

Submission
No 246

**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

8 August 2018

NSW Legislative Council Health and Community Services Committee

Dear Sirs/Mesdames

Implementation of NDIS and provision of disability services in NSW Inquiry Submission

I make a submission regarding the current Inquiry by the NSW Legislative Council's Health and Community Services Committee regarding the implementation of the National Disability Insurance Scheme and provision of disability services in NSW. I set out below my submission based on my experience as a carer, with accompanying personal information to illustrate the issues.

Background

My 18-year-old son J has multiple severe disabilities. He is a beloved, sweet, healthy child who loves music. He cannot communicate meaningfully, he has behavioural problems, is not fully toilet trained, has very limited play skills, no independent care skills and he is highly mobile and overactive with almost no understanding of danger. He is 180cm tall. It is likely he will act like a hyperactive two-year-old for the rest of his life. He has complex care and support needs. He requires constant, high level care to ensure he does not harm himself or others or damage property.

Each year my mental, physical and pecuniary resources were substantially diminished by the impossible task of caring for my disabled son until he was placed into voluntary out of home care (VOOHC) in 2015. I have had years of experience in advocating for J with the NSW Department of Family & Community Services (FACS) and National Disability Insurance Agency (NDIA) to obtain disability services for J. J received his first NDIS Plan in July 2017.

I have lived in Sydney my whole life. I have degrees from the University of Sydney including law and economics (majoring in accounting). Both my sons attend school five days per week. My personal circumstances and location have allowed me actively to manage my sons' care.

Overview

In my opinion the implementation of the NDIS in NSW has been poor and the provision of disability services in NSW is a shameful disgrace.

For many years it has been widely accepted by people informed about the NSW system of public support for people with disabilities that it is woefully inadequate and discriminatory. Significant unmet need for disability services in NSW has been documented.

I consider that unmet need is greater than was documented by FACS (and consultants to FACS) because FACS had a bias which caused it to want to understate unmet need in order to reduce public condemnation of poor service provided by FACS. Unmet need for disability services in NSW is serious and widespread, particularly in the area of supported accommodation for people with high or complex support needs. Research by the Summer Foundation suggests the NDIA's assumptions about the undersupply of supported accommodation are materially understated.

I urge you to focus your efforts on improving the system of public disability support for the most extremely disabled members of our community. I understand your inquiry is giving particular attention to the experience of people with complex care and support needs, which does require particular focus.

I would note that people with disabilities (PWD) are at serious risk based on the actions of the NDIA to provide vital disability services or not. Participants do not have sufficient protections from inaction by the NDIA and the NDIA appears unconcerned about repercussions to the NDIA from poor performance. Accordingly, you should expect that complaints in submissions to your inquiry by NDIS participants and their families will be understated due to fear of repercussions from the NDIA.

Implementation of NDIS in NSW

Experience of People with Complex Care and Support Needs - Overview

In my opinion the implementation of the NDIS in NSW has been poor due to insufficient staffing of the NDIA and poor IT service. Unreasonable delays by the NDIA are common in the preparation of NDIS plans and approval of stated items of expenses in a plan (that require NDIA approval). Appeal and review protections for participants in the NDIS legislation are inadequate. NDIA action to implement procedures and approve eligible participants and properties for Specialist Disability Accommodation (SDA) has been unreasonably slow and insufficient.

I am disappointed by the understaffing in the NDIA and the failure by the NDIA to fully spend its budget on staffing and IT. These actions by the NDIA have caused real hardship to PWD.

My son has been the victim of unreasonable actions and breaches of the NDIS Act by the NDIA despite having complex care and support needs and a well-supported advocate in me. I hate to think how low the level of service is that the NDIA provides to people with disabilities who are poorly educated or have English as a second language. I have heard very disappointing anecdotal evidence of poor service from the NDIA to many people. These issues are discussed below.

The promise of choice and control by participants in the NDIS has not been met and seems a long way off, if it will ever occur. In my experience generally, and certainly for almost all participants needing supported accommodation, choice and control for NDIS participants is minor or non-existent.

I can attest from firsthand experience that the experience of the person in my family with complex care and support needs in developing, enacting and reviewing NDIS plans to the current date is unsatisfactory due to poor service from the NDIA.

Unreasonable delay in reviewing and issuing NDIS plans

The NDIA does not provide services within reasonable timeframes, even when they are aware that this leaves people with disabilities with no funding for clearly demonstrated and necessary support. This causes enormous difficulty and hardship for people with disabilities, including people with complex care and support needs, and causes the accumulation of large debts for disability services incurred waiting for the NDIA to do its job. In our case that debt exceeded \$40,000 (based on SIL eventually approved by the NDIA) simply due to unreasonable delay in the NDIA issuing J's second NDIS plan.

I set out details below to illustrate the issue.

In June 2017, the NDIA was advised of J's need for very high supported independent living (SIL) support and planned cessation of NSW state government support in June 2018 when J's 18th birthday would automatically terminate his voluntary out of home care status. Accordingly, when J's first NDIS plan was posted to me by the NDIA in 2017 that letter included the following statements about NDIA decisions:

"NDIS Plan will be reviewed by: 27 April 2018. The NDIA will contact me about my plan review before the review date."

The review date is very important for J because he turned 18 in June 2018. J was in VOOHC until his 18th Birthday, so the NSW government was paying for J's SIL costs up to June 2018. From June 2018 the NSW funding stopped and SIL funding needed to be taken up by the NDIS. The NDIA was informed in detail in 2017 of the complex and high support needs of J and the planned cessation of NSW funding on J's 18th Birthday. In March 2018, the NDIA was informed again that J's support funds from the NSW government at that time were funded for many \$1,000's per week.

The NDIA did not contact me nor begin J's scheduled review by the required date of 27/4/18. Phone calls by me to the NDIA were fruitless. Due to ongoing NDIA inaction, I emailed the NDIA in May 2018 submitting completed Change of circumstance and Request for review forms, requesting urgent review of J's plan due to the impending cessation of NSW state disability funding. These forms were not really applicable to our circumstance because the change in J's need for NDIS funding was a result of a known event (his 18th Birthday) that was not a change of circumstances. However, there was no form nor avenue for me to get the NDIA's attention to address their own inaction.

Planning and staffing in the NDIA is so inadequate that it did not provide funding for SIL for J's care from June 2018. J's first NDIS plan expired in July 2018 yet the NDIA did not issue his second plan until 5 days after that plan expired.

The unreasonable delay in providing J's second NDIS plan was caused entirely by NDIA failure to act. This year, the NDIA requested 2 SIL quotes from J's service provider and other minor information, which were provided to the NDIA within a total of 6 days of the requests being made. The NDIA was not delayed by other parties. The NDIA simply allowed the very expensive funding for J's necessary support to cease in June 2018 and not be replaced with the necessary NDIS funds which should have been provided from June 2018.

Despite numerous requests I could get no details from the NDIA on who was working on preparing the SIL portion of J's plan nor when it would be complete. I have friends who have been similarly left with very large necessary disability support costs to be carried by families or service providers due to unreasonable delays in NDIA work.

I recommend that your Committee advocate for significantly increased staffing in the NDIA to reduce unreasonable delays by the NDIA that are commonly occurring. **I recommend** that your Committee advocate for the NDIA to alter their processes to give priority to working on plans and requests from people with complex or high care needs to ensure that their plans and expenditure requests are reviewed in reasonable time to ensure ongoing support.

Unreasonable Delays in Processing Requests for Stated Items in NDIS Plans

In May 2018 I posted a request and quote to the NDIA for purchase of assistive technology for J as recommended by a therapist. J's NDIS plan included a sufficient budget for this assistive technology as a stated item that requires a quote be approved by the NDIA before purchase. I still have had no response from the NDIA on this purchase request, despite chasing it up and making a formal written complaint about the unreasonable delay.

I am aware that it is common for the NDIA to take so long to approve quotes that the quote becomes out of date and the administration must occur again to get an updated quote. This is inadequate service by the NDIA.

Alteration of Review Due Date Decision with no Notification nor Proper Purpose

I first noticed in May 2018 that some unknown person at the NDIA had quietly altered the date for J's scheduled review on the NDIS My Place portal from 28/4/18 to late July 2018 without informing me. Presumably this was done to reduce the embarrassment to the NDIA of failing to meet the date by which it had first decided to complete the review of J's plan, namely 27/4/18. Even after this inappropriate deferral of the review date by 3 months, the NDIA did not complete the review by the second date required.

I recommend you require the NDIA to investigate changes by the NDIA (without a request from the participant) to the review date for NDIS plans. **I recommend** you require the NDIA to publish information to explain this type of action (and report on NDIA failure to complete reviews by the due date), as it appears very inappropriate, along the lines of a biased cover-up of poor performance by the NDIA.

NDIA Breaches of NDIS Act

In that second NDIS plan for my son, the NDIA apparently ignored the goals (and description of J's environment and living arrangements) we had provided by email for J's NDIS plan and substituted their own significantly different information and goals without explanation. This is a breach by the NDIA of s33(1) of the NDIS Act but is not a reviewable decision. It appears commonplace for the NDIA to breach the requirements of the NDIS Act with impunity due to inadequate protections for participants.

In that second NDIS plan for my son, the NDIA apparently ignored our emailed request for self-management in the plan. This is a breach by the NDIA of s43 of the NDIS Act but is not a reviewable decision. It appears commonplace for the NDIA to breach the requirements of the NDIS Act with impunity due to inadequate protections for participants.

I recommend that your Committee advocate for a significant expansion of the definition of reviewable decision in s99 of the NDIS Act to give participants more protection from NDIA non-compliance with the NDIS Act.

Inadequate NDIS Appeal Mechanisms

Review mechanisms included in the NDIS are inadequate to protect vulnerable people with disability from an understaffed, uncaring NDIA that has been poorly implemented the NDIS in NSW.

Section 48(5) of the NDIS Act (2013) states that the NDIA must conduct a review before a plan's review date. Even though the NDIA was breaching s48(5) by not completing J's review by 27/4/18, there was no way for me to require the NDIA to comply with its own decision to undertake J's plan review by 27/4/18. If the NDIA had decided not to complete a plan review under s48(2) that is a reviewable decision but is disorganisation and delay in implementing a decision sufficient to characterise the NDIA's inaction before 28/4/18 as a decision not to review the plan? I think not.

Even if the failure to complete the review by 27/4/18 was considered sufficient to be deemed a refusal to review that allowed me to request an internal review by the NDIA, what good would that have done me? It is widely known that the NDIA is extremely understaffed and slow to act so I had no hope that an internal review would be completed expeditiously.

The NDIS legislation includes inadequate protection for participants by failing to set reasonable time limits for the NDIA to complete its work, particularly an internal review. **I recommend** that your Committee advocate to ensure the NDIS legislation is urgently amended to deem a failure by the NDIA to complete an internal review within 60 days of the trigger for the internal review as a refusal of the request for internal review (so it is similar to analogous NSW legislation, see s53 Privacy and Personal Information Protection Act or Chapter 3 Administrative Decisions Review Act).

Inadequate NDIA information technology

The NDIS My Plan portal is very cumbersome and difficult to use. The information about the participant's support budget in the portal is insufficient.

The Information Technology (IT) support for the NDIS via the My Place portal is poor. For example, I had a service provider ask me if their claim for payment had been paid by J's NDIS Plan. The portal has no efficient or easy way to search for payments made to a particular supplier. I had to spend an inordinate amount of time manually checking through every payment to see that the supplier had not been paid by the NDIA. This type of inquiry can be done in seconds using simple off-the-shelf accounting software like Xero, but the NDIS portal can't do it. It is unacceptably poor IT service that many participants cannot use due to it being so cumbersome and user unfriendly.

J's second NDIS plan only runs for 6 months because J will finish high school in December 2018. NDIA staff insisted that their IT system cannot handle the two different funding levels required to cover the period before graduation from school and after graduation from school. If this IT shortcoming is true it is an unreasonably poor system that will regularly cause inefficient doubling of administration.

Due to the inordinate delay in the NDIA completing J's last review, I am very disappointed that the NDIA insisted on a 6 month NDIS plan. It also makes it very difficult for me to plan for J's post school activities because I don't know the NDIS budget for those activities. Service providers will not accept someone for service before their NDIS budget is known and reliable.

Choice and Control

The promise of the NDIS providing choice and control for participants appears to me to be a cruel illusion for families like mine. Aside from the inadequate implementation of the NDIS in NSW so far, the NDIS creates more uncertainty for PWD who have complex care needs. The difficult people with severe disabilities are not fully serviced by the market-driven system of the NDIS. In addition, robust supported accommodation is in woefully short supply.

Who is the service provider of last resort for adults with disability in NSW who cannot find any service provider to meet their reasonable and necessary needs or whose NDIS plan is inadequate? **I recommend** that your Committee act immediately to put in place a service provider of last resort for PWD in NSW and advertise its availability to NDIS participants.

I recommend that your committee require the NDIA to prioritise work for people with complex and severe or profound disabilities. It should target and prioritise those who require constant or frequent support in order to ensure there are no gaps in service. This group is most in need of help and have very distinct specialised needs, such as supported accommodation with high staffing of personal carers on a permanent basis.

Serious Shortage of Robust Specialist Disability Accommodation

The unmet need for supported accommodation in NSW is documented at a high level. This severe shortage of supported accommodation causes enormous difficulty for people with complex care and support needs. Many carers and PWD are living in desperate, untenable circumstances without quality of life due to the absence of supported accommodation.

The NDIS proposal to fund Specialist Disability Accommodation (SDA) to try to address some of this shortage is necessary. The NDIA has moved much too slowly to implement policies regarding SDA and to approve SDA properties and expenditures.

Obtaining reliable information on the unmet need for supported accommodation is difficult. This difficulty is because it has long been common knowledge among families of PWD's that there is no supported accommodation to be had through orderly channels, so few have wasted their time applying for a service they have no prospect of receiving. Accordingly, the tragically common practice of deserting one's family member with severe disabilities at a police station or hospital must continue.

Addressing the severe shortage of supported accommodation services is of a much higher order of importance, and would go a long way in addressing, the objectives for the NDIS, for example, providing certainty for the future, opportunities for employment and community participation and reducing inappropriate models of service. This objective should be the single most important objective of the NDIS. Failure to address the absence of supported accommodation services seriously undermines gains on other, less important objectives.

NDIA refuse to provide written confirmation of whether or not my son is eligible for SDA. It is very difficult for people with severe disabilities like my son to move house. As a practical matter, it is necessary for the NDIA to provide eligible participants with written assurance of their SDA eligibility (separate from the registration of a particular home for SDA) so that the participant can apply to move into a SDA house.

I recommend that your Committee advocate for the NDIA to be required to approve participants as eligible for SDA in advance of, and separate from, a particular house being registered for SDA. This is a necessary practical improvement of the system.

Very few new SDA houses have been registered by the NDIA in respect of non-Legacy group homes that did not exist pre-NDIS. This area urgently needs much more staffing in the NDIA in order to move forward this fundamental service that has enormous unmet need that affects so many other aspects of life for people with complex care needs. **I recommend** your Committee advocates for urgent increase in staffing at the NDIA working on SDA.

The existing SDA Pricing Framework unreasonably favours apartments over houses; Accessible homes over Robust homes; and New Builds over Modification of Existing Buildings. This fails properly to support the supply of Robust Houses in densely populated areas that is required for people with severe intellectual disability and autism with reasonable proximity to family and services. Demand for this type of SDA by this population has been understated by the NDIA using unreliable data.

I recommend that your Committee require the NDIA to publish data on demand for SDA and supply (including planned construction) by geographical area such as local government area.

I recommend that your Committee advocates review of the NDIS Pricing Framework to review the assumptions of demand for SDA and improve funding for Robust Houses made using Modifications of Existing Houses.

Significant inconsistency remains between SDA rules in the NDIS and State and local planning and building regulations. I recommend that your Committee require the NDIA to alert the State Department of Planning and NSW local governments about SDA and advocate for consistency between SDA guidelines and State (and local) requirements.

Negative Impact of Privatisation of Disability Services in NSW

The provision of disability services in NSW is inadequate. The impact of NSW privatising disability services has been negative for people with disabilities.

Privatisation has been used as an excuse to abandon people with disabilities in NSW. What service provider of last resort now exists for people with disabilities in NSW?

My son J was living in VOOHC in a home owned by the NSW Minister for Community Services from 2015 until November 2017. The manner of his eviction from this home and the poor disability services provided to him by NSW FACS were unprofessional and inadequate, as detailed below.

In May 2017 FACS advised J that FACS had decided that the consent from FACS for J to live in that FACS house would expire in August 2017. Despite my requests, FACS offered no alternative accommodation for J and offered no assistance in finding a new home nor service provider for J. Throughout this time and until June 2018, J continued to live in VOOHC.

The service provider arranging staff to provide SIL for J resigned with effect on 30/9/17 and informed the individual workers that their services would no longer be required after 30/9/17. FACS took no steps to replace the service provider. I arranged for a new service provider to provide a quote to FACS for providing SIL for J from October 2017. As at 26/9/17 there was no service provider appointed in relation to J and therefore, no staff rostered to care for J from 30/9/17. Only on 27/9/17 did FACS appoint the replacement service provider (that I had found) and arrange the short term extension of services by the incumbent service provider beyond 30/9/17 with the requirement to arrange emergency staffing from 30/9/17. FACS made it a condition of arranging to appoint an ongoing service provider that J move out of the home in which he had lived for the prior two years.

In effect FACS engaged in an improper game of “chicken” with me by removing vital support from my son in order to force me to comply with their demand that J vacate his FACS home. The threat to my son implicit in FACS unreasonably failing to take action to continue to provide disability services to my son was unconscionable. This threat was more potent due to the privatisation of disability services in NSW so there was no public service for me to petition to obtain disability services for J. In early 2018, FACS sold the house from which J was disgracefully evicted for more than \$4 million and there continues to be a severe shortage of supported accommodation for people with disabilities in NSW.

I know it seems unbelievable that FACS acted in such an improper manner and you may be tempted to assume I have exaggerated. I can provide to you documentary evidence to support all my statements of fact in this submission upon request.

Workforce Issues impacting Disability Services

There is a shortage of workers to provide disability services in the eastern suburbs of Sydney. Applicants for jobs advertised to work in eastern Sydney mostly live at least an hour’s travel time from eastern Sydney. This travel time makes it very difficult to provide staff for disability services in eastern Sydney. Applicants who live closer to east Sydney mostly have working holiday visas and are available to work for a very limited period, which causes high staff turnover and training costs.

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Please do not publicly identify me in any way in the course of your inquiry. You should add my submission to the record of public submissions after obscuring my identifying details.

Yours sincerely