

Submission  
No 281

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

**Name:** Ms Helen Julian  
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Partially  
Confidential

The Director  
Portfolio Committee No. 2  
Health and Community Services  
Parliament House  
Macquarie Street, Sydney 2000

Dear Sir/Madam,

Initially the NDIS seemed like a glimmer of hope to me after being in the 'system' with 3 children with disabilities (now adults) for the last 30 years.

I felt that at least two of my children should apply with my daughter needing the most amount of care going 'first'. I thought it may take a while for a 'call up' when the NDIS arrived on the Coast but it didn't, we received a letter saying that my daughter would be seeing a LAC within the next few weeks, so this part was OK).

We had differing opinions/advice of don't see the LAC in your home or don't see them on their turf (their office), parking is difficult where their offices are so we asked if the person could come to us. A woman called arrived at our home and I would have to say that as a mother/advocate for my kids there have been many horrific experiences happen to my family especially my daughter and the visit by this person would have to be up there.

The interview started with opening up her laptop and then saying OK 'Lets get you a job'. Two weeks prior to this my daughter obtained some casual work and for the first time in 15 years she actually had a real job. We explained this to and I added that my daughter would need help to work on skills to ensure that she could maintain this job. slammed down her laptop and said 'well then what am I doing here'. I went into shock thinking that we had done something wrong and my daughter and I then started apologizing to this woman for potentially wasting her time and for the fact that my daughter had a job?

I assumed that she was going to leave when she opened her laptop again and said that she needed to get personal information on my daughter. She stated to us as she was typing away that 'she was typing up information about the family and that she and the government would only be privy to this information and at no stage would we be allowed to see it'. This was astounding to me as we hadn't told her anything at this stage. then cast her eyes around our house and said 'Hmm I guess that you own this house'. I told her no, its housing commission. This answer angered her and she went into some sort of tirade about her mother's story of living in housing commission and how she ( ) was paying \$560 in rent on 'a dump' house (Her words) a few streets away from us. Unbelievably she then demanded to know how much rent did we pay, when I didn't answer that question she implied that I was lying about 'its housing commission' statement.

I then decided not to speak and let my daughter interact with her and at this stage did ask my daughter about her goals. My daughter talked about her needs/struggles and areas she would need help in. Everything my daughter mentioned, stated 'YOU ARE NOT GETTING THAT', but when the question of the travel allowance which my daughter has been getting for years came up when she said 'No' you are definitely NOT getting that and I will be making sure that it gets chopped when I get back to the Office. I had to intervene at this stage and argue that point with her. It fell on deaf ears.

There was one point where [redacted] seemed very interested in 'handing out a lot of funding' and this came from telling my daughter 'I think the best thing for you is to move out of home' and I can give you a lot of funding if you do this. My daughter told her that while she was interested in gaining independent skills, she did not feel confident enough to move out of home just yet. Unbelievably, once again [redacted] started telling us that she had moved out of home at an early age and that it was the best thing she had ever done and that its something everybody does. She then said 'oh well it doesn't matter you are getting a lot of funding for this purpose ANYWAY'.

At this stage, it became clear that things were not going to improve and I only had one question left, which was Is this my daughter's final plan and can it be altered before she signs on the dotted line.

[redacted] told us 'Oh don't worry this is a draft plan ONLY, Im going back to the office to type it all up and you can look at it and make changes as necessary'. I felt some relief when she said this because at that stage I just wanted this woman out of my house.

After two weeks my daughter received a phone call from [redacted] saying 'your FINAL plan is ready and I need you to come in to our office and sign it. We both started getting very anxious about the 'final' word and I stated to my daughter that I can't do this and don't want to deal with this person again. My daughter then sought advice from her friend and advocate for people with disabilities. My daughter's friend became very concerned about what had gone on and insisted on accompanying us to this 'final plan meeting'. Upon arriving at the Gosford office I asked where the toilet was before the meeting started. [redacted] gave directions and then for some reason locked the door, so the meeting began with me pounding on the door trying to get back in and no apology being offered for this action.

My daughter's friend has cerebral palsy and is in a wheelchair, [redacted] seemed agitated that she was in the room. My daughter's friend argued as best she could with some of the NO statements that [redacted] put up but [redacted] shut her down each time and glared at her. I was close to tears at this time and when my daughter looked over at me, my daughter started speaking up and again asked about the travel allowance this is also when my daughter's friend told [redacted] 'you cant take that off her and then explained why. It was like a kettle coming up to the boil because my daughter then asked if she could get a support worker for an interstate work trip. [redacted] flipped out and started throwing files around the desk and jumped up out of her seat again slammed down the nearest file, threw her seat back and said 'I cant handle this, Im going to get my supervisor to answer your 'questions'. The supervisor arrived and [redacted] did seem to calm down but I had already made the decision to appeal my daughter's Plan and once again just wanted to get out of there and apologise to my daughter's friend who had come down from Newcastle and witnessed this fiasco.

After a week of collecting myself I rang the NDIS, explained our situation and asked for an appeal. I was told it would take 6 weeks. Six months later and this was after correspondence with the Ombudsman who only chose to 'monitor the situation' and 2 trips to the NDIS office in Gosford and also true to her word my daughter's travel allowance was cancelled for that 6 months despite her working, we got a review phone call. My daughter spent an hour on the call and I spent 2 hours (very draining) but at least something was going to happen and after a year from the initial meeting funding started coming through.

Unfortunately, my daughter became very ill over a period of four months and didn't use her funding during this time. ~~We started getting phone calls in January this year from the NDIS office in Gosford saying that the Plan was up for review early April and contact was necessary. I was beside myself and was not ready to deal with another debacle. I did seek advice from my daughter's plan co-ordinator that I did not want to go back to St. Vincent's Office in Gosford and she told me, you have no choice, you have to or nothing will get done. But my reality is that when I pass away there~~

is no-one to care for my daughter and she will need outside support so I made the phone call, sadly the receptionist called out my name loudly and I heard the office erupt in laughter. This is because I lodged a detailed written complaint with \_\_\_\_\_ supervisor about her behaviours with the outcome being a vague verbal apology and no written response.

Thankfully another LAC was allotted to us and the Plan meeting was held at the NDIS office and not at St. Vincent's. I really did not want to attend this meeting due to the feeling that what if this new person is friends with \_\_\_\_\_ and are we going to be punished again for speaking up and I'm not ready for another battle. I did attend the meeting to mainly present the medical evidence of the 4 months of not using the funding. I don't have any proof but all I can say is that my daughter's funding for this year was cut by half and I just keep telling myself just be glad that she is still getting any funding and I have conditioned myself not to go through any appeal process again.

In my opinion, this \_\_\_\_\_ should have been sacked over what she did to my family with the on-going implications that my youngest son after watching what his sister and myself went through wants nothing to do with the NDIS despite him needing it the most at his stage in life. Yet, she continues to work there and because she lives in our area, I do see her around with her best death stare proudly given to me.

I also think from 30 years in a nightmare system that the quality of staff attracted or forced into the disability industry is left wanting. \_\_\_\_\_ came from a retail background and trained for such a pivotal position for a whole 8 weeks or this is what she told us. This is not good enough because this approach/ attitude destroys lives.

While the government has thrown money to the disability industry over the years, I don't think anybody has been auditing or asking the right questions about what is happening or accountability. I have approached many organisations for help over the years, where they listen take a lot of personal details and then do nothing. One day I was fed up and told one organization take my information off your database, a person calmly explained to me that we can't do that because we need your information to get our government funding and keep our numbers up.

On paper the NDIS and provision of disability services looks good and even the answer to many problems faced daily by people with a disability but until some kind of vetting of staff i.e. control freaks, bullies, the intimidators, people who think they are doing PWD a favour by just showing up are given their marching orders. Even at an event I attended last week where the new head of the NDIS Safeguards Commission spoke, a PWD spoke up and asked him for a register of people published by the NDIS where people with bad intent/predators/dubious nature could be accessed. Also there is also a lot of misinformation out there about the NDIS and I was told last year by a Disability employment service in Woy Woy that their interpretation of the NDIS was about people having a social life only.

I'm often told it's not the world it's the people in it and so I think this applies to the NDIS and the disability industry. Until the quality of staff and proper training is improved and clear/concise information is distributed, then this fabulous system of the NDIS is always going to be in a 'broken' state. I am aware that this committee does not address individual grievances but I feel that our story and experience of the NDIS (and if I didn't need to I would not go anywhere near it) needs to be told, so feel free to use what I have written or write me off as a nut either way. Thank you for the opportunity.

Helen Julian

6 August 2018