

27 March 2018

The Chair,  
The Standing Committee on Health, Ageing and Social Services

**Submission to the Inquiry into the implementation, performance and governance of the National Disability Insurance Scheme in the ACT.**

This submission describes my family's experience with the National Disability Insurance Scheme (NDIS) and the National Disability Insurance Agency (NDIA).

I'm the Mother of two boys who both are diagnosed with Autism Spectrum Disorder. I have a degree in Commerce (in accounting), have worked in financial planning and the public sector in project management. I also have a certificate 3 in learning Support and am currently enrolled in a masters of teaching (Primary) at the University of Canberra. I serve as Board Chair on the Cranleigh School Board, am a member of the Cranleigh P&C and also serve on the Marymead Autism Advisory Centre Committee.

My two sons became NDIS participants with the ACT trial in 2015.

My elder son is 10 years old. He is diagnosed with Autism Spectrum Disorder (moderate-severe) and he is *non-verbal*. His diagnoses are complex: he has other co morbid conditions including generalised anxiety disorder, sensory processing issues and dyspraxia/apraxia of speech which is a motor planning disorder that impacts his speech. He attends Cranleigh special needs school and has for 3 years.

My younger son aged 7 is diagnosed with Autism Spectrum Disorder (Severity Level 1). He has an expressive and receptive language delay and range of sensory issues. On occasion, he has complex and difficult behaviour. He attends a mainstream Catholic school in the ACT.

My issues with the NDIS supports for my sons relate to:

- inconsistent funding decisions resulting from the NDIA's varied interpretation of "reasonable and necessary" in the *NDIS Act 2013*, Section 34 (1).
- lack of appropriate knowledge and understanding of Autism Spectrum Disorder specifically in NDIS decision-making and the NDIA's rejection of specialist clinical documentation and advice, e.g. professional and therapist's reports that describe reasonable and necessary services and supports for my sons.
- the lack of transparency between the NDIA and NDIS participants.
- funding cuts including refusal to fund support and therapy from one planning year to another.
- unacceptable waits for NDIA decision reviews.

Before our children became participants of the NDIS in 2015, my husband and I funded and managed an intensive ASD-specific early intervention program<sup>1</sup> for 6 years (from when my elder son was 2 years old). During this time, we were fortunate to access HCWA funding (helping children with Autism) of \$12,000 over two years. This funding covered a little under 6 months of therapy from a consultant each year (\$1,000 monthly). We employed a consultant who specialises in early childhood intervention for autistic children, a speech therapist, occupational therapist and therapy assistants who worked with both my sons from between 12 to 30 hours per week to achieve developmental milestones relevant to their needs.

Territory and Commonwealth Governments promised that the NDIS would lift the overwhelming and unsustainable financial burden from intensive intervention for our two autistic children.

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<sup>1</sup> Using Applied Behaviour Analysis (ABA) which was the only early intervention approach rated as "evidence-based" in advice sought by Government (see <https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/full-review-report> or [the Early Intervention Table](#))

The following shortcomings of the NDIS have diminished our prospect of any relief from the financial and emotional burden of supporting two sons with special needs. The yearly review process has proven to increase the burden of disability on our family instead of providing support and opportunity.

## **NDIS shortcomings**

### **Inconsistency of decisions to fund supports and therapy based on the application of section 34 (1) NDIA Act.**

The outcome of both my sons plan reviews for 2017-2018 resulted in large decreases in funding and a refusal to fund our Autism Consultant who wrote an extensive report detailing the need for specific therapy and intensive hours to achieve our goals and included annual costings (estimates). It was not justified or explained in the review plan why our request for funding for our Autism Consultant was refused. It was only during a phone conversation initiated by myself that I found out that the delegate determined under section 34(1) of the NDIS Act 2013 that the request for funding for our Autism Consultant to work with both my sons on a weekly basis was not considered a support or therapy that was considered reasonable and necessary. I was however, in previous years funded for this therapy and my son's consultant has other clients who are funded for the same type of therapy with children of similar age in this current period. There is a discrepancy in the application of the NDIS Act section 34(1) and lack of consistency in determining what supports and therapy should be funded. In this case it's to the detriment of my children because the time that is lost in receiving therapy is an opportunity lost for improvement. It is well documented and known amongst allied health professionals that the earlier one receives therapy the better. With age a child becomes less receptive to intervention.<sup>2</sup> See published article on early communication development and intervention for children with autism

Other children in the community with Autism Spectrum Disorder or similar age to my 10-year-old son are funded for supports identical to those that I requested and I was refused. Why are other children funded to work with this type of consultant but mine are not?

I am concerned at this inconsistency and feel that the lack of justification and reasons why therapy/supports were denied for my children was unprofessional. I have sought a review of the decisions contained in my 2017-2018 plan for both children where I have clearly stated my concern on the interpretation of Section 34 (1) of the NDIA Act and how it was applied to my children's plan reviews.

I am also concerned about who is determining what is a 'reasonable and necessary' support under the NDIS Act 2013 section 34 (1) for my children who have Autism Spectrum Disorder. FEROS care displayed little knowledge of my children's disorder and complexity of our situation.

**Lack of appropriate knowledge of a range of disabilities (especially Autism Spectrum Disorder) and therefore lack of understanding of supporting documentation e.g. professional and therapist's reports that request services and supports.**

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<sup>2</sup> See published article on early communication development and intervention for children with autism. *Landa R.* ([Menta Retardat on and deve opmenta D sab tes Research Rev ews](#). 2007;13(1):16 25.)

It was very clear during my telephone conversation with FEROS care that the person known as my families LAC (local area coordinator) didn't possess any qualifications or experience with understanding both my children's diagnoses (Autism Spectrum Disorder). This lack of qualification and understanding has proved detrimental especially when presenting the information contained in the specialist's reports which link directly to the supports and therapy funding requests to the NDIA to make a determination.

The reports prepared by my son's therapists were thorough and extremely important when considering funding needs. My elder son has particularly complex needs with regards to therapy. It was obvious when I spoke to the FEROS Care, local area coordinator that she was misinterpreting the information supplied in the reports and this information was clearly conveyed incorrectly to the delegate for decision making. How can a comprehensive support plan be developed for a participant when the delegate is presented with misinformation?

Before commencing the review process the FEROS care forewarned me to provide specialist reports to support my requests for funding for therapy and supports. I had such reports prepared prior to my review. I felt this request was only more of a burden to pay money from our existing support budget to repeat the same requests made from previous yearly reviews. When I found that our funding was decreased it was obvious that the reports were of no benefit in the review process. What purpose does a professional report serve if the person reading and interpreting its contents is not qualified to do so and the request is ultimately denied? Again, these shortcomings are detrimental to my children's progress with therapy and achieving their goals.

Reports prepared about my children are based on years of knowledge and experience plus a working relationship with my child. All therapists working with my boys have extensive knowledge of their diagnoses and therapy needs. The NDIA by refusing to fund a portion of my sons' therapy in the 2017-2018 plan review have dismissed the recommendation by the therapist who has worked with my son for many years and had studied and trained in this field specifically. I believe therapists who have worked with my child have a much better understanding than the NDIA or FEROS care who conduct a 30 to 60-minute review conversation about my children on the telephone.

Since beginning to write this submission I have been in contact with a delegate from the NDIA who has accepted my review application and will work with my family to construct a new plan for both my children. The delegate explained they felt it was difficult to gain a true understanding of a family's circumstances including content of reports. This is because FEROS care do not convey this information in such a manner that is accurate and reflects the interview with the participants/representatives at their review meeting. I question why we need FEROS care then? If they are not providing accurate information to delegates to make decisions then this is a failure and the process needs to be changed immediately. This is to the detriment of participants and is part of the cause for such a big backlog of work for the review process as information is not conveyed accurately and appropriate decisions cannot be made for participants.

#### *Why the need for reports?*

When the delegate agreed to accept my application to review both my children's plans and develop new plans, I questioned if I would need to provide additional reports especially from my behaviour consultant regarding the need for such therapy. The delegate suggested that as it was a new planning process, any additional supporting evidence would be beneficial. He also stated the NDIA won't fund the cost of this report because I'm not self-managing due to the error in making my children 'plan managed' therefore I couldn't choose and control to pay for such a report. As the report is for future funding, the delegate can't authorise a payment in the future until funding is formalised in the plans. Where does this leave me with regards to payment? I am required to pay for an extra report because I need a new plan, because the NDIA made an error in my original plan review in September 2017 where I had already paid for several supporting reports but was denied such funding and denied my ability to self-manage. My family has made the decision to pay privately for more evidence to support our claim for funding but going forward if the future plans do not meet our requirements then we will be worse off because of this process. Is this what the NDIS is supposed to do for families with multiple children with special needs?

## **Lack of transparency between the NDIA and its participants**

My children's last plan review in Sept 2017 resulted in many changes to our position including funding decreases and the removal of my ability to 'self-manage' and control my children's funding.

The review in 2017 took place via a telephone conversation and the topic of self-management was not discussed in any detail.

When I received my review plan in October 2017 I noticed in my support budget there was funding for a financial intermediary and upon querying this I was informed that my sons' plans were to be plan managed and no longer self-managed. There was no explanation for this change from previous years other than a standard paragraph in my review plan stating that I had requested that the supports for my son's plan be wholly self-managed and to assess this request, the NDIA considered whether self-managing the funding for supports would present an unreasonable risk to my son. No further explanation was provided therefore I assumed that if my request to continue self-managing was denied then I was deemed to be an unreasonable risk to my son. (the exact words contained in the NDIS plan)

I spoke to an employee of the Local Braddon ACT office who offered me further information disclosing that the NDIA can change a person's supports to be plan managed if it is determined by the delegate that the person poses a risk to the participant by self-managing, I queried how it was determined that I was a risk to my children to manage their support budget and furthermore I wanted to know why it was not disclosed in writing (via the plan or otherwise). The NDIA stated that this particular information is not disclosed anywhere, however, she was offering me an explanation just to be courteous as I was querying it over the phone. She then looked further into my plan and said that a 'flag' was placed on the plans because of the amount of funding I had withdrawn from the portal for my sons. The delegate deemed that because I had withdrawn from the portal in large amounts rather than individual claims, I must pose a financial risk to my children and it was necessary to remove my choice to self-manage. If the NDIA had approached me and queried why I was making large withdrawals from the portal I would have explained that I had numerous issues with access and making withdrawals from the portal. On the occasions when I successfully accessed the portal I began withdrawing larger amounts into my children's individual NDIS bank accounts knowing that I would be receiving large invoices that would require payment in the near future. I had in the past been left in the position to pay invoices from my own funds because I could not access the portal and the local office was uncontactable to help me resolve my issue. To add to this, I was actually advised by previous planners that it was perfectly acceptable to withdraw those amounts of money especially knowing that I would have many invoices to pay at once. The lack of consistency and transparency with information in this manner has impacted my family greatly. I have very transparent audit trails including invoices that the NDIA could have accessed if they had made any queries about amounts being withdrawn from my children's funding. I am also perplexed as to why a 'flag' would be placed on my children's files because their funding was being drawn down no matter what the amounts were. If funding is allocated to a participant, then isn't it assumed that the participant will spend it in the appropriate manner or are all participants deemed to pose an unreasonable risk once they make a large withdrawal from the portal? Are we assuming that participants are fraudulent or malicious in nature when they spend money?

I'm aware that such flags exist to identify fraud and misuse however further investigation was warranted in my case and had a simple query been made to me as nominee for my children (the participants) I would have produced evidence to extinguish such a flag on my children's files. This would have removed any further query, issue or future administrative work.

I have experienced a great deal of disruption to accessing therapy for my children since the removal of my ability to self-manage their plans as there are providers in the ACT who do not wish to deal with third parties for invoicing therefore my children's funds can't be accessed to pay for these services and they are missing out on therapy and will not get future appointments with these providers who have long waiting lists. I have been with these providers for years and have paid promptly with no problems in the past whilst self-managing.

I was treated very unfairly when dealing with the NDIA on this matter and felt accused and somewhat 'bullied' for spending the support funding that was allocated to my children in the first place. I don't believe the spirit of the NDIA legislation is to penalise people who spend their support budget. This was an error on the part of the NDIA. This has caused great distress to my family and detrimental to my children's progress. The NDIA had promised me a resolution and phone call by 1 March 2018. This did not occur. I was unable to access the local Braddon office via telephone again on March 5, 2018 so I felt it necessary to contact Gai Brodtmann's office (member for Canberra) as her office had agreed to help contact the local NDIA office on my behalf. Since then, I received an email and phone call from a delegate at the NDIA informing me that my application was under investigation and requested that I produce some evidence in the form of invoices as proof of transactions over the period where my son's accounts were 'flagged.' I met with the delegate at the local Braddon Office in the ACT and produced originals of all invoices and in addition, bank statements, reconciliations, reports and all relevant documentation necessary for audit purposes.

As of Wednesday March 21 2018, I was informed by the NDIA delegate who is reviewing my sons 2017-2018 plans that my application for review has been accepted and two new plans will be implemented for my sons I was also informed in the same email that the decision to remove my ability to self-manage my children's supports has been overturned. I am now able to self-manage their supports. Whilst I'm very pleased at this decision, I also feel that as a taxpayer the whole process of my plan review in September and all the events that have followed are a gross waste of public resources and funding. A delegate had to review my situation to decide to re-instate my ability to self-manage my children's funding and is now going to prepare two new plans for each of my children. I question why the two plan reviews that were initially conducted in September were not conducted properly so as to eliminate the need for the whole review process? The NDIA will in effect be constructing four review plans for my family within a six month period. I believe this is inefficient government spending and a waste of resources.

### **Funding decreases including refusal to fund support and therapy from one planning year to another.**

Both my sons have had their funding decreased significantly in our recent plan review. No explanation was provided as to why the requested funding for therapy recommended by specialist reports were denied.

My older son (10 years of age) is non-verbal and complex with his behaviours and diagnosed general anxiety disorder. Finding appropriate medication that decreases his anxiety is proving difficult and we are currently still trialling various medication types. In the midst of this, my son was denied funding for our Autism Consultant who has worked with him since age 2 and knows his issues and behaviours unlike any other specialist who works with him. His Speech Therapist, Occupational Therapist and even newly appointed Psychiatrist all stated that this consultant is the pivotal part of my son's therapy especially while we are trialling new forms of medication. The NDIA saw it reasonable and necessary to deny this funding. Consequently, my son is not able to work productively with the speech therapist as she's not able to consult with anyone regarding my son's behaviours and the OT has reached the conclusion that unless my son is under the care of a behaviour consultant and his anxiety managed, she cannot work with him for the short term. The Autism Consultant ceased working with my son end of November when we were not able to fund her anymore.. We require advice on behaviour management techniques, especially while my son is adjusting to the removal of anti-anxiety medication and it is taking a long time to find suitable medication as a replacement. In the meantime, our family has no support with regards to managing behaviour and our son is spending all his free time during school holidays and weekends in his room refusing to participate in activities and therapy assistants can't work with him unless they are under the guidance of the Autism Consultant

because they fail to understand his complex behaviours without this assistance. Recently my son has begun physically assaulting his younger brother (who also has ASD), kicking and biting his father and scratching and head-butting myself. We understand this is due to an escalation in anxiety due to withdrawal of medication but in the past our Autism Consultant was available to suggest strategies to manage this escalation in behaviours. He has a history of self-harming due to escalation in anxiety, my family fears this will reoccur in the future unless appropriate medication and strategies are in place to manage his anxiety. The funding decrease has greatly affected our ability to manage our son's behaviours and it is greatly affecting our family environment.

I'm now unable to organise any of the therapies that my son requires because of the funding decreases. The NDIA has randomly selected what areas they will fund for my children and this will not work for them as the approach to their therapy is holistic and an ad hoc approach will not work. The additional funding for an Autism Consultant to help deal with behaviours while my children are at such a young age is a far less expense than what my children will cost in the future if they are not receiving the adequate therapy. The NDIA is not thinking long term for the benefit of my children in this case.

### **Long waiting period for reviewable decision application request**

As there was such a discrepancy between what was asked at my sons planning reviews and was written into their plans I was forced to submit an application for a reviewable decision.

I had submitted this paperwork prior to Christmas business closure 2017. I had received a response via email that the NDIA received my review documents and would be in touch in due course. I approached Senator Zed Seselja's office explaining my dilemma and my position seeking a review of decision. They contacted the NDIA who again confirmed to them that my application for review was received and would be addressed. The Senators office advised me to contact them once my application for review was complete. Since then I have contacted the NDIA again querying the status of my review application, I was transferred to the local ACT office where I was informed that there was no written record of a review application. I explained this was not possible as I was advised otherwise in writing. Again, the NDIA insisted that my application was not received so I re submitted and it is currently in the hands of the local NDIA office in Braddon ACT. The delay in the receiving and processing of my reviewable decision application indicates a great failure on behalf of the NDIS and is only to the detriment of my children. When I had spoken to the local Braddon office in ACT I was promised that I would receive a phone call on 1 March 2017 to discuss my application. I wasn't contacted at this time however the NDIA has made contact since and we are in the process of reviewing and re writing new plans for my children. The long waiting period for a response from the NDIA has been to my children's detriment as we are unclear on their therapy plan or funding into the future.

### **Conclusion**

The greatest concerns arising from the above are that the NDIA is not consistent or transparent with its participants and it's to the detriment of the participants who were promised they would not be in a worse off position under the NDIS. The interpretation of the reasonable and necessary section 34 (1) in the NDIS Act 2013 is not comprehensible and very inconsistent.

The NDIS is not behaving according to its goals and needs great improvement otherwise the initiative will fail and will prove to be a waste of money and effort. People in the disability sector are more disappointed and under stress than ever. This is not the spirit of Australia and this is not what the average Australian taxpayer wants for their fellow disabled citizen. Australian taxpayers want their money to be used equitably but also to be effective in helping disabled persons. Children with Autism Spectrum Disorder, however prevalent and on the increase form part of the disabled community of this nation and are part of the future of Australia. The NDIA must not fail the young and vulnerable.

Yours Sincerely,

Daniela, L. Vrkic