Submission
No 202

INQUIRY INTO IMPLEMENTATION OF THE NATIONAL DISABILITY INSURANCE SCHEME AND THE PROVISION OF DISABILITY SERVICES IN NEW SOUTH WALES

Name: Name suppressed

Date Received: 8 August 2018

Dear Sir/Madam,

I am writing to make a submission for the enquiry and I am requesting partial confidentiality (I do not wish my name to be disclosed).

I am an endocrinologist and have trained 20 years in the health system (the majority in NSW). I am also the mother of a 3.5 year old son with autism. When the diagnosis came my husband and I were devastated. With our medical backgrounds, we immediately conducted a literature review on the Ost evidence based approaches to treating autism. We quickly found that Applied Behaviour Analysis (ABA) therapy had the most evidence behind it. I would also state that my husband are not only trained to read, interpret and apply medical literature, we also contribute to it and are both published in Australian and international medical journals. We started our son on an intensive program of 20 hours per week and within 3 months he had transformed from non-verbal to verbal, despite having speech pathology sessions for a full 6 months prior to the diagnosis. I was appalled to find out that the NDIA were not only not endorsing ABA therapy but were actually recommending therapy with NO evidence to support its use in children with autism. During this period the NDIA rolled out, and we like many other families in the autism community experienced inconsistency, inefficiency, and time delays. I have summarised the issues below for your reference:

1. **The NDIA are not endorsing best practice therapy for children with autism:** Randomised controlled trial (RCT) evidence supports the use of 20 hours of weekly Applied Behaviour Analysis (ABA) therapy in these children, over the use of combined OT/Speech path and other early intervention approaches. Yes despite this evidence, the majority of families are being told that the NDIA will not fund ABA therapy. It is currently estimated that 1 in 60 children in Australia have a diagnosis of ASD and this figure is rapidly rising. These children struggle with socialisation, communication, and repetitive stereotyped behaviours. If they do not receive adequate therapy many children who are non-verbal miss out on the opportunity to develop effective communication skills. Ultimately this costs the community more with loss of productivity and institutionalism. There is no evidence to support the ECEI approach in children with autism. In other areas of medicine, for a therapy to be endorsed and subsided by the the government on the PBS, RCT evidence of benefit needs to be demonstrated. I am unsure why we as a country, are allowing our children to go without the only therapy in autism with the best evidence behind it.
2. **Time delays in accessing early intervention:** It is well-known that children's brains exhibit the most plasticity in the early years hence the importance of early intervention to "re-train" the brain. Despite this families are waiting months to years to have a first planning meeting with the NDIS organised - this is critical time in the child's life and important months of therapy opportunity that have been lost. In our own case, it has now been more than a year since we became NDIS participants and we are still waiting at the Tribunal stage for our initial plan to be reviewed due to inadequate funding.

3. **Inadequate funding and inconsistencies:** While it is well known that every individual will have unique needs it is universally recommended by medical literature and by the NDIS's own commissioned report in 2016 regarding supports for preschool children with autism that 20 hours of intensive intervention is recommended for ALL children with autism, regardless of the level of autism. I am unsure why the NDIS are not funding this for some children and funding for other children. It has also been noted through parent advocacy groups that families in Canberra seemed to consistently receive funding for 20 hours of therapy compared to families in NSW who received much smaller sums. In our case, we received funding to cover only approximately 14 weeks of intensive therapy.
4. **Families are being asked to provide therapy themselves:** There is no evidence in the literature to support parents being the primary deliverers of therapy. Families need to be actively and intimately involved in therapy. We generalise the skills our son is learning in therapy across different settings, prepare resources, attend team meetings, learn skills to deal with behavioural challenges, and sensory issues but we do NOT run or oversee his program. Our son has made the sort of gains that he has because we have been actively involved. We are not therapists and we employ trained therapists who have experience working with children with autism. I feel this expectation is beyond what is reasonable to expect parents to provide. I have another child who I cannot simply ignore in order to provide my son with the intensive therapy he needs. In addition, my husband and I also work. Our son does not forgo his right to enjoy a normal relationship with his parents simply because he has autism. My primary role is as my son's mother not as his therapist. In every interaction I have with him whether it be play time, meal time, bath time, or bed time we work to actively promote his development and generalise skills. This is physically, mentally, and emotionally exhausting and not particularly enjoyable. I would love to just spend time with my son and enjoy him. For the NDIS to tell me I am not in fact doing enough and that in addition I should be providing the majority of hours of his intensive intervention is not only unreasonable but offensive.

For your reference I have attached our timeline of interactions with the NDIA along with a summary of the issues. I do not wish these documents to be published - I am asking for full confidentiality with regards to the attachments but am happy for this email to be published with the removal of my name. I am also attaching the NDIS commissioned report for your reference. I have approached a number of MPs regarding these issues including Jodi McKay, Sophie Cotsis, Ray Williams, and Craig Laundy. We even had a meeting scheduled with the NDIA and they then cancelled 20 minutes before the meeting, stating that they could not talk to the families currently in the Tribunal process (this was despite telling them that people who were in the Tribunal process would be there and could sit out if necessary).

A diagnosis of autism is devastating. At a time when families are struggling to make sense of the diagnosis, cope with the day-to-day challenges of having a child with autism, and advocate for their children, it is discouraging that it is so difficult to find help, and appropriate resources. I am medically trained in the Australian healthcare system – 6 years of medical school, 2 years of internship and residency, 3 years of basic physician training, 3 years of advanced training in endocrinology, and several years as a consultant – if I found the system difficult to navigate I can only imagine what other less well-informed families are facing. I hope that in taking these steps, I can advocate not only for my precious son, but for other families and children who are facing the same challenges.

Kind Regards,

Consultant Endocrinologist
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