additional pressures on our family; and
- 3) Saturday monthly group activities have increased in out-of-pocket prices by 50%, and the provider is now adding transport on as an additional cost. We have seen a slow decline in numbers to this activity – and expect it to also be axed this year due to lack of participants.

We are a hardworking, tax paying family who were able to cope with our challenging daughter, due to the wonderful respite and day activities offered pre-NDIS.

Pre-NDIS - we never needed to prove \_\_\_\_\_'s disability and beg for support. We didn't need to verbalise our challenges, answer endless questions about every aspect of her life, and leave our precious girl's access to supports in the hands of a person who hasn't even met her.

Pre-NDIS – enjoyed one weekend per month at short term accommodation. She made friends there and was able to be independent. She often cooked cakes, etc, from scratch – and did things that she won't do at home. We have seen her increase her life skills by watching her peers do things independently.

However – Post NDIS – 'respite' is a dirty word and is seen to be helping the carers – not the participant.

I argue that whilst this is incorrect (it DOES help the participant) – I believe the carers have been the forgotten elements in this post NDIS era and deserve more recognition. We are the 'informal' carers who have already sacrificed so much – from being able to go on a short break, to simply being able to go to the movies with our other kids, or going to a restaurant – all of which are basically impossible with

The respite we'd always enjoyed had been the difference between us functioning as a semi-normal family, and falling apart at the seams. Not getting a break from our special girl will only lead to greater strain on the system, as the time may come that we need to relinquish her 😊

Under the NDIS, we feel like we have to justify our requests for support, beg for money, provide frustrating amounts of extra evidence to show some 'NDIA' agency representative that she has a lifelong disability – and that she's not going to 'get better one day'. Just booking an appointment with a psychologist is a 3 – 6 month epic, and ridiculously expensive (upwards of \$350 to be given a piece of paper to say 'yeah, she's got autism alright'). It's insulting.

The NDIS itself is inefficient and bogged down. On two occasions, staff didn't even know about commonplace disability programs – showing a complete lack of training.

Requests for review of our Plan stayed in the system unanswered for months and months. When the call finally came from the Agency - it was shrouded in secrecy – with no return numbers offered to call them back. It took a week to actually speak to someone from the Agency because they refused to leave a return number.

I know a large network of families in the Hunter Region, all of whom have been negatively affected by the NDIS in some degree.

We are much worse off under the NDIS.