

**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

I accessed the NDIS for both of my children with ASD (as well as other diagnosed disabilities). After waiting more than a year following the approval to access NDIS, I was finally given a planning meeting. During the planning meeting, I was very disheartened to learn that everything I explained I needed for my children was something that I should be doing as a parent. I do everything for my children, I was paying \$300 per week out of pocket for therapy, had them in swimming and Scouts, attempted to engage them in other social activities that were unsuccessful. I was actually worse off financially by working full-time (no access to Family tax benefit, childcare benefit etc), but as I explained, work was my respite. Apparently that is perfectly acceptable for the NDIS. So we got approved for coverage for speech, psych and O/T for a third of the year. I am still struggling financially to pay for the rest of the year. We were denied access to respite because despite having no support network, NDIS thinks the children's ages (7 and 5) mean that Mummy and Daddy need to be there 24/7. We were denied access to support with domestic duties which I requested because I cannot physically maintain my household and cook etc with my children having meltdowns triggered by the smell and sounds of the equipment and destroying my house as I clean it, because NDIS said it is the children with the disability not the parents, therefore we should do our job as parents. I was denied financial support for social and community involvement because I already do this at my own expense (which I cannot afford but have to because my children need it and I cannot get assistance with it!!). I was denied coverage for the resources my children need (e.g. weighted blankets, iPad apps, CalmFit Clothing, chew toys etc) because these didn't come under the correct classification like a wheelchair would. My husband and I have our own health issues and no support network, and NDIS did not care about that at all. I guess NDIS will wait till parents get to breaking point and the worst happens before they ever take notice. Not to mention the fact that if you select provider managed, you can't change it and when things go wrong, you can't intervene or redirect anything. Such a ridiculous system. I wish I could just go back to FASCHIA but unfortunately that was phased out prior to us being able to access it.