

**Submission
No 127**

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

Name: Dr Sushil Anand

Date Received: 19 July 2018

Dear Honorable Members of Parliament and the NDIS management,

Thank you for the opportunity to express our opinion and feedback regarding the NDIS.

Firstly, I would like to congratulate everyone who was involved in the designing and launch of the NDIS. This is an important step in securing the future of people with disabilities, and it's fantastic to see a coordinated government approach. However, the implementation of the scheme has fallen well short of our initial expectations and excitement.

My 28-year-old daughter has Epilepsy, Autism and is severely intellectually handicapped. She is on 5 different medications for controlling her epilepsy and aggressive/violent behaviours and requires 24/7 care and supervision. Her complex and very challenging behaviours have led to serious injuries to herself and our family, including a leg fracture which required major surgery. This has all occurred despite her being on several medications and having gone through multiple behavioural intervention strategies. At home, we have to provide her 2:1 care to keep her and the family safe. To this end, my wife had to leave her job several years ago and my workload is limited to a few hours per week. For several years, our daughter has been on the waiting list for a group home, but without any success.

Prior to the NDIS, our daughter was receiving an IASP package. We were on the verge of abandoning our daughter's care to the state, but ADHC was kind enough to provide a package to care for her at home. When the NDIS was launched, we were very excited to hear that no one would be worse off under the scheme, but then received the letter regarding her package. We were dismayed to learn that the NDIS package was less than half of the IASP package.

After spending a lot of time collecting supporting evidence, we lodged an appeal, and despite several follow-ups, no time frame was provided for a resolution. It took 3 months of following up before the appeal was successfully resolved and her package was reinstated to the pre-NDIS level.

At the time of the next review, we had to go through the same process again. We submitted many supporting documents, to the extent of uploading approximately 100 pictures and videos of our daughter's behaviours, the injuries caused and the resulting damage. But, upon meeting the NDIA assessor we were disappointed to find that they had no idea about our daughter's condition and it appeared that they had not even gone through any of the submitted documents.

To exacerbate the situation, the new budget was again cut down to less than half of the previous year's budget. We called the assessor, who assured us that he would review our submission again. However, after another month of phone calls and emails, there seemed to be no option but to lodge an appeal, leading to another time-consuming process of submitting more documents. This time, it took more than 5 months of follow-ups before the appeal was heard. After spending over an hour explaining the situation to a new assessor, the budget was increased but still short of the previous year. But, during the 5 months of waiting, we exhausted the allocated funds to maintain her care and have an outstanding invoice of approx. \$12,000 to be paid out of our pocket.

Please try to imagine the physical, emotional and financial toll it takes to care for a person with such a complex medical history and disability, and the cost to our family's wellbeing is only exaggerated when we have to constantly chase the NDIS for applications, appeals and funding.

Therefore, we recommend the following options to improve the NDIS offering:

- 1) Employ more staff, and provide proper training to them;
- 2) Resolve appeals in a timely manner (4 weeks is a reasonable time, but 5 months is too long);
- 3) Provide a timeline for the appeals process, including an estimated time for the outcome;

- 4) Assess each application for its own requirements, instead of using fixed templates that may not take into account the applicant's full medical history;
- 5) Improve the IT system. We attended the recently held Q&A program (ABC TV) where it was highlighted that the NDIS IT system is dependent on Centrelink, and this is causing issues for applicants, their families and staff;
- 6) Review the allocated spending to ensure that emphasis is being placed on supporting the people in need, rather than showing a surplus on the budget. We have learnt that last year's spending was \$800m below budget and the current year is approx. \$1.3b below budget. Please review this so that the funds can be spent as per the purpose of the NDIS, and to improve the quality of the service delivery.

Thank you for your time. Please feel free to contact me if you have any queries about our experience with the NDIS or the above recommendations.

Many thanks,
Sushil Anand