

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

**Name:** Name suppressed  
**Date Received:** 8 August 2018

---

Partially  
Confidential

To whom it may concern,

I would like to make a submission to the enquiry in relation to the *Implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales*.

Myself and my 2 children are NDIS participants, we all have a diagnosis of Autism Spectrum Disorder and Ehlers Danlos Syndrome. We have been involved with the scheme since February 2017. Our experiences have been quite negative, and has involved numerous complaints, appeals and reviews. I hope that by submitting a document to this enquiry which outlines our experiences with NDIS, that it will highlight some of the problems currently within the scheme.

I wish to make this submission *partially confidential*, with my name & any other identifiable details removed.

Thank you

**NDIS PARTICIPANT 1 (ADULT)**

DATE	WHOM	INCIDENT	COMPLAINT RELEVANCE
2.3.17	NDIS employee	I receive a phone call from the NDIS telling me that they had received my application & that I was deemed not eligible. When I asked why, I was told that my condition is not severe enough as I am not disabled enough to require supports. It was further explained to me that to meet the eligibility criteria that I must not only be physically impaired, but also socially and communication. I was also told that because only my shopping and cleaning are affected, I am not severely impacted. There was also a remark made that severe means impacting on driving ability with the implication that that doesn't apply to me.	I was told I am not disabled, yet my reports state that I am. I am told that only my shopping & housework are affected, yet don't consider that those were examples of how my disability affects me. The remark regarding driving is not only incorrect but also unfounded. There was nothing in any of my reports mentioning my driving ability. Yes, I can drive, however I do require the use of assistive technology & physical therapy to support this ability.
4.5.17	NDIS 1800 hotline employee	I request further information about why I was denied access to the NDIS. I am told that there is no note on my file to have the formal letter sent out. I request it. I am told it doesn't contain any further relevant information, and isn't necessary. I ask what I need to do to reapply. I am told that I have 3 months from rejection date to ask for a review of the decision.	I was not notified of the decision review procedures. I did not receive a letter like I was supposed to. My file didn't even contain a note to have a letter sent to me.
30.6.17	NDIS office secretary	I went into the NDIS office. We spoke to the receptionist. She listened to our concerns & after educating us about our choices and our rights, she advised us on what to do next. This being a complaint regarding the interactions & communication between NDIS employees and ourselves, and to also do a review of my son's review. She then further advised us on how to reapply for myself & my youngest son & how to put in a complaint regarding our ineligibility for NDIS.	We got more help & assistance in this 1 interaction as opposed to almost 6 months of interactions with various NDIS employees.
21.7.18		I submit a complaint regarding my experiences with the NDIS. I also reapply for the scheme and was accepted.	
15.9.17	LAC office	I go to the office, for my plan handover meeting for my first NDIS plan after complaining & reapplying as a participant. During my plan handover meeting, the LAC's supervisor came into the room with the aim of educating me about what reports I needed to get for a plan review. I had already been in the meeting for 30 minutes, and by this time, I was quite overwhelmed not only because of how hard this entire journey has been, but also due to the mess of a plan, I had just received, of which the LAC was unable to assist with. I was crying and my anxiety was quite high and I was going into shutdown mode. Rather than show some compassion when she could clearly see that I was in distress, she proceeded to completely invalidate me, by hastily sitting down in front of me, then to take out her hearing aids, throw them on the table in front of me and introduced herself with "look it's really not that bad, I'm disabled too, so I know how you feel". During all communication with this supervisor, at every pause the supervisor gave during her 'assistance', she would repeatedly ask me 'do you understand?', "am I making sense?". And despite me trying my hardest to answer each time with 'yes, but I am just quite overwhelmed", she still continued to question my ability to understand. I was then accused by the supervisor of asking for too much therapy/supports and that by me engaging in my required supports, I would be neglecting my role as a parent & carer. When the meeting was finished, I was on my way out the door, when the supervisor told me to "cheer	The comment that I was asking for too much & insinuation that I am neglecting my children is a disgrace.

		up". I simply replied "yea" with a fake smile, in the hopes, she would leave me alone and let me go home. Instead she stops me prevents me from leaving the room, and proceeds to almost throws herself and her open arms at me and practically forces me into a hug, a hug I really did not want. But because by this time I was in shutdown mode & barely functioning physically or cognitively, I allowed it by feeling trapped/forced to return the gesture in the hopes of being allowed to go home.	
18.9.17	NDIS 1800 hotline employee	I rang because I am unable to activate my plan on the portal. He put through a request & told me to wait til a letter arrives, then to ring back & they will activate my plan.	I was not given the proper activation codes to enable me to link my own plan to my MYGOV account.
26.9.17	NDIS employee	Rang & informed me that I need to have my physio fill out an assistive technology form to enable me to have the assistive technology part of my plan reviewed. They told me my plan won't be reviewed til I get this form. They told me that they aren't concerned with the other issues, just the assistive technology.	They argued with me that my physiotherapist could not order braces for me. This is misinformation. The fact that they are not concerned by the other issues in my review is concerning. The issues range from inadequate budgets to misplaced supports.
24.10.17	NDIS 1800 hotline employee	I rang because I still could not gain access to the portal. They informed me, that a request still had not even been sent away for approval. I could then only access my portal & my youngest sons portal. My eldest sons had been removed. It was finally resolved 2 days later.	
13.9.17		I requested an unscheduled plan review, the planner was fantastic & the outcome of this review has meant that I have had a sufficient plan since March 2018. I have not had contact with the NDIS since.	

### NDIS (ECEI) PARTICIPANT 2 (CHILD)

<u>DATE</u>	<u>WHOM</u>	<u>INCIDENT</u>	<u>COMPLAINT RELEVANCE</u>
2.3.17	NDIS employee	I receive a phone call from the NDIS telling me that they had received my son's application & that he was deemed not eligible. When I asked why, I was told that his condition is not permanent. When I tried to argue that it is a genetic condition that he was born with, I was told it is not permanent, because the OT report states he would benefit from 'a block' of Occupational Therapy.	You have employees assessing these applications who do not understand the definition of genetic. His application included genetic assessments which confirm his diagnosis of a genetic condition. Yet your employees who assessed the application clearly dismissed this report when deciding that his condition is not permanent. These same employees also obviously have no understanding of how Occupational Therapy works. Most therapists work in blocks which usually coincides with school terms. They cannot give an exact time frame of required therapy, as they are regularly assessing the child's progress. The sentence in the Occupational Therapists report was read too literally.
4.5.17	NDIS 1800 hotline employee	I request further information about why my son was denied access to the NDIS. I am told that there is no note on his file to have the formal letter sent out. I request it. I am told it doesn't contain any further relevant information, and isn't necessary. I ask what I need to do to reapply for him. I am told that I have 3 months from rejection date to ask for a review of the decision.	I was not notified of the decision review procedures. By the time I was notified of review procedures, I only had 4 weeks to organise further reports, which is not enough time. I did not receive a letter like I was supposed to. His file didn't even contain a note to have a letter sent to me.
30.6.17	NDIS office secretary	I went into the NDIS office. We spoke to the receptionist. She listened to our concerns & after educating us about our choices and our rights,	We got more help & assistance in this 1 interaction as opposed to

		she advised us on what to do next. This being a complaint regarding the interactions & communication between NDIS employees and ourselves, and to also do a review of my son's review. She then further advised us on how to reapply for myself & my youngest son & how to put in a complaint regarding our ineligibility for NDIS.	almost 6 months of interactions with various NDIS employees.
3.8.18		I submit a complaint and reapply for my youngest son. He was later accepted into the ECEI scheme in November 2017, and received a plan in February 2018. I have not had further contact with the NDIS.	
NDIS PARTICIPANT 3 (CHILD)			
DATE	WHOM	INCIDENT	COMPLAINT RELEVANCE
21.3.17	LAC & NDIS	We were notified that on his application that his genetic condition had been left out of the application.	His application had been altered to not include his genetic condition which does disable him
21.3.17	LAC	At this planning meeting, I specifically asked for SELF MANAGED, due to being educated regarding the plan types, payment & judged this as being the best for our situation. I was pressured by the LAC to not choose to self-manage, because I would be required to pay for every service up front. There was also the insinuation that it is <i>too time consuming, &amp; too difficult, &amp; with my disability &amp; having 2 children with disabilities, I probably won't be able to do it</i> . I then asked what were the other types. She told me there were 2 other types, NDIS managed or agency managed (her words). I reminded her that I needed to access unregistered providers, because one of my son's therapists is unregistered. She explained that if I chose agency managed, I didn't have to pay upfront, and could still use unregistered. So, feeling pressured we went with that, thinking it was the next best solution to get what we want.	I was given misinformation regarding how to pay for services using Self-Managed plans. I was pressured to choose a plan type I did not want, based on someone's opinion on the difficulty of self-management in relation to mine & my children's disabilities.
13.4.17	LAC	We have a meeting with the LAC. She discusses our plan & gives me my login details for the portal. She tells me which items numbers are for each of his therapists. And confirms that we are 'plan managed' & able to use unregistered providers. I then realise that I cannot use one of my son's therapist because of the item number they had assigned to her. He is also unable to access exercise physiology in this particular plan. There were also numerous other issues with the plan, so I asked her how to do a review. She advises me to go home & think about it more first. She then tried to advise us against doing a review unless it is extremely necessary, because it can take months to be processed, and we need to start accessing services, so we were under the assumption that we would have no funding during the review period. She told me to email her any questions.	We were misinformed about review processes. Given false information about his plan type. The planning process & his plan did not reflect his needs. Advised we could not use his funding if we reviewed.
18.4.17	LAC	After reviewing the plan & speaking to his therapists, I then emailed the LAC as asked & after no contact from her, I text her again on the 26 <sup>th</sup> .	Lack of communication and assistance from LAC
1.5.17	LAC	I receive a call advising me that she cannot answer my queries and that the planner advises we do a review. She tells me she will email me information on how to do a review.	Lack of assistance from LAC
2.5.17	LAC	I receive the information regarding a review. Basically, she just copied and pasted my email into the review form. I was then told to email it. She emails me this information from a different email.	She used the wrong form to do the review. The review was of poor quality & again contains information that was due to misinformation on her part.
3.5.17	LAC	I add some extra information to the completed review form, to make it more understandable. At this point, I was still under the impression that we	I had not been made aware of our actual plan type. The information given from our LAC was that we

		were plan managed & could still use unregistered providers, thus why I did not request that we be Self-Managed & instead only requested that his unregistered provider's item number be changed.	were plan managed, when in fact we were agency managed.
4.5.17	NDIS 1800 hotline operator	I rang NDIS 1800 number, they told me that the only way to use unregistered is to self-manage. I told her I was unable to do this plan type, because the information I had been given from NDIS previously was that I would have to pay upfront. She told me that this information is incorrect & instead reconfirmed the information which I had been given prior to planning meeting. This is the same information that I was using to inform my decision to self-manage in the first place.	Misinformation regarding using unregistered providers & plan types.
5.5.17		After again getting advice from therapists, and taking into account the information given from NDIS employees & through my research, I then did a whole new review & submitted.	
16.5.17	NDIS employee	An NDIS employee rings & tells me she has been assigned the review case, but cannot find it on his file. I resend it to her.	Important files are not in his file
May ??	NDIS employee	I then received another call from the review employee, she wanted clarification on what exactly I wanted. I specifically stated that I wanted Self-managed. She then explained to me that if I do that, I will have to pay for everything up front. I then went on to state that the information I had was that I only had to pay upfront for unregistered providers, which would not be a problem, as only 1 of his providers is unregistered. She told me that my best option because I cannot pay upfront for everyone, was to go with a plan management agency. I further specifically stated that he needs to also access exercise physiology.	I was given misinformation regarding plan types. And again pressured into choosing a plan type.
20.6.17	NDIS	I receive the plan. I am unsure of how to begin using the plan.	There was no phone calls or letters from NDIS nor an LAC, to explain his plan & how to implement it.
21.6.17	NDIS 1800 hotline operator	I ring the NDIS 1800 number. The operator tells me that the plan is ready to use & that because all of it is plan managed, I can use unregistered providers. He tells me that when I use unregistered providers, all I need to do is upload the invoice and I will be reimbursed.	I was given misinformation regarding his plan type, use of his plan, and also that the plan was ready to be used from receipt of plan. Operator doesn't advise me that we need to find a plan management agency.
28.6.17		I receive invoices for some therapy sessions, and I attempt to upload them, which was unsuccessful.	I was given misinformation regarding my ability to claim for services.
28.6.17	NDIS 1800 hotline operator	I ring the NDIS 1800 number and the operator tells me she has no idea how to fix the problem.	Operators who are unable to assist clients. Operator doesn't even advise me that because we are plan managed that I cannot claim personally.
29.6.17	NDIS 1800 hotline number	I ring the NDIS 1800 number, they advise me on the phone, that with the management type of his plan, that we cannot use unregistered providers, because we are not self-managed. She then further told me that we most likely will be unable to do a review, because we have not used any of the funding since the first plan.	I am given misinformation regarding his allocated plan type, use of unregistered providers & the review process & eligibility.
29.6.17	NDIS 1800 hotline number	One of our supports, rang NDIS around 12pm, and with our permission asked for a plan review to make our plan self-managed. Which was granted. They then told her on the phone that our plan is both NDIS & plan managed.	No record of this phone call on the database. No record of this review request. Inconsistent information given regarding plan type.
30.6.17	NDIS office secretary	I went into the NDIS office. We spoke to the receptionist, who advised us that the phone conversation in the 29th June was not logged. She listened to our concerns & after educating us about our plan, our choices and our rights, she advised us on what to do next. This being a complaint	We got more help & assistance in this 1 interaction as opposed to almost 6 months of interactions with various NDIS employees. The information gained during this interaction has meant that I am

		<p>regarding the interactions &amp; communication between NDIS employees and ourselves, and to also do a review of my son's review. She then further advised us on how to reapply for myself &amp; my youngest son &amp; how to put in a complaint regarding our ineligibility for NDIS.</p>	<p>aware that as well as the above complaints, the following is also complaint worthy:</p> <ul style="list-style-type: none"> <li>• no one assisted us with implementing this review, we were unaware that we had to find a planning agency.</li> <li>• we should have been allocated someone to assist us with enquires</li> <li>• we should have been notified of our exact plan type</li> <li>• the exact way that self-managed plans work are exactly how I thought they worked. However, for the past 6 months or so, I have been led to believe that what I thought was true was wrong, and so was pressured into choosing plan types I didn't want.</li> </ul>
12.7.17		<p>I submit a complaint. I also submit an updated review. I DID NOT ask for any further funding for supports. I simply asked for some of the money to be taken from one budget &amp; put into an addition budget, so he could access his exercise physiologist. I however did include support coordination, after receiving information from the NDIS that we were entitled to it, regardless of whether we wanted it or not. I again requested that the plan type be self-managed. I also request support coordination, due to needing a point of call for NDIS related stuff, due to all the hassles &amp; misinformation received from NDIS staff. I also requested that the core supports budget of \$1200 and the AT budget of \$1750 stay.</p>	
16.08.17		<p>We meet with planner &amp; redo his plan. I submit numerous subsequent supporting reports from his various therapists.</p>	
4.10.18		<p>Planner rings, and confirms that his plan has been approved. He confirms that he has approved funding for exercise physiology, support coordination &amp; we are self managed like we asked in the review.</p> <p>I check the plan online &amp; see that support coordination hasn't been approved, and that his <i>CB Daily living</i> budget has been slashed by \$8640.33. Core supports has been reduced by \$179.</p>	<p>His funding was slashed, with no justification. All I asked for was some money to be taken from one budget and put into another. So now there is not enough.</p> <p>The goals we requested were not put in the plan.</p> <p>1 of the longer term goals are inaccessible, as there was no funding to even work towards these goals.</p>
6.5.18		<p>I submit another complaint. I also submit another review notifying the NDIS that because of their cuts to his funding, he was almost out of funding, which would mean he would then have to go without for 5 months before his scheduled plan review.</p>	<p>No follow up</p>
12.6.18		<p>My son attends his last exercise physiology session. With his other therapies already ceased due to no funding.</p>	
8.8.18		<p>I have not heard from the NDIS regarding this complaint or the review dated 6.5.18. My son still continues to be without therapy and his plan does not end for another 2 months.</p>	