

Submission
No 168

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

Name: Ms Christine Read
Date Received: 8 August 2018

Partially
Confidential

To Whom It May Concern,

My name is Christine Read, feel free to use my name, I am a 52 year old single mother of three special needs adult children and work full time. The implementation of the NDIS has been a disaster. My experience with NDIS has been far and wide. I have had to lodge several complaints. There have been several issues that have come about that shouldn't have come about.

When my children were given their first package it was a great deal larger than what they are allocated two years down the track. I don't understand this though NDIS has given a not accepted explanation which is untrue. I was told that the initial packages were based on what funding they were allocated under ADHC. But that can't be true given that two of my daughters weren't under ADHC in the first place. Even though all three children have more complexed needs now.

I thought the NDIS was supposed to make it easier for carers and participants. It sure as heck is not in the best interest of participants.

Back in 2016 before the NDIS was rolled out we were in the final stages of getting our bathroom renovations approved. We even had a company that was going to pay for it. But then the NDIS was coming out so nothing could be done. Now two years down the track we still don't have a bathroom. Money has been allocated for the bathroom in a previous plan and the current plan. All the documents were submitted back in April but when the girls' plans were reviewed this time I was told that the documents were only lodged on 06.07.2018. Which is totally untrue as I could see the documents attached to one of my daughter's records back in April.

Talking to NDIS staff that have no idea on what they are talking about. I have caught them out several times with wrong information. I have grave concerns for people who are taking NDIS staff at their word as they clearly have no idea what they are talking about.

Getting told that someone will contact you by the end of the day and months later you are still waiting on that call.

Staff doing the wrong thing at plan stage and it takes three months to fix the issue. When we are told that it is a simple fix. Extended version is that my daughter was allocated transport in her previous plan and as stuffed up at plan stage wasn't paid her transport allowance on a fortnightly basis. We had to fight tooth and nail to get the transport money

paid. By the time it was paid she was owed over \$1,000. How is this in the best interest of the participant?

There are no consequences for the staff that do the wrong thing. We don't even get an apology from the person that did the wrong thing. This is our lives that they are dealing with.

Most of the time I am speaking with staff where I know more about NDIS than they do. Go figure

We are not given the whole information at review stage. We offer information that has been gathered and get told that they don't require the documents. We will let you know if we need the documents. Then we are not contacted the plan comes out and the funding is inadequate. Then we are asked why didn't we submit the documents at plan stage? Then we have to go through a review to get the adequate funding.

We submit documents that relate to all three girls for each of their reviews and then after the new plan comes out they tell us that they need individual reports/letters. Why were we told this in the first place? Also this has always been sufficient when specialist converse with doctors and other specialist. Why is it not sufficient for NDIS?

We are required to submit everything in writing. But when it comes to NDIS nothing is put in writing in their responses. They may be held accountable for what they say if they put it in writing. This is double standards.

Also requiring proof for a syndrome that cannot be proved through DNA or blood tests. The syndrome is not tested that way and they won't accept a letter from a professor.

There needs to more work put in to who is hired as NDIS staff. Just because people have worked in the industry doesn't mean that they are any good to deal with carers that are living the life with special needs. Also save the people that can speak more than one language for the people who need it. Don't have people with strong accents on general calls. It doesn't work.

Through dealing with the NDIS I have found that the information required and the way that it is requires changes every review. There has been no consistency since the Scheme went live. This makes it very difficult to know what is needed. Also due to the fact that the staff don't even know what is required and how to interpret the information.

When things don't go right for the NDIS staff they flood us with excuses.

NDIS is only new. Well we have to get used to it so do the staff.

We have a new system. Well get used to it or find another job.

I am sick of hearing excuses on how the staff can't cope with their roles. Please get people that can do the work required. The public shouldn't have to deal with the incompetence of staff in such an important area.

The policies and procedures of the NDIS seem to change from day to day. There is no way for the public to keep track of when things change. We are just expected to know what has changed and abide by the rules.

There is no consistency when dealing with the staff of NDIS. As you are told different things by different staff.

With the old system families has case workers. These case workers were employed by ADHC and they knew all about the family and what the family needed. Now families don't have their own connection with NDIS. And please don't so that is what a coordinator does. That is not correct as our case workers use to know the ins and outs and the goings on of ADHC. Coordinators are not employed by NDIS per say. They are as much in the dark as the families are.

Regards,

Christine