

30th October 2022

NDIS General Issues Inquiry:

The committee is seeking information about the implementation, performance, governance, administration and expenditure of the NDIS.

To Whom It May Concern,

My name is Jody Lindsay and I am a mother to two boys, both with disabilities and both access NDIS funding. My elder son has been accessing NDIS funding since it came in many years ago. Having so much involvement with NDIS with two sons has been, at times, difficult and cumbersome.

Administration:

The nature of my children's disabilities are not going to change over a period of one year. Asking for an updated OT assessment every year is wasting valuable funds and precious OT time in reassessing for the same report. And even then, when the report is submitted to NDIS, often the report is out of date because it is not viewed in a timely manner, and the planner again asks for an updated report. It would be beneficial to push this updated OT report out to once every 5 years if the nature of the disability shows minimal change. If it does change, then clients/carers can put through a change of circumstance form and request the supports required. Different age ranges would deem different categories. Toddlers and younger children could show changes within 2 years, whereas adults may plateau and remain very similar for a number of years. Reports are necessary when funding amounts of money, however, asking for resubmission because they did not get to the file in time is wasteful.

Administration of NDIS lacks transparency. There are no clear procedures, and if there are, they do not associate time. This is not accountability. Parents/carers/organisations need to know how long submissions are going to take, how long the wait is so equipment, supports can be appropriately placed while waiting. One example of my own includes:

Waiting for a 'review' of my son's SIL funding from the Home and Living Team. My older son has been transitioning to his first home (supported home with similar-aged, young males). He already had SIL funding in his package due to his long-term goal of seeking the right accommodation for his needs, however it was taking over 5 weeks to get a response. The NDIS Call Centre could not give any information as to where this review was up to, so I had to make a complaint through MP Bill Shorten's Office. This took three phone calls within three weeks to speak to a person from NDIS regarding my complaint. In doing so, the Complaints Officer read through the notes, and then told me it was with the Home and Living team (which I already knew); he then told me that he would inform me of the outcome when it came through, was this fair and reasonable? In which my reply, was 'no, this is not fair and reasonable'. I discussed with him that he has not told me anymore information than what I knew 7 weeks ago, and gave examples of the information such as where is it – is it in a queue, is it with a specific person reviewing it; has it been approved? He then tried to clarify in which he then told me that it had been approved and had to be approved and signed off by the senior delegate, this usually takes about 2 days.

This is only one example of how the administration is not transparent and forthcoming with information. There are many other examples, and not just my own, but in many discussions with parents/carers who wait for information and clarity.

I have made many complaints regarding Behaviour Support funding and how providers gauge this money without providing in-home interventions. And again, I am not the only parent who has had these same problems. My son has received Behaviour Support funding for the last 5 years, however, he has not been assisted in anyway except to have a 40 page behaviour support plan each time. I made a complaint to the Commission regarding the last provider, and I have not had a response from them regarding it (and it was very detailed, outlining the faults and problems with it), and it has now been 5 months.

I am a special needs teacher who has a Masters in Behaviour and proud to teach in the state school system. I have experience with Behaviour Support plan writing and providing interventions, it is frustrating to see that providers spend 20 to 30 hours writing these reports and not administering interventions in the home. I understand that this is not all providers, however the last four that we have had, have all done the same and no provider has come into the home to assist in implementing the plan.

I believe the fault lies in the policy for Behaviour Support. The policy should indicate the amount of hours required to write the plan (max 15 hours) with a specific allocation for 1:1 implementation (eg minimum of 5 hours) in specified settings (whether it be at home, community, school, care program etc). Only then will behaviours be supported. If the provider requires more funding to finish the report, they need to submit reasoning as to why they need more hours (such as complex cases).

Expenditure

With changes to the behaviour supports policies, and requirements of OT reports yearly will have a direct impact on expenditure within the NDIS federal budget. There are many other small changes that could be made that would benefit the entire budget.

The view exists among carers/parents that if you do not spend it, the next year the funding will be less, and this is not the view that should exist with the NDIS. There are many valid reasons as to why families, carers, clients are unable to use all of their budget, and these should be taken into account. This perception needs to change amongst carers/parents and that what is not spent is simply rolled over into the next year's budget, or rolled back into the NDIS budget if not required.

My son has complex needs, and will require 1:1 support for the rest of his life. He is unable to care for himself, he has physical and intellectual disabilities as well as permanently blind in one eye and minimal sight in the other. He is a lovely young man who enjoys the social life of being with other people. His reports are comprehensive and outline his disabilities and what supports he needs in all areas. Yet, when his plan is approved, it seems that his necessary supports are not covered. And this is the same story amongst many parents/carers.

The original idea of the NDIS was to have a planner that would know the family and continue the journey with that family, so supports were adequate and the need of the client was being met by the funding. This would eliminate the need for repeated documentation (that planners and NDIS workers do not read, therefore do not understand the needs of the client) and cut down on funding that is not necessary. As an example, *I had a planner who tried to tell us that my son did not need a dedicated communication device (although she did not know my son and did not read the Speech therapist report) and that for \$500 he could purchase a device that would read to him. This just showed the person's lack of understanding about my child's disability, therefore*

contributing to decisions about budgets and denying amounts that are fair and reasonable. And I know that there are many other stories that are similar.

Governance:

The NDIS Call Centre is really good when you have general enquires, however, if there are questions or concerns or you are seeking specific information, then they are unable to assist.

Concerns arise when you (as a parent/carer) are contacted by a specific person from the NDIS and you miss the call. There is never a number to return that call, or even an email address. It is difficult to organise that phone call again, and it sometimes takes a week to receive it again. The Call Centre emails specific people regarding your concern, and you might be lucky to hear anything about it. This is very frustrating for parents/carers. I worry for the clients with a disability who are trying to get answers for their concerns and they do not have the knowledge or understanding to try and find the answers they seek.

The Call Centre seems to be the face of NDIS, and only that. Effective communication is key for all stakeholders, therefore there should be a variety of numbers to call for answers, depending on the nature of the enquiry. The Call Centre should be able to put the call through to specific areas for answers to questions and concerns, eg Home and Living Team; Planning Team, New Submissions Team etc; specialist, helpful people who understand the nature of the phone call.

Performance:

Over the years of completing NDIS plans with planners, it has become evident of the vast differences of their understanding of disabilities. It has proven that some planners have not read the reports prior to the planning meeting, asking for documents that have already been submitted and poor organisational skills. Although my two sons have the same disability, there is a large discrepancy between the funding amounts. The only difference between the two disabilities is that my younger son can walk independently (although he has many falls and is unstable and is able to toilet himself during the day (with support)). There are many differences in funding amounts and it is very clear which planners have that understanding while others do not. Although there are individualised plans, there needs to be equity among the level of disabilities and funding, so other clients are not disadvantaged by lack of funding due to limited understanding of their disability. There needs to be ongoing training and parameters set so there is a funding baseline for disabilities that meet the need of the client.

I am available to discuss my submission and I can be contacted on the following details below.

Thank you for taking the time to read my submission.

Kind regards

Jody Lindsay

Parent of two children with disabilities on the NDIS