

**SUBMISSION**

by

**AEIOU FOUNDATION  
for children with autism**

to

**NDIS Costs  
Productivity Commission Position Paper**

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## About this submission

AEIOU Foundation welcomes the opportunity to provide a submission to the Australian Government Productivity Commission's (PC) position paper on the National Disability Insurance Scheme (NDIS) Costs.

AEIOU submitted to the PC's Review of NDIS costs in March 2017, demonstrating there is a large gap and disparity in services and outcomes for children with autism, and their families.

In this document, AEIOU responds to the Position Paper's draft recommendations, selected findings and information requests on:

- How is the scheme tracking?
- Scheme eligibility
- Scheme supports
- Boundaries and interfaces with the NDIS
- Provider readiness
- Governance

## 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 that 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 a minimum of 20 hours of transdisciplinary therapy each week in a group 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 Autism Research and Innovation Committee, 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.

AEIOU Response to:

## **How is the scheme tracking?**

### **2.4 Draft Finding**

*Early evidence suggests that the National Disability Insurance Scheme is improving the lives of many participants and their families and carers. Many participants report more choice and control over the supports they receive and an increase in the amount of support provided.*

*However, not all participants are benefiting from the scheme. Participants with psychosocial disability, and those who struggle to navigate the scheme, are most at risk of experiencing poor outcomes.*

AEIOU Foundation supports the draft finding that the National Disability Scheme is improving the lives of participants, their families and carers. However, as an organisation invested in transitioning to this new scheme, we believe participants are struggling to navigate the scheme, and are at risk of experiencing poor outcomes.

General feedback from families attending AEIOU indicates they are having significant difficulty in the initial access stage.

There is confusion regarding the NDIS registration process, with families waiting very long periods for phone calls from NDIS representatives and experiencing lengthy delays for planning meetings.

Research shows that due to the nature of human brain plasticity, the earlier the intervention, the larger the impact on outcomes (Hadders-Algra, 2011). Delaying access to reasonable and necessary supports to receive effective autism early intervention reduces the window of opportunity to achieve lifelong impacts.

Families have also expressed frustration with accessing basic information on the NDIS website that is relevant to their needs. Dividing the NDIS information into early intervention 0-6 could be a starting point. Issues accessing the NDIS portal are also causing undue stress.

Creating an App notifying participants and providers of changes, would be an efficient and cost effective solution.

Recognising these issues will have an impact on outcomes, AEIOU Foundation has invested unbudgeted funds to employ an NDIS Support Coordinator, to work directly with families, and assist them to navigate their way through the process.

## **Scheme Eligibility.**

### **3.1 Information request**

*The commission is seeking feedback on the advantages and disadvantages of maintaining 'List D- Permanent Impairment/Early Intervention, Under 7 years – No Further Assessment Required' in the NDIA's operational guidelines on access. Feedback is sought on the extent to which the list:*

- *Reduces the burden on families to demonstrate that their child will benefit from early intervention and/or provides certainty that support will be provided*
- *Reduces the burden on the NDIA of assessing whether children are eligible for early intervention support under the NDIS act 2013 (Cwlth)*

- *May be contributing to supports being provided to children who are unlikely to benefit from such supports*
- *May be discouraging or inhibiting exit from the scheme*

Autism is a lifelong neurological developmental disorder for which there is no known cause and no established cure. We advocate for children diagnosed with autism at level 2 and level 3 to be placed on List D-Permanent Impairment/Early Intervention, Under 7 Years.

AEIOU proposes children with autism diagnosed at Level 1 to be included on List A. Clearer guidelines on the assessments accepted by the NDIA will result in better outcomes for the participant, provider and the NDIS.

Maintaining children diagnosed with autism Level 2 and Level 3 on List D, reduces the risk of burden on families to demonstrate their child will benefit from early intervention, and reduces the burden on the NDIS of assessing whether children are eligible for support. It enables children to access early intervention, which evidence shows gives them the best opportunity to reach their full potential.

In establishing guidelines for the NDIS, the Productivity Commission recommended the use of toolkits that could be broadly applied and nationally rolled out. As highlighted in previous submissions, AEIOU Foundation supports the introduction of these toolkits that link severity to appropriate early intervention programs. The tool kit will remove subjective assessments, provide a more frictionless process for families whilst reducing risk for the NDIS.

Families who access NDIS packages to attend AEIOU Foundation have experienced significant disparity in the funding they receive. As a provider, we have received no information on why these differences exist. Providing diagnosing practitioners with access to a toolkit that measures severity of the impairment and aligns with appropriate early intervention programs will remove burden on the NDIS.

AEIOU continues to propose the NDIS commits to an approach that values formal diagnosis, objective assessments and regular reviews. This will provide the best value to both the autism community, and the broader community.

### **3.2**

#### **Information request**

*The commission is seeking feedback on the benefits and risks of maintaining 'List A – Conditions which are Likely to Meet the Disability Requirements in section 24 of the NDIS Act'. In particular*

- *To what extent does List A reduce the burden for people with permanent and significant disability of entering the NDIS under the disability requirements?*
- *Is there any evidence that people who do not meet the disability requirements are entering the scheme under List A?*

It is important the NDIS allows flexibility to enable all children in need of early intervention to have access to NDIS supports.

Families of children with autism diagnosed as Level 1 should remain on List A, to not be at risk of increased burden. Children diagnosed at Level 1 should have access to resources that are readily available and low cost, while they undergo further assessment.

Currently, as List A stands, it increases the burden to families of children with autism Level 2 and Level 3.

### **Scheme Supports**

#### **4.1 Information Request**

*Is the NDIS act 2013 (Cwlth) sufficiently clear about how or whether the ‘reasonable and necessary’ criterion should be applied? Is there sufficient clarity around how the section 34(1) criteria relate to the consideration of what is reasonable and necessary?*

*Is better legislative direction about what is reasonable and necessary required? If so, what improvements should be made? What would be the implications of these changes for the financial sustainability of the scheme?*

The current criteria for what is “reasonable and necessary” support is effective for determining appropriate therapeutic supports for children with autism. However, there is evidence partners and planners are not fully informed on the legislation, increasing the risks that families of children with autism will not receive the required funding to access effective early intervention.

#### **4.1 Information Request**

*Should the NDIA have the ability to delegate plan approval functions to local area co-ordinators? What are the costs benefits and risks of doing so: How can these be managed?*

Where Local Area Coordinators have the ability to delegate plan approval functions for children with autism, there is increased likelihood plans are processed quickly. This benefit however, is outweighed by the risks, including:

- Local Area Coordinators/Partners are required to provide support to people across all disabilities, and are unlikely to be formally qualified to make sound and informed decisions.

Local Area Coordinators /Partners are responsible for drafting and finalising participant plans, removing objectivity when it comes to plan approval. This process is open to conflict of interest.

#### **4.1 Draft recommendations**

*The National Disability Insurance Agency Should:*

- *Implement a process for allowing minor amendments or adjustments to plans without triggering a full plan review*
- *Review its protocols relating to how phone planning is used*
- *Provide clear, comprehensive and up-to-date information about how the planning process operates, what to expect during the planning process and participants’ rights and options*
- *Ensure that Local Area Coordinators are on the ground six months before the scheme is rolled out in an area and are engaging in pre-planning with participants.*

AEIOU supports the implementation of the above recommendations.

Experience illustrates these actions would improve the process for participants, reduce stress, and advance efficiencies for the National Disability Insurance Agency.

## **PROVIDER READINESS**

### **INFORMATION REQUEST 6.1**

*In what circumstances are measures such as:*

*cross-government collaboration*

*leveraging established community organisations*

*using hub and spoke (scaffolding) models*

*relying on other mainstream providers*

*appropriate to meet the needs of participants in thin markets? What effects do each have on scheme costs and participant outcomes? Are there barriers to adopting these approaches?*

*Under what conditions should block-funding or direct commissioning of disability supports (including under 'provider of last resort' arrangements) occur in thin markets, and how should these conditions be measured?*

*Are there any other measures to address thin markets?*

There are barriers for early intervention providers such as AEIOU Foundation to adopting the above approaches. AEIOU Foundation provides a specialised autism specific program that includes a minimum of 20 hours transdisciplinary therapy. Our curriculum and model is delivered across all centres, regardless of location and relies on staff trained in autism and our program.

As a specialist provider in a thin market, we experience difficulty attracting suitable staff, due to increased competition and an undersupply of qualified and experienced therapists. The supply issue is also partly a function of Australian Universities not offering courses that are widely accepted elsewhere as being important in the early intervention for children with Autism.

## **WORKFORCE READINESS**

### **Information Request 7.1**

*What is the best way for governments and the National Disability Insurance Agency to work together to develop a holistic workforce strategy to meet the workforce needs of the National Disability Insurance Scheme?*

Increasing demand for services under the NDIS requires an urgent need for the NDIA to address the strain on its workforce, created by lack of qualified staff and lack of clarity on policy and process issues. Engaging directly with service providers and providing relevant forums for them to table ideas and feedback, should be put in place.

In the short term, consideration must be given to ensuring a suitably qualified workforce is readily available. The government can address the shortage of qualified health and education professionals, by reviewing university access and restrictions on occupations for employer sponsored visa programs.

## GOVERNANCE

### Draft Recommendation 9.3

*The National Disability Insurance Agency should publicly report on the number of unexpected plan reviews and reviews of decisions, review timeframes and the outcomes of reviews.*

To ensure the NDIA is accountable to and transparent with participants, providers and the public, it is important the organisation publicly reports on the number of unexpected plan reviews and reviews of decisions, review timeframes and the outcomes of reviews. This information will drive the direction of the NDIA, continuously improve participant experience and measure success.

This would be useful in the initial years of the scheme as an indicator of the efficiency and effectiveness of the planning and review process. It also ensures the NDIA has a measure for reference.

### Information Request 9.1

*The Commission is seeking feedback on the most effective way to operationalise slowing down the rollout of the National Disability Insurance Scheme in the event it is required. Possible options include:*

- *prioritising potential participants with more urgent and complex needs*
- *delaying the transition in some areas*
- *an across-the-board slowdown in the rate that participants are added to the scheme.*
- *The Commission is also seeking feedback on the implications of slowing down the rollout.*

The NDIS is the most significant social reform Australians have experienced since the introduction of Medicare and will provide people with disabilities access to funding so that they can receive the supports they need to live their best possible lives. The NDIA says the NDIS will mean peace of mind for every Australian – for anyone who has or, might acquire a disability. Slowing down the process will remove peace of mind, and cause undue stress for those who urgently require disability supports.

While the Commission is seeking feedback on delaying transition in some areas, the NDIA has announced early rollout in Ipswich and Bundaberg due to unexpectedly low take-up. However, the experience in Ipswich suggests participants may not have plans approved for 3-4 months after the launch in the area. The NDIA has reported greater than expected numbers of people with autism entering the scheme. With this in mind, AEIOU advocates for the NDIS to increase its qualified workforce to ensure the NDIS is rolled out efficiently and effectively and children with autism can access the therapy and care they need in time.