

AUSTRALIAN ADVISORY BOARD ON AUTISM POSITION ON NDIS EARLY INTERVENTION APPROACH (ECEI) FOR CHILDREN DIAGNOSED WITH AUTISM

1. INTRODUCTION

There is growing consensus that the NDIS Early Intervention (ECEI) approach is a step backwards for children with autism and their families; and urgent change is required.

Research clearly demonstrates that Early Intervention for children with autism is critical in minimising the trajectory of disability over time. However, the ECEI approach is compounding the difficulties of children with Autism with its long delays; its lack of understanding of the needs of children with autism; and its use of inappropriate tools and processes that are not fit for purpose with the autistic population.

As autistic people are the largest proportion of NDIS participants by primary diagnosis (29 per cent of all NDIS participants, with higher percentages in ECEI), there is a need for immediate action.

2. EVIDENCE SUPPORTING EARLY INTERVENTION FOR AUTISM

The ECEI approach is clearly not meeting the needs of autistic children as understood by a reputable wide body of Australian and international research. In fact, the ECEI approach is a step backward for children with Autism.

There is an abundance of research that demonstrates the benefits of early autism diagnosis and early intervention. The research shows that earlier diagnosis leads to positive outcomes for autistic people into adulthood. The importance of specialised timely early intervention for young children with autism is well documented (see supportive evidence).

Studies have also found that autistic children who receive intervention prior to the age of 48 months make greater improvements than older children who enter these programs in later years. Further research also shows that children receiving appropriate early intervention demonstrated better verbal and overall cognition, and were more likely to attend mainstream school and required less ongoing support, than children who accessed support later. Also early diagnosis and intervention leads to less need for ongoing support.

In short, research clearly demonstrates that there are substantial short and long term benefits from appropriate **timely** intervention.

3. **SIGNIFICANT DELAYS IN ACCESSING EARLY INTERVENTION UNDER NDIS**

The current NDIS ECEI approach is causing significant delays in accessing early intervention for children with autism across Australia. Timeliness is the most common subject of complaints to the NDIA, amounting to one third of all complaints by participants.

Across Australia, there are reports of the ECEI process taking 12 months (or longer) to complete resulting in children missing critical early intervention. In Victoria, it is reported that there is between 6 to 18+ month delays from time of entry to ECEI to receiving a Plan (provided there is referral for a plan, which is not a certainty). In Queensland, the waiting period reported is 5 -9 months; in NSW 9 – 12 months and in Tasmania it is in excess of 12 months.

The Royal Children's Hospital has advised that approximately 2,000 children in Melbourne's West are waiting for a planning meeting or waiting for a plan to be approved.

In contrast, the Helping Children with Autism (HCWA) package and State based initiatives made real progress in recent years to provide a timely response to children newly diagnosed with autism. In most cases, applications for HCWA were processed on average in less than 3 weeks.

The Joint Standing Committee into the NDIS 2019 Progress Report has identified the issues in wait times for ECEI, recommending improved waiting times and reporting on these through the Quarterly Report.:

The Australian Autism Alliance is calling for immediate action to address these unacceptable waiting times and that all children with a diagnosis of autism should:

- **Receive an NDIS plan within 6 weeks of approved access and bypass the ECEI process.**
- **In recognition of the current unacceptable delays families must receive an immediate interim funding allocation to access NDIS registered Early Intervention Providers and clinicians until such time as this is replaced by an active plan.**

4. **LACK OF UNDERSTANDING OF AUTISM BY NDIA AND PARTNERS**

The processes to determine the needs of autistic children are not transparent (or consistent). In addition, what is known of them, would not be supported by those professionally or clinically involved with this population. This includes the use of tools (to determine eligibility and level of need) that were not designed for this purpose; and this is despite advice to NDIS from the Autism Advisory Group and other professionals.

In addition, children are being assessed on a tool called the PEDI CAT which is not sensitive to the disabling condition of Autism and is skewed to

the needs of other populations. This is the considered view of academics and clinicians involved with this population; and advised to NDIA by the Autism Advisory Group.

In addition to the specific experience of families of young children, multiple surveys suggest that the NDIA and partners do not understand the impact of Autism on the person and their related needs:

An Amaze survey found that 65% of respondents rated their planner's knowledge and understanding of autism as none to a moderate.

A recent Autistic Self Advocacy Network Australia (ASAN) survey regarding experiences of the NDIS from members found that:

- 86.2% of adult participants reported that NDIA employees did not have good understanding of how to communicate and interact with Autistic people.
- Only 6.6% of adult participants reported that they always felt respected and listened to when interacting with NDIA employees.
- 50% of adult participants reported that neither LACs, planners nor support coordinators had a good understanding of autistic support needs.

5. AUTISM ELIGIBILITY

NDIS eligibility (above 7 years) for autism is established through the NDIS Operational Guidelines – List A, which identifies the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) diagnostic criteria of Level 2 or Level 3 as likely to meet the disability requirements in respect to section 24 of the NDIS Act. This is problematic noting that the DSM-V states that *“the descriptive severity categories should not be used to determine eligibility for and provision of services; these can only be developed at an individual level and through discussion of personal priorities and targets.”*

There are concerns that the eligibility criteria for DSM-5 are also being used to determine eligibility to ECEI, despite ECEI having separate legislative criteria for eligibility (under section 25 of the NDIS Act). For example, we have reports of children with an autism diagnosis (Level 1) not being given access to support. This is particularly important, given the environmental and other factors that impact on the child's severity overtime. For example, a child with a diagnostic report of Level 1 at the age of 2 years, may increase in needs (Level 3) without appropriate intervention or support. In turn, a child with a Level 3 diagnostic report may decline to a Level 2 with appropriate support.

In addition, there is significant reporting from families of being asked to undergo a diagnostic reassessment where the report states a diagnosis of Autism but does not give a Diagnostic Level. This is costly for families, distressing, with long waiting periods – and totally inappropriate and unnecessary.

6. SUMMARY OF RECOMMENDATIONS

- i) All children aged 0-6 with an autism diagnosis will receive and NDIS plan for early intervention within 6 weeks of approved access.***
- ii) All children aged 0-6 with an autism diagnosis awaiting a Planning meeting are provided with an immediate interim payment to access approved NDIA providers until the backlog is cleared.***
- iii) To ensure best practice, evidence based therapies are provided to children, the NDIA to:***
 - Create an autism and neurodevelopmental stream.
 - Continue a Commonwealth Autism Advisor type program to support the NDIS planning process. This will provide parents of children with an autism diagnosis the support they need, including pre-planning information on best practice early intervention therapies.

CASE STUDIES OF IMPACT OF LONG DELAYS FOR AUTISTIC CHILDREN

Case Study – CHARLIE

Charlie is 2 1/2 years of age and was diagnosed with autism in 2018. He also has a 4 year old sibling with autism. Both boys require a high level of support for communication, independence skills and behaviours of concern. Charlie is nonverbal and engages in self-injurious behaviour. His parents report he is unable to cope in mainstream childcare due to extreme sensitivity to noise, and as a result will not eat for up to 8 hours.

Over a period of 6 months, the family were contacting their local ECEI partner to get support and access to early intervention. However, they were unable to get any response. They resorted to using their life savings including their superannuation, to fund therapies. With the support of an advocate the plan was finally approved in March. However, this did not happen until the parents lodged a complaint to their local member of parliament. Over this 6 month period the family went through significant distress.

“...If my boys do not receive access to Early Intervention soon the consequences will be dire. We are already seeing more self-injuring behaviours from them and it absolutely breaks my heart.

“My husband and I are not sleeping. We are up nights worrying about how we are going to pay the Early Intervention bills. We both find ourselves physically nauseated most days with these worries. It is really upsetting because this is not us!! We are the couple who scrimped and saved to buy our dream home and create financial security for our future children.....

“We were told that we would hear back before Christmas. I sent numerous emails to NDIA to let them know we are struggling and did not hear back.

“It is not fair that the NDIS has caused our family so much stress and uncertainty.”

Case Study – JOEY & JESSICA

Siblings, Joey 4 years and Jessica, 2 years had recently received a formal diagnosis of autism. Both children have significant communication challenges and were frequently overwhelmed and distressed. The family are under a significant amount of stress trying to understand the implications of their child's diagnosis and, adding to this, how to navigate NDIA to access support and services.

The family contacted NDIA to get their eligibility confirmed with the hope of getting immediate support and intervention for both of their children. Joey was confirmed by NDIA to meet eligibility for NDIA, however the planner requested more information about Jessica to determine eligibility. For 8 months the family liaised with NDIA, providing various reports and documents to show their daughter's disability had an impact on her life. The family were repeatedly told that they did not have enough evidence and that the diagnostic report was not enough. Totally exasperated, the family contacted the Federal Minister, and within one week the family were given eligibility for their daughter. Six weeks after this they received funding, taking the whole process to a total of 9 months. The family was so

distressed that this process significantly impacted the relationships within the family and the children's behaviour significantly declined over this period.

Case Study - DEXTER

Dexter, is a 5 year old boy with autism who was diagnosed in October 2018. Dexter was at school and required lots of support. His mother had recently separated and needed support to keep Dexter enrolled in school. His mother submitted an access request in November 2018 in desperate need of support and services. The family only received email responses saying that their application was "in progress" and that someone would be in contact with her in 21 days. The family were given no interim support or information to help understand their child's diagnosis or how they were going to get help. It is now April 2019 and Dexter still has not had any contact from NDIA, despite being told they would be contacted 21 days from the original contact. By chance the mother contacted an Autism Advisor and is getting support to understand her son's diagnosis, evidence-based interventions, and strategies to support her son at school. . Dexter's mother is working extra shifts to fund her son's intervention and this is creating significant stress for the family. This is not sustainable. Despite the mother going to an NDIA office 3 times and lodging 4 complaints, there still has been no progress.

Case Study - JAKE

Jake is a 6.5 year old boy who has been accessing the NDIS for 3 years. Jake's parents went to an ECEI partner when he was 3 years old asking for support because they believed that Jake had autism. The ECEI partners told Jake's parents that their son did not need a diagnosis and could get support through NDIA to work on his speech development. The ECEI directed the family to get blocks of Speech Pathology. Across this period of time, Jake's ability to participate in school significantly declined. He was not able to participate in the activities being presented to him, and challenging behaviour simultaneously emerged. Jake's parents and school teacher did not understand how to support him. The school recommended that Jake have a diagnostic assessment. Within 3 months Jake received a diagnosis of an Autism Spectrum Disorder and, fortunately, this meant he was eligible for school aged therapy under NDIA. Jake is now getting the Autism specialist support he requires that matches his disability needs. Jake's parents are still very distressed and upset that this was not identified when he went to ECEI at three years old and that he missed access to the right intervention earlier.

SUPPORTING EVIDENCE

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