

Submission
No 274

**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

Below is my submission to this review. I would like my name to be kept confidential. I have only responded to a couple of the terms.

(a) the implementation of the National Disability Insurance Scheme and its success or otherwise in providing choice and control for people with disability,

Assuming there are funds to sustain this truly wonderful initiative the main problems with implementation seem to fall into two categories:

Firstly, systems and processes. For example Portal issues, how do I pay this person?, does the worker need insurance?, how am I charged for transport?

These could hopefully be solved relatively easily but certainly do need to be attended to.

Secondly, developing the plan – what a mess!!

Unfortunately there is no transparency, consistency, continuity or clear guidelines/rules. It is an extremely unprofessional distribution of taxpayer funds and an unprofessional response to the needs of people with disabilities. If the health dollar was administered in this way it would most certainly not be considered acceptable.

1. Transparency

I spoke to an NDIS person a while ago and mentioned the disparity between someone else's plan and my daughter's (\$40,000 compared to \$150,000 for people with similar needs) and she replied in a shocked voice "Oh, you shouldn't tell anyone what you get". I found this quite astounding. Firstly it disempowers PWD and all taxpayers – are we not supposed to know how the funding is dispersed. Secondly it speaks to an inherent unfairness and inconsistency in the plans that are developed.

Is there something the NDIS is worried about? [Well yes, given all the problems you will have read about in other submissions, the planners possibly do have great concerns about their (and their colleagues') ability to develop consistent and fair plans.]

We are not permitted to see the information that is written up – information provided by us in the planning meeting – before it is passed on to the (mysterious, unnamed) person actually responsible for developing our plan. How many requests for a review of an inadequate/incorrect plan could be avoided if the PWD was allowed to check this information before it was passed on?

In the medical profession a doctor must be open and fully disclose information about their diagnosis, prescription, procedures etc. They are open to scrutiny. Why not this service as well? Because its "welfare" and can be "rorted"??.

2. Consistency

Again, in reference to the above mentioned disparity in funding for very similar PWDs, when I mentioned it to another NDIS person they said "Tell me who they are so I can look up their

file and see what their planner wrote” – the NDIS person thought they were being helpful but it was an unbelievable admission that a PWD’s funding depends on how well their NDIS person writes their story.

There are countless stories where PWD and their supports simply cannot fathom why they have been denied funding when someone else has received it.

There is, rightly or wrongly, a perception of very haphazard decision making going on.

3. Continuity

Having to engage with different NDIS representatives all the time with seemingly no one actually responsible for helping you, individually, sort out an appropriate plan is frustrating and demeaning. It is not respectful. Repeating your story over and over - on a yearly basis or more if there is a problem with a Plan - knowing that this NDIS person will probably reinterpret it in a different way to the previous one (but how would you know because you can’t see what they write!). This is all exhausting and debilitating. And I don’t believe it achieves the best outcomes for the NDIS organisation either.

4. Clear guidelines/rules

Even just simple things such as “Yes you must bring your PWD to the planning meeting/no you don’t have to.” Why don’t NDIS people know what the rule is here!? And unfortunately it is obvious that, as they don’t view it as important to know, they must not understand how such a requirement may impact on people in so many ways.

There are pros and cons for bringing the PWD. In an ideal world it would help the NDIS person’s understanding of your individual situation however you, for example, a) run the risk of the planner thinking they can judge your situation better than the specialists who have written your reports b) may traumatise/humiliate your PWD by listing their disabilities to prove they need funding c) can’t concentrate because of the behaviour/needs of the PWD.

And then there are all the seemingly ad hoc decisions made on what basis?. It is often hard to see what guidelines the planner might be following.

What can be done?

I believe the key to all of the above is the education, expertise and perhaps also aptitude of the NDIS people who meet with the PWDs and create the Plans. Current NDIS personnel might be “trained” in the processes but they are not necessarily smart, educated and aware of the nature of different disabilities and the impact of disabilities at a highly cognitive level. I believe that, in many many cases, they are not really competent to be making the decisions – the judgements - they are making. There are very complex decisions to be made and these decisions have far reaching effects on people’s health and wellbeing.

I believe the planning process should be carried out by people at least at the educational level of teachers and with some specific training in disability (types as well as the socioeconomic impacts of disability).

They should also have access to specialists when necessary. Experts can provide accurate information on what impacts a particular disability may have on a person's life, the range of services, tasks and activities that a particular disability may benefit from and even what is available in the local region.

This may sound like a costly path to take but one good decision could save countless hours of reviewing and repairing bad decisions. Not to mention the benefits to the PWD.

The constant attempt to pull back funds only pushes PWD and their supports into a very negative space where they feel they need to demand everything just to get something. With more educated and specialised personnel perhaps there could be a more collaborative working out of the most effective way to manage a person's life in the most cost effective way.

LAC stands for Local Area Coordinator – but there is no “coordination” going on. People are still in silos with individual funding for activities that then need someone else to organise. A thinking, creative, collaborative LAC could be looking at their region as a whole and might be able to put, for instance, two or three PWDs who have similar interests/goals together. Minimising funding and creating community connections and social bonds which are the markers of a good society.

There are so many specific issues that come up all the time. To mention just a few:

- Respite This is a concept no longer permitted under NDIS. I understand the rationale for the NDIS is to provide funding for what is deemed reasonable and necessary for the PWD to live as normal a life as possible. But if there is no “respite” how does the parent/carer also get to live as normal a life as possible? Funding may be offered on the basis of the PWD developing independent living skills, but this isn't always honest. Why do we have to use dishonesty to achieve what is surely reasonable and necessary in our lives.
- The divide between social care (NDIS) and health care services is confusing and does not take into account the complexities of life faced by PWD. Health care workers don't understand the complex needs of PWD who enter the health system, but disability SWs can't be expected to understand health issues. Funding can't simply be one or the other but needs to work together to create the best outcomes.
A personal experience – PWD was in hospital with a non-life threatening but still serious complaint. PWD has limited communication skills but also has a tendency to say yes or no – quite assertively as though the response is well thought through – without an

understanding of the question asked. On two occasions when the parent wasn't in the hospital room the PWD was asked about medical services. The parent learnt later that the PWD had said "No" to the offer of IV fluid (IV fluid!!! – it was needed!!!) and "No" to the offer of "pain relief". The nurse had almost zero awareness of the inappropriateness of asking the PWD these important questions (particularly the IV fluid) nor of the use of Plain English. "Pain relief" should so obviously be rephrased as "a tablet to stop your pain". It was extremely obvious that someone needed to be with the PWD at all times. However there is no line item in the NDIS that allows for this. If the PWD is in a group home it is apparently up to the way the home may be structured so that – if you're lucky – a worker will be able to come out of the house and be in the hospital. If health care is separate to social care provided under NDIS then there needs to be processes and practices funded and put in place in hospitals for whenever a PWD is admitted.

- Staff don't understand how a plan is translated into an activity – there is a real disconnect. The plan has categories which are not always clear and many people I have spoken to do not understand that the funds in some category can be moved flexibly between each category, while others cannot.
- A friend cites a LAC who didn't know what a seizure was.
- There are enormous delays in approving equipment or equipment repairs that may have a massive impact on a person's independence, physical health and mental health. Then trying to pay the lowest possible amount for an inferior product. The rationale cited for refusing a specialist's recommendation are generally clear indicators of the lack of knowledge and the inexperience of the NDIS personnel.
- The 'use it or lose it' policy of having unutilised funding removed (despite explanations as to why those funds were not spent at that time) undermines the sustainability and participant-focused aims of the scheme. Lives don't go to plan and a person should not be penalised because of that.
- A person with severe CP and high support needs has been provided with funding to live in a group home. However, there is no funding for this person's care needs (hoist etc) if they want to spend a night with family. Support Workers cannot apparently be spared from the house. So the PWD is effectively denied the opportunity to be with family – surely a reasonable and necessary activity for any adult. Why not this one?

There are positive stories and I can see the potential. I do also believe there is, ostensibly, more choice and control in choosing a variety of providers and individual support workers. But it is a lot of work and takes skills that many parents/carers don't have.

(b) the experience of people with complex care and support needs in developing, enacting and reviewing NDIS plans,

(c) the accessibility of early intervention supports for children,

(d) the effectiveness and impact of privatising government-run disability services,

There is a conflict between providing a personal service that supports a person and/or family generally living in a difficult situation and making money. Private providers don't have "recurrent funding" that might allow them to develop creative responses to needs they identify in their community.

Where is the funding for providers – or anyone – to create opportunities for PWD.

(e) the provision of support services, including accommodation services, for people with disability regardless of whether they are eligible or ineligible to participate in the National Disability Insurance Scheme,

(f) the adequacy of current regulations and oversight mechanisms in relation to disability service providers,

(g) workforce issues impacting on the delivery of disability services,

(h) challenges facing disability service providers and their sustainability,

(i) incidents where inadequate disability supports result in greater strain on other community services, such as justice and health services,

(j) policies, regulation or oversight mechanisms that could improve the provision and accessibility of disability services across New South Wales, and

(k) any other related matter.

Thank you