

Submission
No 240

**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

9 August 2018

Hon Greg Donnelly MLC

Chair

Portfolio Committee No 2 – Health and Community Services

Re: Inquiry into the implementation of the National Disability Insurance Scheme (NDIS) and the provision of disability services in NSW

Good afternoon,

Thank you for the opportunity to provide a submission into this inquiry. I write this submission both as a community advocate in the NDIS space, a government employee with 15 years' experience administering legislation and designing government policy and procedures (primarily in the Work Health and Safety space) and as a parent to a child with a disability.

Please note that I request partial confidentiality as it relates to this submission. I am happy for the submission to be included on the website but request that any identifying information is redacted and kept confidential. Also, whilst I make it as a private citizen, I do work for the public sector and wish to confirm that I do not make this submission on behalf of my employer.

Please find my responses to the relevant terms on the pages below. If you have any questions please do not hesitate to call me for further information.

Kind Regards,

A. The implementation of the NDIS and its success or otherwise in providing choice and control for people with disability

I can only talk about my experiences with the implementation of the NDIS and while I am very grateful for the funds provided for my son to receive therapy to help him manage the challenges that he faces as part of his disability I have to say that the NDIS is exhausting for parents and other informal supports.

I understand legislation and am able to advocate for my son, I even went back to university to gain qualifications in my son's disability so that I could more effectively advocate for him as well as undertake informal therapy with him in the home setting. However, the NDIS system is designed in such a way that it is almost unable to be effectively navigated. For a start we are distanced from all decisions, there is a complete lack of transparency and parents (particularly of young children) are treated as though we know nothing and that we are trying to rip off the system. I dread every interaction I have to have with the NDIA and the LAC partner because I know it will be lengthy and I will have to go around and around in circles trying to get the LAC's to actually listen and not make a quick judgement call on a situation then refuse to listen to any explanation as to why a requested support is reasonable and necessary. LAC's have treated me as though I am stupid and in my last meeting with the LAC team leader I was told (at least 5 times) that nothing I say will be taken into consideration by them as I am his mother and unable to be impartial. Even though I am my son's nominee and am able to effectively and appropriately articulate my son's needs.

Having the LAC's make decisions to deny support requests without proper consideration of the situation or even an understanding of the disability and the gains to be made from acceptance of the requested support severely limits the participants choice and control.

Even when dealing with the local NDIA office, processes are so convoluted and time consuming that I need to prepare myself for any interactions. For example: I visited the local NDIA office a couple of weeks ago with a question – the business support officer was lovely and helpful but wouldn't allow me to speak directly to a planner. Instead they went into the back office and asked the planner and came back to tell me the answer. Of course, the answer lead to more questions and resulted in her walking back and forth between myself and the planner (in the back office) reciting the questions and answers back and forth. This took over an hour. Had I been able to speak directly to a planner it could have been resolved much quicker and without the associated stress. Unfortunately, this experience is not uncommon.

C. The accessibility of early intervention supports for children

On the almost all therapists across the range of modalities (including occupational therapists, psychologists, speech therapists etc) are all full and have long waiting lists. Children regularly have to wait months or more to gain access to these critically important supports with no assistance during that waiting period. Even when children do gain access to these services they are unable to access them at the rates required to facilitate improvements and progress towards the child's stated NDIS goals. For example – my son need's weekly OT sessions, however he is school aged so can only attend sessions outside of school hours. He has an amazing OT but unfortunately, he can only access fortnightly sessions as they are fully booked up and don't have a weekly appointment available. This means that he won't use all his funding. This is considered by the NDIS at plan reviews so it is likely that he will receive less funding in this area next week, even if his needs remain the same simply because we did not use all of his funding in this area. The fact that it was not spent due to the unavailability of therapists and not due to us not bothering to spend all his

funds will not be taken in to consideration. Past use of funds should not dictate the amount of funds provided in following years – but they are, regardless of the participants changing needs.

Also, the decision by the NDIA to change the partners on the from approximately three agencies to one new agency (primarily to remove potential conflicts of interest, which is a positive thing), it has meant that children are now on even longer waiting lists in order to be assessed regarding eligibility for the NDIS and to be able to access services. Early intervention is recognised as being critical for children who have been diagnosed with a disability or who have been identified as having a developmental delay across one or more areas of development. The previous access partners had waiting lists and now the new access partner has taken on all the waitlists. Parents have been told that there will be longer wait lists as the new access partner makes their way through the list. This means that parents and children who need access to services are going without as they wait to be assessed for eligibility for access to the scheme.

F. The adequacy of current regulations and oversight mechanisms in relation to disability service providers

The introduction of the NDIS quality and safeguards commission is a positive step in regulating the activities of disability service providers. The commission only regulates those providers who are registered with the commission, this means a range of providers are not being regulated or captured by the commission in any way.

There is also a mis understanding of service providers in the disability industry. The introduction of the NDIS has greatly disrupted the industry. Gone is the old model of large traditional service providers who employ therapists and support workers, now more than ever before the disability industry is being serviced by sole traders and small contractors. The costs involved in being a registered provider through the commission and undergoing audit requirements on top of their business costs is prohibitive for many small businesses and sole traders. There is a lot of talk in provider groups that costs and the time involved in preparing for verification or certification requirements is such that they will relinquish their registered provider status and only provide services and supports to participants who self-manage or plan manage their plans. There is a very real danger that this will thin out the already thin market (particularly in the therapy and capacity building space) and reduce available supports for participants whose plans are agency managed.

G. Workforce issues impacting on the delivery of disability services

There are a range of issues impacting the delivery of disability services. The NSW department of industry has estimated that an additional 25,000 – 30,00 workers are needed in NSW by 2019 to support the estimated 142,000 NDIS participants living in NSW ¹. As stated above, the introduction of the NDIS has greatly disrupted the disability industry. Now more than ever sole traders and ‘independent contractors’ are entering the disability industry, a number of whom have no experience in the disability industry.

The National Disability Insurance Agency (NDIA) themselves have encouraged this shift by talking about workers as being supports that a purchased, commodities rather than people engaged as workers. A number of online ‘platform matching services’ have also arisen out of the NDIS model. These companies are essentially ‘tinder for disability’. Their function is to provide a service where participants and support workers can find each other. The platforms do not consider themselves to be labour hire companies and most require support workers to have an ABN and be operating as a

¹ <https://www.industry.nsw.gov.au/business-and-industry-in-nsw/assistance-and-support/dssu>

sole trader or a 'contractor' even though they likely won't meet the ATO contractor requirements. Also, more than ever before participants are choosing to remain in their own residential premises which is wonderful, however it does mean that their residential home is now the workplace of support workers (or 'contractors'). Work Health and Safety regulators are considering the impacts of the NDIS Act on the requirements of work health and safety legislation, at first glance it appears that the two pieces of legislation have a number of areas where they intersect.

There are currently no requirements for base levels of qualifications of disability support workers, rather participants and their families are left to hire contractors or directly engage workers as part of the 'choice and control' of the NDIS. The NDIS have released some very high-level documents, including the 'NDIS guide to self-management' but really participants and their families are left to engage workers with sometimes little knowledge of the responsibilities they have in these workplace scenarios.

Much more work is needed in this space to understand the changing nature of the disability industry and the impacts of the changing workforce on the sustainability of the delivery of disability services under the NDIS model.

H. Challenges facing disability service providers and their sustainability

Although not a traditional service provider, I interact with a range of service providers through my various work streams and as a parent of a child who is an NDIS participant. These interactions have demonstrated that there are a range of challenges facing disability service providers and their sustainability. Some of these challenges include:

- The way that payment is structured under the NDIS is around actual face to face work, it doesn't recognise that there are many non-billable activities associated with remaining in business, for example auditing requirements under the NDIA Quality and Safeguards commission. I am aware of a small OT business spending nearly 10,000 preparing for and undergoing certification to remain a registered provider. Even though the NDIA has started to implement some changes in this area as a result of the McKinsey report, these types of costs can prevent long term provider sustainability
- The NDIA is currently pushing the line that professionals like OTs, physiotherapists, psychologists etc should be limited in the time they spend with participants and that their role should be more about assessment and designing programs that parents or support workers hired as 'therapy aides' should be used to implement the programs. The NDIA require that the therapist 'oversee' the therapy aide therefore take on responsibility for the therapy aides work. Many therapists are unwilling to take on such responsibility and with good reason. Not only does it increase their insurance costs by having unqualified workers undertake such work but it also greatly devalues the work of these allied health professionals who have spent many years training in their fields. It also places participants at risk of injury working with untrained therapy aides rather than qualified professionals. All because the NDIA would rather pay a therapy aide approximately \$50 an hour than a professional therapist at close to \$200 an hour.
- A number of innovative service providers are starting businesses trying to fill the gap in services however, the NDIA and LAC partners refuse to provide funds for these activities, particularly where they relate to children's activities. If the NDIA registers these small service providers then refuses to allocate funds for participants to use these services, they will fail and the market will eventually collapse. For example: the NDIA refused to fund a weekly social skills course specifically for children on the autism spectrum for my son on the

grounds that it wasn't reasonable and necessary because all parents are responsible for paying of after school activities for their children. When I explained that this wasn't a regular after school activity and was a therapy group specifically teaching social skills to kids on the autism spectrum, that it was recommended by his psychologist and that the business owner was a registered NDIS provider. The Local Area Coordinator reviewing his plan said she didn't care that the business was registered that anyone could be registered but that didn't mean she would ever approve the activity. This type of attitude from the NDIA and it's LAC partners puts the sustainability of the service provider at risk of collapse.

J. Policies, regulation or oversight mechanisms that could improve the provision and accessibility of disability services across NSW

There are many issues with the way the NDIS is implemented in NSW. I recently had the opportunity to participate in a focus group with Labour Shadow Minister Linda Burney. This group contained people with various disabilities as well as parents (informal supports). While all had very different needs and situations, it was clear that all are experiencing a range of problems with the NDIS legislation, policies and procedures and how they are implemented both by the NDIA and the LAC partners. These problems related to processes around:

- Access to the scheme – trying to determine what information should be supplied
- Plan reviews – having to constantly prove that the participant is still disabled enough to receive support, then having support requests denied by a LAC with limited understanding of disability as not being 'reasonable or necessary'
- Home modifications and equipment requests – this process is long and complicated with multiple reports required only to have requests often come back denied as not being reasonable or necessary when they are actually critical to a participant's independence and sometimes could have been purchased with the cost of the OT reports
- Reviews of internal decisions – the NDIS Act doesn't put any timeframe on the NDIA to make a decision on a request for internal review of a decision, this means participants are waiting months before hearing of the outcome of a request for internal review of a decision. Sometimes a new plan is put in place before the review request has even been finalised. Most pieces of legislation assign a timeframe for the agency to complete the review. This needs to be rectified as soon as possible.
- Change of circumstance reviews – the same situation applies to change of circumstances reviews.

The majority of the problems relate to the lengthy timeframes it takes for any request to be processed combined with the inability to speak to the right person within the NDIA in order to have any questions answered.

Other areas of concern as it relates to policies and regulations include:

- Insufficient support for informal supports – the NDIS is only focused on the needs of the person with disability, not their family's needs. Also, NDIA expectations that informal supports should be providing high levels of care as a way to decrease the amount of funding required for support workers leave informal supports such as parents and siblings exhausted and without any support as they try to navigate the requirements of the NDIS.
- Lack of transparency around policies and how funded amounts are determined – for example I recently put in an FOI request to try and understand how the decisions around the

level of funding my son received in his plan and the documents that the NDIA uses to determine what supports are appropriate that were provided were so heavily redacted that the document was useless. The justification from the NDIA was that if I was provided this information then I would use it to inappropriately gain more funding. This attitude from the NDIA is a real indication of how participants and their families are treated and made to feel like they are ripping off the government by asking for reasonable and necessary supports. Information around how the NDIA as a government agency makes decision should be proactively released along with guidance material to assist participants in what may be considered reasonable and necessary requests.

K. Any other related matter

The interaction between work health and safety legislation and the NDIS has yet to be fully investigated. The NDIA want as many people as possible to self-manage their plans, as part of their values of choice and control. This means though that participants and their informal supports who directly engage support workers (and possible those who indirectly engage through platform matching services) have duties under WHS legislation and therefore may be responsible for creating a safe workplace for their workers or at the very least be considered the person with management and control of a workplace.

There are a range of other situations and emerging issues where the WHS legislation may interact with the NDIS Act including where the NDIA refuse to provide equipment necessary to control risk of injury to workers (e.g. provision of a hoist to prevent manual handling injuries) stating that it is not reasonable or necessary but may be considered an appropriate risk control from a WHS perspective. Relevant government agencies should be working together to identify areas of intersection between the two pieces of legislation because disability support workers are entitled to a safe workplace at the same time as participants are entitled to 'choice and control'.