

**SUBMISSION**

by

**AEIOU FOUNDATION  
for children with autism**

to

**Review of NDIS Costs  
Productivity Commission**

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## About this submission

AEIOU Foundation welcomes the opportunity to provide a submission to the Australian Government Productivity Commission's review into the costs of the National Disability Insurance Scheme (NDIS).

There is a large gap and disparity in services and outcomes for children with autism, and their families.

As the largest social reform since the introduction of Medicare in Australia, The NDIS brings huge change and more opportunities for providers and participants. The Productivity Commission's review on the sustainability of scheme costs, how the NDIS impacts mainstream services, efficiencies achieved, scheme design and funding of government arrangements will drive the final design of the full scheme.

For children with autism and their families, there is risk under the proposed early intervention models for children with autism by the National Disability Insurance Agency (NDIA).

The NDIA's approach does not meet guidelines set by the Productivity Commission (PC) and the National Disability Insurance Scheme (NDIS) and is in conflict with national and international research for best practice autism-specific early intervention.

This submission identifies why the NDIA's proposed approach to early intervention does not meet the PC and NDIS legislative requirements.

In this document, AEIOU proposes a model which is supported by a large body of evidence that will adequately support children with autism with a cost-effective approach and an emphasis on safety, efficacy and reliability.

This submission will address questions raised in the Productivity Commission's issues paper, released in February 2017.

### About AEIOU Foundation:

As a provider of full-time early intervention services for pre-school aged children with autism we believe it is critical to address factors which will improve the wellbeing of people with disability; provide better options for people with disability for education, independence and inclusion; and improve efficiency gains and cost savings.

AEIOU Foundation is a leader in the provision of effective and affordable autism early intervention and family support in the Australia, and is committed to creating a lifetime of opportunities for children with autism, and their families.

Our program, which includes at least 20 hours of transdisciplinary therapy each week, in a long-daycare setting, is built on evidence-based practices and acknowledges the Guidelines for Good Practice 2012.

Our staff of behaviour therapists, occupational therapists, speech and language pathologists, educators and skilled learning facilitators are all autism trained.

Families are supported through one-on-one meetings, workshops, home visits, community experiences and incursions, to build their skills and capacity to address behaviours that challenge, access the community and achieve lifelong outcomes.

AEIOU prioritises research and assessment, both internally and through external partnerships. In addition to our own Research Advisory Group, AEIOU Foundation is a key funding partner of the Autism Cooperative Research Centre, the world's first national cooperative research effort focussed on Autism, which takes a whole-of-life approach to Autism Spectrum Disorder, from focussing on diagnosis, education and adult life. AEIOU is also a founding-partner of the Griffith University Autism Centre of Excellence.

### Eligibility Requirements:

***Is the ECEI approach an effective way to ensure that those children with the highest need enter into the NDIS, while still providing appropriate information and referral services to families with children who have lesser needs?***

The NDIA states it has developed an approach to deliver Early Childhood Early Intervention (ECEI) informed by best practice and clear evidence. The approach was influenced by evidence commissioned by the NDIA on autism spectrum disorder and foetal alcohol spectrum disorder with findings from this research aligning with the best practice guidelines on early childhood intervention developed by Early Childhood Intervention Australia (ECIA).

The NDIS ECEI approach is intended to provide support to children with disability or developmental delay and their families through organisations and services in their local community.

*The approach fails on a number of key aspects of the Productivity Commission and NDIS legislative requirements, as listed below.*

#### ***1. Evidence: NO***

At no time has the NDIA provided any of the stated evidence for its proposed model for children with autism. Rather, the requested review undertaken by Roberts and Williams, the previous reviews of Roberts and Prior, and associated recommendations, have been ignored. When this position was challenged, *the EICA Vice President quoted research on children with intellectual impairment and acknowledged her and her organisation's lack of knowledge about autism when the differences were explained.* There is support in the literature for the NDIA plan for children with high functioning autism but only where programs are developed with high levels of planning, training and fidelity.

#### ***2. Safety: NO***

Enrolling an autistic child with moderate or severe impairment in social communication and challenging behaviours in a traditionally inclusive program presents series safety issues.

Specifically, children with severe behaviours such as biting, head-banging and escalating, prolonged tantrums require support from specialist staff. In a mainstream setting, these behaviours can injure the child as well as other children and educators. As such, children must be supported by intensive investment in evidence-based behavioural strategies led by highly trained behavioural specialists. The risk is substantial to the child, their mainstream peers, and to the staff working in these settings.

Insisting on a mainstream inclusive environment for these children demonstrates a failure of duty of care to the workforce, as well as young children.

In the Terms of Business for Registered Support Providers it states on page 3 (regarding serious incident reporting):

*'Providers are required to report serious incidents to the National Disability Insurance Scheme State Manager and to the relevant statutory authority in the local jurisdiction. A serious incident is:*

- *The death of, or serious injury to, a participant,*
- *Significant damage to property or serious injury to another person by a participant'*

The adaptation of the ECEI approach is problematic as it is probable that this approach will lead to an increase in the number of serious incident reports submitted to the NDIA. These events have the potential to subject the National Disability Insurance Scheme to high levels of adverse public scrutiny due to the adaptation of the ECEI approach and the NDIA disregarding the research on the most established evidence-based treatment for children with autism.

Wong et al. (2014) identified established evidence-based strategies for children, youths and young adults with autism spectrum disorder. This study identified the following evidence-based strategies for challenging behaviours; functional behaviour assessment, functional communication training, antecedent-based intervention, differential reinforcement, reinforcement, extinction. The use of these evidence-based behavioural strategies should be overseen by a highly trained behaviour specialist.

The adaptation of the ECEI approach and the disregard of established research for children with autism appears to also be in conflict with the guidelines on what is 'effective and beneficial and current good practice' (3.2 and 3.3 NDIS Rules 2013: Supports for Participants).

### *3. Cost effectiveness: NO*

The cost of the NDIS approach needs to consider the costs to the NDIS and the additional cost burdens to the mainstream setting to include a child with moderate or severe autism who has not received intensive evidence based early intervention to address social communication and behaviours that challenge.

In the case of Education Queensland kindergartens, the additional cost is approximately \$20,000 and for mainstream Childcare the cost exceeds this (inclusion support worker, inclusion support training). Added to the proposed NDIS funding of \$16,000, the cost to deliver childcare plus the funding for special needs support and training exceeds the cost of to deliver early intervention via specialised settings.

Therefore, the funding for a typically inclusive setting would amount to a \$16,000 increment over and above the cost of mainstream service delivery, and children are still not receiving access to autism-specific therapy which meets the 2012 Australian Good Practice Guidelines.

Further, prospective studies (Roberts J., Williams, K., et al, 2011) demonstrate there are no differences in gains compared with children who did not attend playgroups.

#### *4. Development of tools to objectively assess needs: NO*

Valid reliable, rigorous and cost effective tools already exist to assess children upon diagnoses and at various intervals during early intervention. These tools (ADOS2, VABS-II, Mullens) are cost effective available to deliver for around \$1200 per child. They can ascertain severity of diagnosis, identify strengths and weaknesses, but to this point have not been considered or discussed as part of the assessment process that remains dogged by subjectivity, conflict of interest, and a degree of "randomness" placing the agency at risk.

#### *5. Assessment of compliance, requirements and audit of registered providers of support: NO*

There is no requirement for formal diagnosis and no current use of objective assessment tools to measure a child's needs, strengths or weaknesses or their gains during engagement of early intervention. Further, there is no specific audit requirement for registered providers to demonstrate the outcomes of their service, linked to the individual benefits of children accessing the support.

#### *6. Choice and no disadvantage: NO*

The NDIA model is prescriptive of inclusive models of support. While this is ideologically attractive the approach for children with moderate to severe autism is not supported by evidence, has real potential to be unsafe, is not cost effective, and removes choice. Families may be greatly disadvantaged. For 12 years Queensland families have had access to full-time, evidence-based early intervention. It has also been affordable, demonstrating excellent value for money and training for families to support long-term development. Turning back the clock, or reducing funding currently available would be detrimental to hundreds of children and their families each year.

#### *7. Risk*

- A.** Safety: see point 2, above.
- B.** Child: cost studies conservatively estimated the lifetime cost of autism at around \$3.5M (Synergies Economic Consulting, 2013), with largest components related to cost of care and underemployment. These Australian studies match well with US and UK studies. Benefit cost modelling using conservative outcomes in care needs and employment achieved through EI building skills in social communication and addressing behaviours that challenge such that the child is able learn and participate demonstrate life time savings of \$1.6M (moderate) and \$2.1M (severe autism).
- C.** Family: a WA study estimated the annual cost impact to a family of raising a child with autism at \$34,000, equating to more than \$500,000 from diagnosis to the age of 18.
- D.** Class Litigation: estimates of the prevalence of moderate to severe autism are not available however older data (2010, WA registry) suggested 1:250 children diagnosed with autistic disorder (DSM IV), or around 1200 children pa nationally. Taking lost family costs and lost costs to the child through the NDIA "knowingly" ignoring evidence, the PC guidelines, and the NDIS legislation, the potential loss could be as high as \$3 billion pa. The history of autism is littered with class actions for which the evidence was far less compelling.

***Are there early intervention programs that could reduce long-term scheme costs while still meeting the needs of participants?***

The autism community advocates for children with moderate to severe autism. These children align to level 3 (higher levels of support) of the NDIS Operational Guideline and require significant care and support related to a permanent disability

Roberts and Prior (2007) undertook a detailed review funded by the Commonwealth Department of Health, releasing guidelines for best practice in early intervention for children with autism. These guidelines were updated in 2011 by The Commonwealth Department of Social Security and more recently further reviewed by the NDIA.

Key components for best Practice Guidelines identified by Roberts and Prior include:

1. DSM V / ICD 10 based diagnosis including severity, level of function and co-morbidities with detailed profiling of strengths and difficulties.
2. Support families: parent support groups, respite.
3. Family centred.
4. Individual planning: child, family, environment.
5. Aims: social communication and minimise behaviours that challenge, leading to enhanced learning and participation.
6. Manage co-morbidities
7. Start: as soon as autism is diagnosed and the family is ready.
8. Intensity: 15-25 hours per week of transdisciplinary therapy for approximately two years
9. Staffing: Autism trained professionals: majority at least 2 years' experience, staff professional development, mentoring coaches.
10. Ratio: no fewer than 1 adult to 3 children.
11. Quality: manualised curriculum, built in fidelity measures, systematic evaluation.
12. Transition Support.

There needs to be real commitment from service providers, and the NDIA, to evidence based models for moderate to severe autism, which includes measurable, quality outcomes for children and their families. To address the needs of vulnerable children with moderate-severe autism, the autism community proposes a connected universal services model, providing integration between the early intervention programs based in specialised and in mainstream settings.

The proposed early intervention model needs to meet the key best practices of the National Guidelines for Best Practice in Early Childhood Intervention (2016), the Productivity Commission and the NDIA legislative guidelines and acknowledges the Guidelines for Good Practice (2012). It suggest a best practice approach to optimising inclusion for children with moderate to severe autism, and their families, while ensuring safety and quality are met. The NDIS should have a degree of confidence that services and support models that meet these criteria will provide high quality outcomes for participants and hence reduce long term scheme costs.

The connected universal services model (below, Figure 1) proposes that children with moderate-severe autism begin in the intensive early intervention provided by specialised services but as skills develop, they transition with support to early intervention provided in mainstream services.

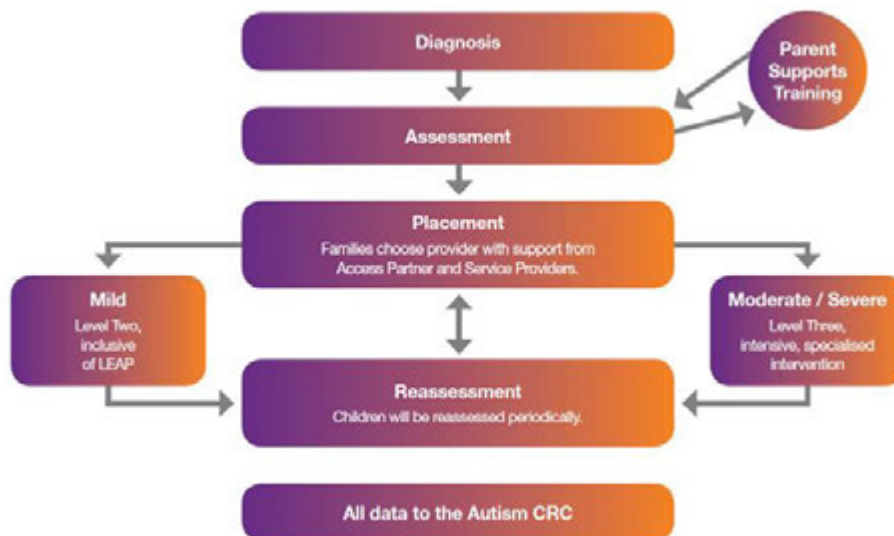
Services should incorporate inclusion into their programs as appropriate to the needs of the children.

Early intervention provided in mainstream services (as per the ECEI) is by nature inclusive and is therefore most appropriate for children with low needs. Services should align to the needs of Level 1 (low needs) of the NDIS Operational Guideline<sup>1</sup>.

Intensive early intervention provided in specialised settings would be provided for children with moderate to severe autism and therefore requiring moderate to high, and in some cases, severe needs. Specialised intensive early intervention provides the highest level of support and intervention, while providing some aspects of inclusion as appropriate for the needs of children while ensuring for their safety and the safety of others.

This service aligns to Level 2 (medium) and Level 3 (high needs) of the NDIS Operational Guideline<sup>2</sup>, and on a case by case basis, the necessary and reasonable funding for children with the most severe autism – as per NDIS Operational Guideline ‘higher levels of support’<sup>3</sup>.

**Figure 1: Connected Universal Service Model for Children with Autism**



<sup>1</sup> NDIS Operational Guideline – Planning and Assessment – Supports in the Plan – Supports for Early Childhood (v 1.0), p7.

<sup>2</sup> NDIS Operational Guideline – Planning and Assessment – Supports in the Plan – Supports for Early Childhood (v 1.0), p7.

<sup>3</sup> NDIS Operational Guideline – Planning and Assessment – Supports in the Plan – Supports for Early Childhood (v 1.0), points 35 and 36, p.8



The benefit of specialist early intervention, when looked at over the lifetime of a child with moderate to severe autism is significant. Synergies Economic Consulting (2013) estimates the lifetime benefits of accessing good practice early intervention for children with moderate to severe autism are at an average of \$1.2 million and \$1.3 million respectively. While some literature notes the greatest gains are achieved in higher functioning children the Synergies Economic Consulting Report (2013) demonstrates the most powerful gains are to be made for those with moderate to severe autism, this is particularly evident when considering much larger economic gains and lifetime cost savings to the NDIA and society as a whole.

The investment in supporting the connected universal services model over a two-year period, would be a fraction of this total cost.

## Assessment tools

### ***Do NDIA assessment tools meet criteria? What measures or evidence are available for evaluating the performance of assessment tools used by the NDIA? No.***

Autism diagnosis is subjective. To access a Carer Allowance and other social security payments, diagnosis can be provided by a general practitioner. To access the Helping Children with Autism package, diagnosis is provided by a paediatric psychiatrist.

The Productivity Commission, in establishing guidelines for the NDIS, recommended the use of tool kits that could be broadly applied and nationally rolled out. The current assessment tool (Pedicat) is more appropriate for children with a physical disability and does not identify the needs of an individual with an intellectual disability.

As highlighted in previous submissions, AEIOU Foundation proposes the introduction of a tool kit which links severity to appropriate early intervention programs. This will determine costing of packages to link early intervention pathways, and include ongoing assessment, outcome reporting, ongoing package allocation and research. See attached 'A Pilot Study of the Effects of an Australian Centre-Based Early Intervention Program for Children with Autism' (Paynter J., Scott, J., et al, 2012).

The Productivity Commission's proposal to use a "toolbox", identifying different tools suited to particular needs of support, states the following:

- The tools must be valid, reliable, vigorous, and cost effective.
- The assessments should be as objective as possible, the people making the assessment should be independent of the client, be properly trained in the use of tools, and be approved or appointed by the NDIA for the purpose of conducting assessments.
- The support provided should be necessary and reasonable.
  - *Necessary* is defined by the support being or likely to be effective, beneficial to the participant, having regard to current good practice.
  - *Reasonable* is defined as the support providing good value for money in that the costs of the support are reasonable relative to the benefits achieved and the costs of alternative supports.



Families who access NDIS packages to attend AEIOU Foundation have experienced disparity in the funding they receive, due to subjective assessments by unqualified planners who have no access to a toolkit which measures severity of the impairment and aligns with appropriate early intervention programs.

The commitment to an approach which values formal diagnosis, objective assessments and regular reviews will support the NDIS to provide the best value to both the autism community, and also the broader community. While autism is a permanent disability, early intervention for preschool aged children can change the trajectory of a child's life, giving them the best chance to access inclusive education models and lead productive, fulfilling lives (Synergies Economic Consulting, 2013).

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