

Submission
No 190

**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

To the Director Committees

Thank you for the opportunity to discuss our experience with the transition from ADHC and the implementation of the NDIS in NSW. This submission has been written with the expectation that it will be publicly available.

My wife and I are Carers for a disabled child and we are advocating on her behalf as well as our own. I mean no disrespect when I refer in this submission to the "Person with a Disability" as "the child". I have done this as I wish to publicly share our experiences with the transition from FACS/ADHC to the NDIS whilst respecting and maintaining the privacy of the "Person with a Disability" and our personal privacy.

We are the Carers for a child with severe intellectual and physical disabilities and are authorised kinship Carers by FACS. This child is diagnosed with a genetic condition resulting in severe global development delay, unable to speak or feed herself, requires assistance to move, has severe intellectual and physical impairment and requires fulltime assistance and supervision in every aspect of daily life activities. We have been involved with this child since birth and assumed full parent responsibility when she was 18 months old when the mother was unable to care for her.

We experienced the transition from Family & Community Services, Ageing, Disability and Home Care (ADHC) to the NDIS and are taking the opportunity to raise our concerns and the impacts that it has had on us.

In 2013 and 2014, ADHC provided therapy and home visit services for her, and support for her young mother who was not coping with a disabled child. These early intervention services included integrating physiotherapy, speech therapy and occupational therapy. ADHC provide fantastic early intervention support and services including attending both home and childcare centres and training Carers and staff in her social environment to ensure that her therapy was integrated into all aspects of her care and life.

In mid-2014 we were told by our ADHC Therapists that all early intervention services provided by ADHC would cease as they were going through a restructure and that our therapy would be transitioned and outsourced to other Non-Government Organisations (NGOs) service providers in preparation for the NDIS. Access to the NDIS was not made available to us until 2017

By February 2015 all ADHC services for occupational and speech therapy ceased. Through lobbying we managed to retain our physiotherapist until approximately April 2015. We had raised our concerns with ADHC management about the transition process, but were advised that it was a Government Directive that all early intervention services provided by ADHC had ceased and had been transferred to NGOs. Unfortunately, the NGOs were not set up or resourced to provide these services. This demonstrated to us a callous disregard by Government policy and ADHC for the needs of particularly vulnerable disabled person.

We had a 9-month period where ADHC early intervention services had ceased and we were unable to obtain therapy for the child, even private providers had a minimum of a 6 month wait list, with many stating they would have availability in 12 months during this period. This was a critical phase in the child's early intervention program and there were no services available to ensure continuity of professional oversight of the child's early intervention program.

In February 2015, we were placed on a 6-month waiting list for 2 different NGO transition providers. In July 2015 we had an assessment with one of the NGOs and signed a service agreement. This NGO advised that they could provide services similar to ADHC, i.e. focused on social inclusion, the services would be provided at home and in the childcare centre. We advised the other NGO of this arrangement and was taken off their waiting list. By August 2015 the first NGO that we had signed with then advised us that they did not have the resources to undertake the work in our area and were unable to provide the services that had been agreed upon. We then contacted the other NGO and were placed back on their waiting list. Our services gradually commenced with this NGO in late September, but they were unable to provide the full suite of services until November 2015.

There was another issue that emerged from this transition, the ADHC services had been focused on social inclusion, i.e. the services were provided at home, in the community and in the childcare centres, the new NGO service provider did not provide these services. All services provided by the NGO were located at their facility which involved us having to travel to them weekly, in excess of a 2-hour return trip. This NGO did provide high quality services from 2016, however they were limited as the NGO services were predominantly centre-based, not focused on community integration and social inclusion like the ADHC services.

We commenced drafting our first NDIS plan in early 2017 with the assistance of this NGO. Neither ourselves or the person assisting us understood the application and drafting process. Our first plan was inadequate in defining goals, identifying and providing for the services and needs identified and allocating the funding to the correct areas of the NDIS Plan. We found this out the hard way when we were not able to access funding from the plan as it had been allocated to the incorrect areas within the plan. Our early intervention transition providers, Local Area Coordinators and the NDIA could not provide accurate advice in drafting the plan. In addition, the NDIA kept changing the rules and moving the goal posts. Each time we interact with the NDIA, they have changed the rules since we finalise our plan, meaning that it is incorrect. As a result, we have had to apply for 2 additional plan reviews this year. This is a complex and time-consuming process and we are currently on our 3rd plan within a 15 month period.

Despite being kinship Carers appointed by FACS, no support or assistance was provided by FACS during this process. We asked our FACS Caseworker on numerous occasions for assistance but none was forthcoming. We were surprised at her ignorance of the process, her lack of empathy and understanding of what we were experiencing with the NDIS, and her lack of support in assisting the child. She demonstrated to us a callous disregard. She did not understand the process and made no attempt to assist us during this period. No assistance was forthcoming from FACS in negotiating the transition to the NDIS. We have received a letter this year

from FACS informing us that a person would be appointed to assist us with our NDIS plan development. There was no contact phone number or email address to contact the person. This letter arrived more than 12 months after we had already finalised our first NDIS plan and more than 15 months after we started requesting assistance from the Caseworker.

Both my wife and I are employed in fulltime high-level professional roles. We are used to dealing with complex customer relations system implementation, organisational change processes, people management, complex legislative changes and legal processes, and adult education and training. We are competent and experienced in dealing with complex government systems, however we are struggling with the NDIS implementation and processes. It is extremely complex, rules constantly change, goal posts and sidelines get moved regularly, and information and advice provided to us is often conflicting, incorrect, or redundant in a short period of time.

We are struggling with navigating the NDIS, and I am raising serious concerns with the Committee regarding the impacts on less experienced people, Persons with a Disability, Carers, and NGOs trying to navigate the NDIS processes.

The Assistive Technology process through the NDIS has been an atrocious experience. We have been trying to finalise home modifications, including additional handrails in bathrooms and other areas and an access ramp into the house and have spent thousands of dollars from our plan on the assessment and application process with occupational therapists and builders without having achieved one modification to date.

When she outgrew her wheelchair, it took over 8 months to get wheelchair modifications due to conflicting information from providers, suppliers and the NDIA. We found this totally outrageous and unacceptable as both ourselves, Carers, and teachers were putting ourselves at personal risk to assist her to get into and out of a wheelchair that was not suitable for her current size or capability.

There is now a huge time commitment involved in managing a NDIS plan. On our last plan review, we moved to self-managed which requires in excess of 8 hours a week (1 working day) just on balancing books (paying invoices and claiming back from NDIS). The child has fulltime care needs so this is done whilst the child is asleep. This has a huge impact on the emotional wellbeing of Carers as well as adding to the fatigue and stress levels that we already deal with on a daily basis.

In self-managing an NDIS plan, "People with a Disability", informal supports and Carers are effectively running a micro or small business on behalf of the federal government. This business model has introduced a major cost-shift to the most vulnerable portion of the community and offers no financial compensation to those who are self-managing, but rather, detrimentally consumes financial, time and other resources of individual citizens. All support for fulltime Carers have been removed with this transition. The only reward is the emotional reward of being a Carer. Unlike the previous model, no respite to Carers is offered under the current model as the NDIS plans are solely focused on the "Person with a Disability". I would like the Committee to consider the health, financial, economic and social impacts of what occurs when Carers burnout due to a lack of support.

The federal government is actively encouraging NDIS participants to move to Self-Managed Plans *“because it is all about encouraging the choices available to the Person with a Disability.”* As I mentioned previously, this model effectively means that a Self-Managed Plan is operating as a micro or small business. For the purposes of Work Health and Safety this means that the “Person with a Disability” or their Plan Managers (who are predominantly family members, informal supports and Carers) become a *Person in control of a business or undertaking* for the purposes of work health and safety legislation.

According to the information available, as a Self-Managed Plan manager who directly engages workers, service providers, suppliers and contractors (as most Self-Managed Plan managers do), I am a *Person conducting a business or undertaking* (PCBU) and I have duties under the *Work Health and Safety Act* that make me liable for criminal prosecution. Being Self-Managed, I am conducting an undertaking and also exercise “control” when I indirectly engage, control and influence these people while they are working with the “Person with a Disability” or in my home.

It appears that as an informal support (a Carer) and a Self-Managed Plan manager, I am a PCBU, my home is a workplace and I have all the duties of a PCBU to provide a safe workplace, plant and equipment, personal protective equipment, and training and supervision of workers without any funding, capability, experience or information on what I need to do. I have attached the Safe Work Australia Information Sheet on the NDIS for your reference. When I looked into this matter further, I found that the Safe Work Australia paper understated and underestimated the work health and safety implications and responsibilities that unpaid persons have been forced to assume by the NDIS/NDIA and the Commonwealth Government. We have noted the information provided to us by the NDIA regarding our responsibility to pay tax and superannuation contributions, which are under the Commonwealth jurisdiction, however we have noticed their silence on work health and safety requirements. It appears that there is joint work health and safety jurisdictional coverage under the NDIS but no information is available about this complex jurisdictional overlap.

At no stage has the NDIA, NGOs or LACs advised me regarding my work health and safety responsibilities as a PCBU or a worker. When negotiating the child’s plan, we have asked about complex home modifications and providing basic personal protective equipment such as disposable gloves for dealing with bodily fluids and solids for work health and safety reasons, and it has been denied. We have asked about hoists and lifting equipment provided for manual handling. As a PCBU I would have to provide training to the support workers on their safe use, however the NDIS plan does not cover the provision of this equipment to ensure the safety of workers unless we can justify it “reasonable or necessary” for the “Person with a Disability” not the support workers. No consideration has been given to a Self-Manager providing training to support workers or the ongoing maintenance or regular inspection of equipment. This is a much larger issue than is currently identified in the scope of the Committee, but I am drawing it to the Committee’s attention and ask them to consider extending or referring the matter for further investigation of the ramifications of this.

We are also expressing our concerns regarding the recent proposal to transition the NSW Supported School Transport for children with a disability to the NDIS. Our concerns, as previously identified in this submission, regarding the transition of services to the NDIS, highlighted the gap between the NSW Government closure of the service provision and the implementation (or partial implementation) of the NDIS. We raised the 9 month period that we were without services for the child, the 2 years that it took for the NDIA/NDIS to fill the gap, some of the issues and problems with the transition. As fulltime Carers and fulltime employees we are absolutely petrified by this proposal. Our experience has been that the NSW Government has not managed the changes and the transition to the NDIS with appropriate safety nets, competence or empathy, and we fear that this proposed change from a currently effective working model will follow the previous path to another inept and dysfunctional model. Based on the previous experience, if they handle this proposed change to the disabled child school transport scheme in the same manner that they handled the previous ADHC/NDIS changes, then many disabled children will not be able to attend school.

If the proposed model for disabled child school transport is adopted, it will mean that we, as a NDIS self-managed plan managers, we will also become Logistics Coordinators and will have additional unpaid work and coordination requirements, as well as extending our work health and safety duties and responsibilities even further.

Whilst we support the NDIS in principle, we understand that handing over all NSW services to the Commonwealth is fraught with risk. Our experience, as Carers, of the NSW Government's transition of services to the Commonwealth / NDIS has been that they have extremely inept. It has been poorly planned and executed, demonstrated exceptional callousness and disregard of the most vulnerable persons in the community, their Carers and support workers. The lack of an effective change process and ensuring that safety nets were implemented demonstrated to us, as recipients of this behaviour, serious maladministration, negligence, a major lack of understanding of our circumstances and life experience and, as understatement, was extremely disappointing. They failed dismally and miserably in the provision of support to Persons with a Disability and their Carers in this process.