

TO

JOINT STANDING COMMITTEE ON THE NATIONAL DISABILITY SCHEME

Provision of Services under the NDIS Early Childhood Early Intervention Approach

07/08/2017

My name is [REDACTED] and I am the maternal grandmother of [REDACTED] an NDIS participant. [REDACTED] is 3 years old his date of birth being 18/07/2014. I am writing this submission for the committee as I feel it is important for the committee participants to have a snapshot into the experience of a young child with ASD and his family.

[REDACTED] is the only child of [REDACTED] [REDACTED] who is 22 years old. [REDACTED] and [REDACTED] have always resided with me. I am a registered nurse who was employed by SA Health and commenced unpaid leave to care for [REDACTED] mother [REDACTED] and support her in her role as [REDACTED] mother in October 2015.

This was necessitated by a diagnosis of borderline personality for [REDACTED] several admissions to Helen Mayo House an acute inpatient mental health facility for mothers and their children under 3 years old, and an intervention plan by Families SA (now the Department for Child Protection) that required [REDACTED] to have supervision of her care of [REDACTED] at all times by myself.

[REDACTED] subsequently engaged in mental health services and the Circle of Security parenting course with therapist input and improved to an extent displaying improved self-care abilities and basic parenting skills. Around the age of 18 months [REDACTED] presented with symptoms of regressive autism. He lost all spoken language, stopped looking at people and reciprocating eye contact and started repetitive behaviour autistic stimming. This lack of communication and escalating autistic meltdowns meant his day to day care became increasingly difficult to manage.

Any progress his mother had made with parenting over time was lost and I as his grandmother became his main carer. The plan that [REDACTED] was to parent herself with community supports and myself return to work was not able to be proceeded with.

At the age of 2 year and 2 months I borrowed money to pay for an assessment of [REDACTED] as the public wait time was around 1 year. This was necessitated as [REDACTED] autistic meltdowns, inability to communicate or interact with his family was having a significant impact on [REDACTED] ability to parent and [REDACTED] was again being subjected to severe verbal abuse when she was not able to cope with his behaviours. I was aware that early diagnosis and accessing NDIS funding was of vital importance for the outcomes of children like [REDACTED] and particularly in light of his compromised social circumstances and previous Families SA involvement as a vulnerable child.

[REDACTED] was diagnosed with severe autism on 17/09/16 and from that date I have been his advocate in accessing NDIS support as his mother is not capable. After approval of the first plan but before commencement of therapy [REDACTED] behaviour toward her son continued to deteriorate with severe verbal abuse escalating and physical abuse occurring. He was on numerous occasions told to 'f... off' and called a 'f...ing autistic c...t'. It was at this stage and after numerous reports being made to the Department of Child Protection by myself, [REDACTED] paediatrician, and three other allied health profession that I made the decision to remove his mother from the family home and protect [REDACTED]. This difficult decision was made in his best interests so that he would be in a safe consistent home environment and participate in ABA therapy. His mother has agreed to this and she understands she is not able to safely meet [REDACTED] complex needs and she continues to engage in her own therapy and see [REDACTED] weekly in supervised 1-2hour interactions.

[REDACTED] has been participating in ABA since and this coupled with less anxiety and no conflict in his home environment has seen him made significant inroads as outlined in several Inclusive Directions reports furnished to NDIS. What this means for [REDACTED] at home is that he now gives full eye contact, can indicate with pointing his needs and using some speech, has regained receptive language and wants to communicate as he is not locked in his own world. Although these gains are significant he still needs much targeted therapy to enable his communication development and ability to interact with adults and his peers.

Daily life with [REDACTED] is like communicating with a stroke victim, guessing his needs to avoid

autistic meltdowns. He needs to be afforded the opportunity via intensive therapy to maximise his individual potential to navigate life and meet his basic needs of communication and integration. This is important for every autistic child but with [REDACTED] his need to communicate and express acceptably his daily requirements are of vital importance in light of his tenuous social circumstance. I am the only relative who is able and willing to care for [REDACTED]. This means that if for some reason I am not able to do this ie death or incapacity he needs to be in an optimal state to return to his mother's care and to sustain himself in a potentially difficult family situation. Additionally if [REDACTED] therapy is optimally funded and he makes solid progress and his mother continues to participate in her mental health therapy there is the real potential that in years to come [REDACTED] may be able to live with and be cared for by his biological mother, [REDACTED]. I feel that this little boy has a fundamental right to fully access interventions which afford him the opportunity to be safe and equipped for his day to day activities in his family life.

I as [REDACTED] grandmother am his willing partner in accessing current services including ABA therapy, speech therapy, targeted preschool preparation in the form of 'little steps'. At home we do targeted ABA sessions as supported by Inclusive Directions with myself as the therapist. I take every opportunity to generalise ABA and speech therapy techniques in his daily life.

I am committed to optimise the potential for this child however I need financial aid to access services to enable this. The CEO of Inclusive Directions indicated in the most recent NDIS planning meeting that there is the real potential that [REDACTED] may only need NDIS support in the preschool years and that by age 6 he may slot into mainstream services. This belief is evidence based by ABA research and also by the significant results in [REDACTED] individual case as seen in the reports furnished to NDIS post the initial weeks of therapy.

[REDACTED] is currently underfunded by \$50,000 in his current plan. This figure was reached by Inclusive Directions who have outlined his therapy needs for 12 months. I have requested a review of a reviewable decision from NDIS on 23/05/17 and apart from an initial acknowledgement of receipt have received no further contact from NDIS. I am being supported with advocacy by Brain Injury SA with this appeal. I have requested the advocacy of my local parliamentary member to appeal to NDIS for prompt review of [REDACTED] case.

Early effective evidence based intervention at the research based necessary weekly hours is necessary for [REDACTED] and children like him to reach their full potential and function within

society. Every delay in accessing these vital services because of delays with NDIS and accessing adequate funding beyond being frustrating and putting unnecessary stress on the family unit, means that the window of opportunity for early intervention is becoming smaller.

██████ will reach his full potential. I will continue to advocate for him and access help through bodies like Brain Injury SA, therapy units like Inclusive Directions and politicians like Amanda Rishworth MP. I am very aware though that there are many little children like ██████ who will not be afforded this opportunity. Their parents are weighed down by the hardships of daily life of caring for children with disabilities and this level of advocating for their children's fundamental rights is beyond them and negotiating time delays in accessing adequate funding would be just too hard.

On a personal note I had one selfish wish about therapy. Something I wanted for me. I wanted to know what his voice sounded like. I didn't know if I would ever hear it and would have accepted if ██████ remained non-verbal but I have heard that little voice now. I hear it all the time now as it grows stronger and surer of itself and ██████ grows into himself.

It is with much hope that I am looking forward to the findings of this committee and the potential changes that will be forthcoming.