Submission
No 289

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

Name: Ms Brigitte Krstanoski

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SUBMISSION TO PARLIAMENTARY INQUIRY

I wish to make this submission public.

My name is Brigitte Krstanoski.
I make this submission as the parent of a person with a disability.
My son is 34 and lives at home. He is severely intellectually and physically disabled from birth, recently diagnosed with epilepsy and requires 24-hour support.
Due to my own health issues, my husband has had to retire to assist in caring for our son.

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, 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
I believe that as parents we should automatically become our son's nominee rather than having to prove our identity and fill in forms to be able to act on our son's behalf.
The annual review system is overly complex, and it should be unnecessary for us to constantly repeat all the information we have already provided. Our son's situation will not improve as he ages, and it would be easier for everyone (including the NDIS) if we only had to report changes in his 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 son's story over and over again every year, which is a distressing process for families. 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.

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 our son can choose where he spends his funding, the NDIS will choose what they will fund and the level of funding they will provide. Therefore, some of the activities chosen, may not be funded, so he has no real choice and definitely no control.
- Our son requires ramps to be able to leave our house. Our OT assessment stated he required a ramp at both the front and back of the house. We were concerned to be told that NDIS had used google maps to check our house (an invasion of our privacy) and then refused a second ramp for the back door as there was an existing ramp at the front door.
- 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 plan included adequate funding for personal care from Monday to Friday, plus community access etc. One of the service providers did not keep their billing process up to date so that there was funding remaining at the end the year. This lead to all of that personal care funding being removed from the second year funding plan. However, the need for that personal care is still highly necessary. It seems our son has been punished for the error of a service provider in his second plan (the funds having been removed). We have asked for a review of this situation, however, this has already taken 5 months without any result.
- Another result from the second year plan was the removal of funding for Support Co-ordination. In the initial plan, this was a valuable support to our family. We already have to spend enormous amounts of time co-ordinating and arranging support services and dealing with NDIS staff. Without the extra assistance of a support co-ordinator, that role has increased to the extent that it is impacting on my own health and family relationships are suffering. This extra strain has resulted in a deterioration of our married life.

- 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 son's welfare that he has consistent, well trained, permanent support workers. It is clear that some service providers cannot provide consistent staff to meet his needs, using both casual and agency staff on a fairly regular basis. This impacts on our son's confidence in the support workers and his 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 son will not be able to have his current choice of providers and support workers. This will increase his stress and impact on his 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 someone who previously needed and received only 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 supports. Obviously, this means the support worker can assist fewer with disability.
- 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 actually 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. I have many other examples of our experiences with the NDIS and I would be very happy to be contacted in the future to offer my thoughts, experience and suggestions. I can be contacted on at any time.

My genuine plea is for the NDIS to be made to work effectively and as it was explained to us in the first place. I would like to be able to become a wife and mother again, rather than the administrator of my son’s supports. As I am ageing, I would like some peace and quiet back in my life and a reduction of the huge stresses that dealing with the NDIS has imposed on my family.

Again, thank you for this opportunity.

Yours sincerely

Brigitte Krstanoski