

**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

When the NDIS was first launched on the NSW Central Coast, my youngest daughter was automatically taken into the system quickly, easily and efficiently. Her first plan was very broad and generous, covering everything the planner felt she would need.

Our experience in trying to find service providers, however, was difficult and frustrating. When we did find a provider, they would promise to provide all sorts of amazing services, and then fail to deliver the service they promised. Between the incorrect services and difficulty in finding appropriate providers, it was difficult to receive services and use her funding.

By the time we had her second planning meeting, the rules and parameters had changed, and I had to learn everything all over again. It has remained difficult to find appropriate services for her, even though there are more available, and the services that we have chosen are so high in demand that there are long wait times for appointments. It feels like there are disability services popping up all over the place now, and it is immensely frustrating when they promise you the world, but cannot deliver on the services they promise. It feels like a cash-grab in this new lucrative market.

We are relatively new to the world of disability funding, and I feel like I am ten steps behind those who had funding under the old system as I start from scratch, not even knowing which services I should be seeking.

Thankfully we have an excellent disabilities expo locally once per year, and the organiser is extremely knowledgeable about the disability service industry. I do know that when I go in for our next planning meeting, that everything I thought I knew will have changed, and I will have to learn it all again. I appreciate that the NDIS is still in its infancy, but it's frustrating when the boundaries and rules are constantly changing.

My second experience in applying for NDIS assessment for my oldest daughter was incredibly frustrating, and should never have happened. I called, and spent 45 minutes on the phone with an NDIA employee, who assured me that application paperwork would be posted out to me, but it would take some time. Many people told me that I shouldn't even bother to chase it up for three months, because that's how long it was taking. Five months later I could not wait any longer, so I called again. This NDIA employee emailed me the form immediately, and could not give me a reason why that couldn't have been done five months previously. By this time, the rules had changed, and an old diagnosis wasn't good enough for the application. I simply could not afford the \$1,000 price tag that comes with a fresh autism diagnosis, and given that there is no cure for autism, I don't understand why a second diagnosis was required.

My daughter is 19 years old, and so cannot be diagnosed under the care of a paediatrician any more. I admit ... I gave up before I finished the paperwork. The system is not easy for an adult with autism to get into without a significant financial outlay, and that feels very wrong to me.

Everybody I meet who is working through the NDIS is exhausted by the confusion caused by constant parameter changes and the sheer daunting task of the time, resources and frustration of the application process ... some don't even apply, and struggle on alone.

Make it consistent, remember that autism is a spectrum and there is no cure, so please don't make us prove it over and over again.