

Submission
No 344

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

Name: Name suppressed
Date Received: 9 August 2018

Partially
Confidential

SUBMISSION TO PARLIAMENTARY INQUIRY

I wish to make this submission partially confidential.

My name is

I make this submission as the parent of a person with a disability.

My daughter is 28 and lives with us at home. She has Down Syndrome, with limited decision-making ability, some heart and thyroid problems along with scoliosis. She requires 24-hour support.

I am also the carer for my husband, so now caring for two people.

In this submission I will discuss the following issues, as noted in the Inquiry's written Terms of Reference:

- The implementation of the National Disability Insurance Scheme (NDIS) and its success or otherwise in providing choice and control for people with disability,
- The experience of people with complex care and support needs in developing, enacting and reviewing NDIS plans,
- The effectiveness and impact of privatising government-run disability services,
- The provision of support services, including accommodation services, for people with disability regardless of whether they are eligible to participate in the NDIS,
- The adequacy of current regulations and oversight mechanisms in relation to disability service providers,
- Workforce issues impacting on the delivery of disability services,
- Policies, regulation or oversight mechanisms that could improve the provision and accessibility of disability services across NSW, and
- Any other related matter.

Before I detail my family's direct experience of the NDIS, I would like to make the following general comments:

What is going right

I believe the NDIS is a good concept and my daughter has received an adequate funding package. However, the implementation of the scheme needs to be friendlier, more easily accessible for families, with less stress on families, doctors, therapists, etc regarding the extreme levels of documentation required constantly.

What is going wrong

We have found that the NDIS is not always responsive to families with language and specific cultural requirements. For example, my birth language is Maltese and it would be much easier for me to understand the complexities of the NDIS if someone would speak to me in that language.

It would be useful if we were able to have a family friend as an alternate nominee for my daughter. Her father is no longer able to act as nominee, I am ageing and there are no extended family members able to assist with this. The friend I had requested to be a nominee, is ineligible under the NDIS as she is already nominee for her son and another person. It is disappointing that the NDIS will not allow us to have this person as a nominee for our daughter as a safeguard for the future.

The annual review system is overly complex, and it should be unnecessary for us to constantly repeat all the information we have already provided. My daughter's situation will not improve as she ages, and the current system means we must gather reports from doctors, service providers, therapists and specialists every year. It would be easier for everyone (including the NDIS) if we only had to report changes in her circumstances when needed.

What could be done about it

The NDIS has a thorough initial assessment process that should be used for annual reviews. This would mean we do not have to continually repeat our daughter's story repeatedly every year, which is a distressing process for us. Also, our doctors, therapists, specialists and service providers need to provide reports every year, which puts great strain on their time which could be better used, and they frequently say they are unable to do this for us.

More specifically, examples of my family's direct experience with the issues noted in the Inquiry's Terms of Reference include:

- We have not seen the level of choice and control we had expected. While my daughter can choose where she spends her funding, but NDIS chooses what they will fund, and the level of funding provided. Therefore, some of the activities that she may choose, might not be funded, so she has no real choice and no financial control.
- Our daughter requires specialized access to be able to leave our house. We required an OT assessment, which was difficult to obtain as there are too few OTs available, so the waiting time is very long.
- Both planned (annual) and unplanned reviews take far too long to complete. We are concerned that the NDIS legislation caps the number of NDIA staffing, which we believe impacts on the timeliness of the services they can provide to families. This also puts strain on the NDIA staff to get reviews done, to handle the complaints from families and respond to our needs.
- By privatising NSW government-run services, we now have no access to what was ADHC emergency supports, including case managers and ADHC facilities. This leaves families with no effective backup support in emergency situations, such as a carer parent being hospitalised or a death in the family.
- Our initial support co-ordination provider found that this was not a viable service, so pulled out of that service. The next support co-ordination provider is in the city, is too far away and is therefore using too much of the funding for travel. Therefore, this leaves us with too

little actual support co-ordination funding to assist our family. We have had to take on more of that role which is very stressful and upsetting to us.

- The oversight mechanisms for service providers seem to be quite adequate. However, we are unaware of what the arrangements are to oversee the operations of the NDIS itself.
- We have real concerns regarding workforce management for service providers. It is important to our daughter's welfare that she has consistent, well trained, permanent support workers. Some service providers cannot provide consistent staff to meet her needs, using both casual and agency staff on a regular basis. This impacts on our daughter's confidence in the support workers and her day to day living.
- Our concerns regarding sustainability of service providers centre around the tight budgets and costings for service providers. If these providers are not viable, they will go out of business and our daughter will not be able to have her current choice of providers and support workers. This will increase her stress and impact on her behaviours, thus making our family life even more difficult.
- An example of the financial sustainability decisions of service providers impacting on our family has been the decision of some providers to set minimum support and travel times. This means our daughter who previously received a half an hour for a simple shower, now must use a minimum of 1 hour of support funding as the provider no longer does half hour support shifts. Obviously, this means the support worker can see fewer people with disability in any day.
- Adequate, ongoing funding for supports and services is essential. So, we are concerned about the long-term financial sustainability of the NDIS itself. Without policies and regular reviews of the funds required, there is a risk that existing and future needs will not be covered.
- The legislation that caps the staffing levels of the NDIS is of great concern. Not only does it mean inadequate response times from NDIA staff, it also means that the agency will spend more of its funds on consultants and contractors. That expenditure will use funds that should go toward supporting people with disabilities.
- We have experienced great frustration in attempting to phone the NDIS for answers to various questions. Firstly, it is difficult to get someone to answer the phone, but more importantly, we have received different answers to the same question from different NDIS telephone staff. It is very stressful and frustrating to feel that we cannot get true and consistent information and answers from the NDIS. We feel we cannot trust the information given to us as another NDIS staff member will give us contradicting information.

My recommendations for improving future outcomes under the NDIS include:

- Remove the cap on NDIS staffing so that the agency can operate effectively.
- Improve the training for NDIA staff regarding the impact of various disabilities on the lives of those people and their families.
- Initiate an emergency process for those times that carer families require immediate support.

- Improve the knowledge of NDIS telephone staff regarding procedures and policies so that they are confident to give accurate information to people with disabilities, their families, nominees and others.
- Ensure that the pricing structure for supports is adequate for service providers to remain viable and therefore to continue to provide short shifts to meet client needs.

In closing, I would like to thank the NSW Government for providing this opportunity for me to comment on our experience with the NDIS.

My request is for the NDIS to be made to work more efficiently. I would like to have better access to culturally sensitive staff who can talk to me in my native language. My family needs to have some peace and quiet back into our life and we need a reduction of the huge stresses that dealing with the NDIS has imposed us. That would give us the opportunity to act as a family again and for me to be a wife and mother again.

Again, thank you for this opportunity.

Yours sincerely