

Submission
No 145

**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

Hi,

I am pleased to at long last that the government is looking into the NDIS. I have good and bad.

Background -My son was diagnosed at 32 years of age with Motor Neurone Disease. This was devastating to a young self employed carpenter who was still playing Rugby Union representing the Illawarra Rugby Team with a 5 year old daughter. He of course had been given a death sentence and told 1-2 years. I am pleased to say he has survived 7 years BUT can only move his head.

The good - when NDIS was introduced what the big, most important thing to my son, was that he could have more carer hours to lessen the load on us his 60+ old parents. Another big plus for him was that he could have carer hours to be able to take him to watch his daughters weekend sporting event, school events and take to the movies. For that alone, it changed his world. He couldn't run or play with his young daughter but at least he could spend enjoyable quality time with her. She is now 12 years of age and I am so thankful that he has been able to have this quality time as I was always scared and sad that she wouldn't remember him. But that is definitely now not the case.

Another good thing from NDIS is that given he cannot move any part of his body except his head he sits in a chair from 8am until 10pm each day. Imagine sitting in a chair for 14 hours every day not being able to move and having nothing to do. But the computer program that he has on his laptop, allows him to type on the pop up keyboard using a small silver disc placed between his eyebrows. This program allows him to email, send message to my mobile if needed, change the tv channel, facebook, turn on and off the air conditioner and as his daughters mum and he live separately, his daughter facetimes him every night to say good night. Without this wonderful program his life would be much much worse. So thanks to NDIS he was able to get an updated laptop a larger tv. NDIS has definitely made his restricted life that little bit more bareable.

The bad - My son moved in with us a couple of years ago and our house was able to accommodate his wheelchair etc. But our bathroom is a 3 way bathroom. This of course did not allow the entrance for a wheelchair. We were able to set him up on his chair in the tiled area in the shower/bathroom using a shower rose on a lead. This set up was suppose to be a stop gap until the room could be made suitable for him. This shower process also had to have 2 carers for an hour and was dangerous as the carer would have to 'walk' him from the bathroom entrance to his chair. His co Ordinator had allowed in his plan for changing the bathroom set up to one big room to accommodate his requirements. We started the process and had all the professionals come and look and drawn up plans etc. When I saw the floor plan and drawings I said that I didn't want railings and I didn't want the taps they recommended etc etc. One of the professionals contacted me that we had to have the railings and the taps etc. I tried to ring NDIS over 5 days waiting for someone to answer the phone. I hung up each day after waiting somewhere between 50 minutes to an hour. I can't remember how long it took before I got a hold of someone but never under a 45 minute wait. I told them that I was enquiring as to why we had waited 3 months for something to say the bathroom reno was approved and to commence getting quotes. I spent the next

half a hour getting transferred to various people. I was promised a return call but of course that never happened. So I wrote a very damning letter to someone in NDIS and told them that this was the last attempt to get some satisfaction before I went to the media. I did eventually get onto someone in Penrith office who was supposed to help. She did get the plans sent to me to get quotes. But the items I said were not required were still part of the plan. I again phoned and was told that my son was disabled and disabled people have to have railings etc etc. I asked if they had reviewed my sons condition and they said yes. I asked that if they reviewed his report and they knew he had MND then why would they insist on railings. They said that as he is disabled I have to have the rails. I then told them not to tell me what my son does and doesn't need as I know fully what he requires and railings and special taps are not one of them. If they bothered to read what MND was about and his file they would have understood that he would not be able to use the rail or the taps. They obviously had employed anyone that could answer a phone as they definitely could not answer any questions. I and a lot of other people using NDIS certainly do not need some young upstart telling them that because their disabled what they need. As I told the person on the phone that just because people are disabled there are different levels so read the persons condition before you speak to people. The wait time for NDIS to approve the review after 12 months. Why would NDIS question his condition after 12 months incase there had been any improvement. Once again, don't know or understand his condition. Don't insult the patient or their family with stupid statements.

When you are dealing with peoples welfare and you have to speak to absolutely stupid people that certainly have no care about their work and not interested in assisting it is extremely frustrating.

As NDIS is using taxpayers money someone needs to take charge and clean up the system. As we were involved with NDIS just after it commenced, it was obvious that the processes were being made up as they went. This was obvious that no one knew anything. This was not only at the junior end of the organisation but also at the top. No one could make a decision or answer any question. Is it the old saying that there are too many on the top and the ones doing the work are at the bottom and have no idea. Well that's certainly how it looks from dealing with NDIS. I can honestly say that I have yet spoken to anyone at NDIS that does what they promise. If you cannot return a persons phone call or promise to look into it then don't say it as people take you on your word especially when you are dealing with their life. Your customer service phone people need training.

I hope that there is a definite investigation into NDIS and that people don't have to waste time on the phone for someone to answer to then be told they don't know and transfer you and the next doesn't know or you get cut off.

But as I said earlier there was the upside that gave my son some pleasure in his life.