

Select Committee on Autism

Submission by AEIOU Foundation for Children with Autism

17 July 2020

Introduction

Thank you for the opportunity to make a submission to support the inquiry and report into the services, support and life outcomes for autistic people in Australia.

AEIOU Foundation is one of Australia's largest providers of autism-specific early intervention, with 10 centres located across Queensland and South Australia. Established in 2005, AEIOU enrolls around 300 children who aged 2-6 each year. Over the past 15 years, the service has supported thousands of children to develop life skills that support them to engage in everyday life, and participate at home, in the community, at school and in the workforce.

Children are supported by an expert team of clinicians and educators, who share the responsibility of assessing, planning, delivering and evaluating each child's individual plan. Teams are comprised of speech pathologists, occupational therapists, behaviour therapists, teachers and early educators.

Executive summary

AEIOU is committed to ensuring every child has the best opportunity to access the supports they need to live their best life, and believes every family should have the ability to exercise choice and control over the services they engage with when accessing vital supports in the early years of a child's development.

This submission addresses the following terms of reference:

G. The social and economic cost of failing to provide adequate and appropriate services including to support key life stage transitions of autistic people.

H. The adequacy and efficacy of the National Disability Insurance Scheme (NDIS) for autistic people, including:

- i. autism understanding within the NDIS*
- ii. the utility of the Early Childhood Early Intervention Pathway for autistic children*
- iii. the ability of the NDIS to support autistic people with complex needs*

Providing early intervention to autistic children (at its most conservative estimate) has been shown to produce a net benefit of \$365.7 million and a benefit-cost ratio of 4:1.*

Despite evidence such as this which demonstrates that it makes good economic sense to invest in the therapy and education of young children with autism, significant barriers to accessing evidence-based supports remain. Young children are routinely provided with inadequate plans by planners who appear to have limited understanding of autism or effective early intervention. In other cases, planners might have this knowledge but are basing recommendations on actuarial models, i.e. within the confines of financial targets.

Once these inadequate plans are approved the parents of young children with autism come to realise there isn't enough support to meet their child's needs. The parents are advised by planners that they can seek a review of the plan. This is often complicated, unwieldy, and puts the burden of proof upon parents/carers who are often already facing emotional and financial stresses.

The result is the removal of choice and control for participants.

AEIOU recommendation overview:

- that as soon as a child has a diagnosis of ASD, their parents are able to access specialised autism services immediately rather than ECEI partners – specialised autism services have far greater experience at ascertaining the needs of the child and supports required
- clear definition of 'complex needs' and greater understanding of support needs during early childhood learning, including the first years of school utilising a collaborative approach between governments
- the re-introduction of draft plans to facilitate parents/carers having increased choice and control over the providers they work with.
- Reinstate small-group intervention price guide line-item in the 2020-2021 iteration of the NDIS Price Guide in the ECEI space
- the NDIS commits to reducing the number of plans requiring review, through a redesigned ECEI pathway involving specialist services to provide immediate support for children, provide clinical reports and standardised assessments to guide more effective early intervention and greater plan satisfaction
- Inform families of the service available and the Australian Good Practice Guidelines. Ensure genuine flexibility in developing child's plan.

Submission

G. the social and economic cost of failing to provide adequate and appropriate services including to support key life stage transitions of autistic people

In 2016, Synergies Economic Consulting published a review to assess the impact of providing good practice early intervention to children with autism, the level of funding required to do so, and the cost benefit of this investment.

Growing evidence supports the effectiveness of good practice early intervention (that is, intervention which meets the recommendations in the NDIA-commissioned report: Roberts, J. & Williams, K. (2016). *Autism*

spectrum disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers.

It is acknowledged in the report the provision of early intervention to children with moderate or severe autism (i.e. level 2 or level 3 diagnoses) is not effective. Shortfalls in adequate staffing, expertise and training threaten the developmental outcomes of this students (2016:3)

Based on children receiving supports from trained and experienced clinicians and educators, the report estimates the net economic benefit of providing good practice early intervention to children with level 2 or 3 autism diagnoses is \$1.15 million and \$1.25 million per child respectively over the course of their lives, reflecting savings both for the individual and the community through improved access to community, education, employment and independent living.

The report recommended the NDIA line item for specialised group early childhood interventions be applied to accredited service providers of good practice early intervention – however in June 2020, the NDIA removed this line item from the price guide.

This table (fig.1) (Synergies Economic Consulting,2016) demonstrates the estimated cost of early intervention for autistic children with moderate to high needs, and the subsequent savings:

Fig.1: See Appendix 1.

Table 3 Lifetime economic benefit of good practice EI for a cohort of children with autism

Group	Ave. benefit per child	Cost of EI per child	Net benefit per child	Cost Benefit Ratio
Severe autism	\$1,351,240	\$104,758	\$1,246,482	12.9
Moderate autism	\$1,251,457	\$104,758	\$1,146,699	11.9
HA	\$770,481	\$104,758	\$665,723	7.4

Note: Lifetime benefit estimates were calculated using a real social discount rate of 3 per cent. The purpose of a discount rate is to determine the Present Value of benefits and costs which are to be incurred in the future, thereby allowing policy makers to compare cashflows across different time horizons. A real discount rate of 3 per cent is consistent with the rate used by the Australian Institute of Health and Welfare.

Source: Synergies modelling.

Children with autism do not have a biological marker to identify their condition or their needs: the way this condition presents is highly subjective and individual. Likewise, the way children with autism, including those with co-morbidities and intellectual impairment, respond to early intervention differs. Their progress is not linear: it will peak and plateau at various stages during their development. Likewise, while progress may appear minimal next to the benchmarks set for typically developing peers, the progress they do make is significant in terms of enabling them to live their best lives, i.e. with greater ability to manage self-care and hygiene or communicate their needs and wants.

The current system relies heavily on parents understanding what services are available before they get to see their planner, what evidence-based practices are, and how to advocate for them, all at a time that is often guided by stress and grief. It is subjective to the opinions and lack of training or the time constraints experienced by planners. By failing to provide a straight forward pathway and equal access to funding for every child with a diagnosis (regardless of how they present to the untrained eye), there is a failure to recognise the human rights, and the potential of these children, the opportunity for families to exercise choice and control and the long-term benefit of early intervention.

AEIOU seeks to ensure families are not disadvantaged based on where they live, the knowledge they have regarding the supports available, being from a culturally diverse background, their level of education or their financial or mental wellbeing.

Delays to a child's entry to early intervention may have a direct impact on their entire future, with irrefutable evidence that young children with autism who receive the recommended early intervention have a much greater chance, later in life, of living independently, securing employment and developing meaningful and lasting friendships and relationships with long-term research showing benefits for children as they grow and develop (Howlin, 1997).

Recommendation:

The current ECEI pathway needs review:

- Families need access to planners or autism advisors to provide guidance in the early years of an autism diagnosis, with expert, unbiased advice
- *Reinstate small-group intervention price guide line-item in the 2020-2021 iteration of the NDIS Price Guide in the ECEI space*
- *the re-introduction of draft plans to facilitate parents/carers having increased choice and control over the providers they work with.*

h. the adequacy and efficacy of the National Disability Insurance Scheme (NDIS) for autistic people, including:

i) Autism understanding within the NDIS

AEIOU believes there is a lack of understanding at agency level regarding autism and evidence-based treatments for children aged up to six years, perhaps viewing it as a more transient condition rather than a permanent disability which warrants long-term investment. The alternative is there is a lack of understanding about what can be achieved for these children via quality, evidence-based early intervention and both the personal and the cost benefit over the course of an individual's lifespan. Instead, providers and participants are met with barriers at every step of their journey via the ECEI pathway, with what appears to be a plan to cost cut and delay access to supports for children with autism. Certainly, adults with autism do not experience the same delays as their younger counterparts.

Under the NDIS, despite promises no individual would be worse off under the Scheme, children with level 1 diagnoses are unable to access this baseline of funding in order to access the therapy supports they need.

The Agency and its staff often refer to the variability of the effects of autism and the impacts of autism on the individual over time.

This appears to be based on the agency's assumption that there is a clear trajectory of improvement over time for people with autism, which is incorrect. Variability is not a neat upward curve. Rather, it has many peaks, plateaus and troughs. ASD is a lifelong condition that will require varying amounts of support from year to year, in the early years and beyond. AEIOU's interactions with the agency show a clear desire on the NDIS's part to decrease supports over time, regardless of the needs of the participant. This is demonstrated in the lack of support available to children as they transition into school environments and for the duration of primary and secondary education.

A lack of understanding about autism is also demonstrated by the Agency's disregard of a clinical diagnosis, in favour of functional ability and the use of instruments that are neither reliable nor valid for people with autism. We have seen further evidence of this when the agency inadvertently removed Autism L2 from list A. It could be inferred that the agency incorrectly views autism as a transient condition, rather than permanent and lifelong.

In the NDIA's own annual reports, autism is often identified as a threat to scheme sustainability which requires management. One of those management strategies is 'scheme exits'. It was identified that scheme exits were lower than expected, especially for children with high functioning autism.

The spectrum of autism varies, but this demonstrates misunderstanding regarding the unique effects that autism has on individuals and the supports children will continue to need as they grow and develop.

By providing the appropriate investment in the early years of these children's lives, without discrimination and while maintaining quality supports throughout an education, these children will have the best chance to engage and participate within the community as adults.

ECEI planners are well-trained to limit access to intensive supports, with families and providers forced to produce further assessments, reports and advocacy in order to secure funding for intensive supports. Planners at times base their recommendation to families and NDIA delegates based on their personal opinions or the cost of a provider's service, which disempowers these young participants and their families, delaying access to vital early intervention which has the potential to change the course of that child's life.

Recommendations:

- Train all NDIA delegates and ECEI planners to ensure they understand the autism spectrum, its lifelong impacts and the evidence-base of available supports. Or, have specialist experienced planners and delegates with a clear understanding of reasonable and necessary supports for young children with autism.
- Re-introduce autism advisors, to provide informed feedback and recommendations to families who might be experiencing their own personal barriers to accessing supports – for example, through mental health challenges, education, communication.
- Streamline the pathway to ensure children do not experience such serious delays to access supports, and to engage with these children and their parents / carers with compassion, empathy and understanding.

ii) The utility of the Early Childhood Early Intervention pathway for autistic children

This is pertinent with the Nous Review commencing in 2020. There is significant anecdotal evidence to demonstrate the pathway is not working, and presents significant barriers for children seeking access to appropriate funds for evidence-based supports.

It is apparent the rules, operational guidelines and legislation have been created with adult participants in mind, with ECEI failing to properly consider the needs of children and families. Parents with very young autistic children simply do not have the knowledge and understanding of both the needs of the child and the kinds of support likely to gain positive outcomes. Subsequent review processes are poorly equipped to be able to react to the changing needs of the child in a timely manner.

As a result, it is virtually impossible for a parent to get an appropriate support plan for an autistic child within that critical early intervention window without delay or need for review. The implications of this are significantly increased costs for health and community services in the future.

Arguably, an entire cohort of children (i.e. Level 1 autism diagnoses) are principally disadvantaged through the lack of funded supports for evidence-based intervention. These children previously received a minimum of \$6,000 per annum for two years.

Further, the process is cumbersome. Communication between delegates and participants and delegates and providers is near impossible, making it impossible to respond to questions or misunderstandings in real time. The result is the rejection of plans, requiring further reporting, advocacy, reviews and ultimately, delays to accessing the supports needed.

There should be a faster way to connect children with the supports they need. Early intervention is urgent. Children already experience significant delays to access a diagnosis and granting access to life-changing intervention is time sensitive – this will ensure children have the best opportunity to overcome the disabling aspects of autism within the appropriate windows of early intervention. By delaying access, the futures of these children are compromised, and financial and emotional wellbeing of families is compromised.

“Early intervention or support should start as soon as autism is diagnosed. Having well trained professionals working as a team to support the child with autism and their family is needed. Parent or peer training is promoted, as long as it is incorporated to consider a family-centred approach”

- (Autism spectrum disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers, 2016).

Case Study:

A current child in service at AEIOU has been receiving supports for three months.

The reports and assessments were completed and provided to the ECEI partner, who wrote the plan recommendation for continued enrolment at AEIOU, and submitted it to the delegate. The delegate deemed there was not enough ‘progress’ represented in the report to warrant a further 12-month plan.

At no stage was there opportunity in real time as a provider and expert in this field to respond to the delegate's query, nor did the delegate demonstrate any understanding for the process, which is AEIOU provides three month reports to demonstrate the child's needs, not their early gains. The child has profound autism and is unable to function in any other childcare environment, and ad-hoc therapeutic supports will not be of any benefit. The delegate required further reporting AEIOU, again, via the ECEI planner. This draws out the process, creates stress, uncertainty and confusion for the family, and puts unnecessary administrative burden on the service provider. This is not a unique scenario.

Recommendation:

- Greater flexibility for children to be able to move in and out of intensive supports during early childhood learning, including the first years of school. This reflects the variable nature of the needs of young autistic children (rarely a neat upward trajectory of skills development).
- Move away from relying on an ECEI partner, and establish a plan to partner with all specialised early childhood service providers
- When a child presents with an autism diagnosis of level 2 or level 3 autism, they should automatically have access to a two-year plan which factors 20 hours of early intervention each week.
- Inform families of the service available and the Australian Good Practice Guidelines. Ensure genuine flexibility in a developing child's plan.
- Do away with the ECEI pathway and introduce a simpler, fairer system for ALL scheme participants.

iii) the ability of the NDIS to support autistic people with complex needs, including those transitioning from prison settings

The complex needs of young autistic people is often misunderstood, and the lack of supports available to these children results in poorer outcomes for these individuals as they age.

In the early years, parents, carers and providers work exceptionally hard to advocate for appropriate funding and investment into early intervention. The children who receive this opportunity make significant gains: simply, they *learn* how to learn, developing the foundation skills they need to connect with loved ones, establish social skills, participate within the community and access an education.

However, beyond the early years, there is limited support for children in school environments. As they grow, anxiety, school refusal and challenging behaviours create significant barriers for these children, who typically regress. This support should be available for every child as they approach a new school year as they pair with a different teacher, with different classmates, and cope with new workloads and demands.

AEIOU also notes the term 'complex needs' is not defined clearly, and is therefore subjective. A parent/carer's experience is likely to vary based on which planner they speak with. A planner's view on this can be coloured by previous experience and trying to compare disability supports in monetary terms. Discussions with ECEI partners suggest that budgets play a part in what is deemed as complex and what is not. This is not in accord with the intent behind the NDIS.

Recommendation:

- greater understanding of support needs during early childhood learning, including the first years of school utilising a collaborative approach between governments
- The term 'complex needs' should be clearly defined. Re-introducing 'autism advisors' to provide guidance to families and referrals to approved services will assist families navigating the early years of a diagnosis, and will assist planners with unbiased recommendations.
- Planners need to be trained to understand the diagnostic tools used to assess children with autism, and what those assessments mean. They must also have training to understand the evidence-base of specific interventions and the efficacy of those interventions.