Submission
No 73

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

Name: Name suppressed

Date Received: 13 July 2018

Our experience:

Our daughter, 10 years old, was diagnosed last year with Autism Spectrum Disorder, level 3. The diagnosing doctor informed us that in order to access the NDIS, we needed to work with an external agency who would guide us through the process, and who would guide the doctor on how to set out the reports including what information to include, that the NDIS would need. Our doctor advised us that in his experience, anyone who had applied for the NDIS without using an external agency had been rejected, regardless of diagnosis or level.

We completed the Access Request form, with advice from our daughter's doctor, and submitted it in January 2018. We heard nothing until May 2018, when we received a letter advising further information was needed, which we provided within 7 days. During this time we attempted to make contact with the external agency, but due to how busy they are, we were unable to speak with them to get guidance on what information was needed.

A month later I received a call from an NDIS assessor advising me that my daughter was not eligible for the NDIS. The reason given was that the doctor's report did not include all of the supports our daughter would need. Our doctor was not aware that this is what he needed to put in the report, as he relied heavily on the external agency to guide him, and this agency was not returning our calls.

We have since appealed this decision and are currently awaiting the outcome. We have sporadic contact with the external agency, who often does not return our calls or emails. We have found this process to be extremely stressful and frustrating.

Key Issues:

- Advice given to us that we are required to use an external agency in order to be accepted into the NDIS. This has been our experience also. This is extremely problematic for people who either are unaware these agencies even exist, or who are attempting to use these agencies but are not being supported due to their lack of capacity to help in a timely manner.
- The idea that external agencies have "inside information" regarding what the differing supports the NDIS offers and what needs to be done in order to have an NDIS application approved.
- Length of the process. The longer the process takes, the longer it is before appropriate supports can be put in place for those living with disabilities. This is especially frustrating and stressful as a parent, who daily is seeing her child struggling with life, and in desperate need of support.
- A key goal of the NDIS is accessibility of early intervention supports for children. It is incredible that a child with a diagnosis of Autism Spectrum Disorder, Level 3, could be knocked back for any reason. The fact that our child was knocked back due to a broken system where doctors do not know how to write appropriate reports, external agencies are simply not able to meet demand, that to be successful with the NDIS you need to have inside knowledge, means that our daughter and others like her, are not receiving the early intervention supports that would make a huge difference in their lives.

- According to the NDIS access criteria, those that have a diagnosis of Autism Spectrum Disorder of level 2 or 3 should be able to access the scheme. Why is it, that the scheme is accepting some with this diagnosis but not others?
- The flow on effect – the longer it takes for people with disabilities to be supported by the NDIS, the more the load is shifted to other areas such as health. The longer my husband and I support our daughter alone, the higher our stress is, often causing sickness. The NDIS assessor advised me that psychology is considered a health issue, not an issue for NDIS, even though psychology is needed due to negative behaviors associated with Autism.