

Queensland Productivity Commission Inquiry into the National Disability Insurance Scheme (NDIS) market in Queensland

Submission by AEIOU Foundation for Children with Autism

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Introduction

Thank you for the opportunity to make a submission to support the Inquiry into the National Disability Insurance Scheme (NDIS) market in Queensland. AEIOU Foundation first began operating under the NDIS when it was within a trial phase in Adelaide in 2013.

Since that time, we have evolved our service to ensure it remains viable and delivers the excellence in therapy and care to young children with autism. There have been several impacts upon business operations, with staffing and service structure the most impacted, along with an increased need for advocacy on behalf of families struggling to navigate the NDIS in their child's early years.

AEIOU commends the Queensland Government for its support of both participants and providers during the transition to the NDIS in Queensland. Without this level of commitment, many participants would have been unable to continue accessing, or commence accessing the supports they needed.

The changing nature of the NDIS presents unique challenges to providers in the early childhood early intervention sector, and AEIOU will address this in line with the terms of reference in this submission. 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 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.

AEIOU was founded in Queensland, with the Queensland Government proving to be a leader in the provision of supports for young children with autism, delivering block funding for all children under six years with a diagnosis to ensure they have the best opportunity to develop life-long skills.

Since the rollout of the NDIS, this kind of support is less predictable for many families, and children with a 'level one' diagnosis typically receive minimal support, certainly not enough to access evidence-based services which meet the Good Practice Guidelines. This is despite the premise of the NDIS, which was based on a promise that nobody would be worse off following the rollout of the scheme.

There is a level of uncertainty for both providers and participants during the founding years of the NDIS, inarguably the largest social governmental reform experienced by this generation of Australians.

Since the NDIS was established across the country, many providers have experienced 'thin markets' and subsequent challenges with staffing, along with significant pressure to staff with increased reporting needs and additional time spent managing paperwork and advocacy.

AEIOU must continue to adapt its service offering, being flexible to ensure it can meet the needs of children but also respond to the diverse and often insufficient plans provided to children. These are often less than a child with the same diagnosis would have received prior to the NDIS rollout, and are not always consistent with a child's needs. Increasingly, they are indicative of a parent or guardian's understanding of their child's changing needs, the services available and their ability to advocate on their behalf.

In addition to these challenges, changes to the Price Guide with minimal notice, challenges to the review process for both participants and providers, and a general lack of understanding of autism and how it impacts individual children and their family unit, and lack of understanding of good practice early intervention, are significant issues AEIOU must respond to when engaging with the NDIS.

This submission addresses the following terms of reference:

- the efficiency and effectiveness of the NDIS market
- structural, regulatory or other impediments to the efficient operation of the NDIS market
- factors affecting specific markets or market segments, including in rural and remote areas
- options for improved policies and measures to ensure the NDIS market meets the needs of participants now and in the future.

Submission

Here, AEIOU addresses four terms of reference:

- **the efficiency and effectiveness of the NDIS market**

A weakness in the planning approach is that NDIS and Partner develop plans with a 'one size fits all' approach; this is a barrier to the efficiency and effectiveness of the NDIS market. Families with children diagnosed with Level 2 or Level 3 Autism are most often given a "typical support package". This is valued at approximately \$20,000 and results in just 1-2 hours therapy per week for those seeking private therapy.

However, the Australian Good Practice Guidelines recommend each child with such a diagnosis will benefit from between 15-25 hours of early intervention therapy each week. This scenario not only causes disadvantage for the child and family, **it charts a substandard developmental trajectory for the child, thus reducing effectiveness of the therapy.**

This approach demonstrates that the NDIS is not completely embracing the development of a broad diversity of supply solutions and is not encouraging a competitive market outside of this price bracket. It also does not allow for innovation in the delivery of supports which is a key component of being the market steward.

Other consequences include driving support models within this price bracket, impacting the future of the NDIS and creating financial burden within the community in terms of the increased need for longer term support, which far outweighs the cost of investing in a child's skill development for future inclusion and community engagement in the future.

Further, where the NDIS has developed efficient practices, these have not always proven effective for families, or providers.

How families are affected:

Families often struggle to understand the bureaucracy of the scheme, compounded by the fact that during the early years of their child's diagnosis, they are still gaining knowledge about autism, their child's changing needs, and their family needs while raising a child with autism. The short time frame they are provided with to gather understanding about what is considered good practice early intervention and/or evidence-based services, compounds their struggle.

This is impacted by the lack of transparency around what the NDIS will and will not fund, the review process, and the terms of reference which change. For example, the level of supports available to a family presents inequity. The awarding of funds and plan to families based on a child's 'classification' rather than their needs, or based on their parent or guardian's ability to advocate on their behalf, has emerged as a major issue.

Likewise, the length of time they can receive those supports for and the level of support a child receives when transitioning to a school environment is unpredictable and often inadequate.

There appears to be a fundamental belief that once a child commences at school, it becomes the State Government's responsibility to facilitate transition and ongoing support. This should be a partnership to ensure a child has the best chance to access their education and become part of their local community. Instead, there is a tapering of funding, with an assumption a child will improve at a linear rate, and a lack of understanding about the ongoing need for intensive supports, even for children who may be developing their skills at a slow rate.

Children ready for Prep have their plans significantly cut, rather than allocating ongoing funds to support that child therapeutically during their first years of school. This equates to a fundamental belief it is a State government issue, rather than a national interest.

How providers are affected:

The subsequent need to advocate and support families during these years places pressure on service providers, in addition to the unpredictable nature of enrolments and plan renewals, with providers such as AEIOU taking financial risk to maintain the enrolment of children during their review periods.

There are other issues which affect providers, with a recent example being the changes to the NDIS price guide.

Where the NDIS aims for efficient practices, it has with less than one month's notice, removed an entire line from the price guide. Notwithstanding the inadequate notice period to implement significant changes to the price guide, there was also a lack of consultation with providers, and a lack of regard for evidence-based, best practice supports currently available to NDIS participants.

The management of this price guide launch did not take into account the time it takes to revise billing structures to ensure business continuity and feasibility, or the time it takes to consult with participants regarding changes to the price guide, how it impacts them and how it will influence their service delivery and billing structures. Other impacts include the time it takes to rewrite and issue hundreds of service agreements and ensure families have adequate time to review, sign and return these documents.

- **structural, regulatory or other impediments to the efficient operation of the NDIS market**

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 underpinned by stress and grief. It is subject to the opinions and lack of training or the time constraints experienced by planners. By failing to provide a straightforward 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 ability for families to exercise choice and control and experience the long-term benefit of early intervention is also hindered.

AEIOU seeks to ensure families are not disadvantaged based on where they live, the knowledge they have regarding the supports available, their cultural 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; long-term research shows benefits for children as they grow and develop (Howlin, 1997).

An example of a structural process which requires improvement is the review process. While improvements have been made to timeframes it is no easier for families to navigate. In summary:

1. Children with level 2 and 3 autism diagnoses most often receive a low value plan, which makes reviews a necessity for families seeking service providers like AEIOU who specialise in providing more intensive supports.
2. The process of getting the review has been between a 2-4 month timeline at best for AEIOU families, but we acknowledge this is in regard to both s48 and s100 reviews. In the Quarterly Report Data, is it stepped out whether the speed-related result could be skewed in terms of the numbers of reviews that are unsuccessful? We are also mindful that this trend might differ in different age groups and be based on the reviewer's understanding of an individual's needs.
3. While the funding structure under the NDIS presents unique choice of reasonable and necessary supports to families, the reliance of low value plans and subsequent reviews present barriers or delays for families, and pressure points for providers who deliver intensive supports in addition to an unnecessary build-up of reviews for the NDIS. An option we have canvassed is to introduce a more robust intake assessment from the beginning. However with the volume of families we would

need to do this for, it would certainly incur further costs which AEIOU would need to pass on to families at least in part.

One of the greatest challenges with autism is that each individual can present differently, and it is not a physically obvious condition. Some planners understand the nuances while others do not, and are of a false belief that a mainstream enrolment with 2 hours of therapy per week will be sufficient. While inclusion is our end goal, we know the children with level 2 and 3 diagnoses have the best chance to achieve success in those inclusive environments with the right support from the beginning.

AEIOU Foundation responds to requests from families who require supporting documentation or advice as they navigate the review process for their children's plans. In our experience, unscheduled reviews are becoming a standard event for those children with Level 2 or 3 Autism who have received a typical support package but have need of intensive support. These reviews are taking an extraordinary amount of time, often between four and eight months. This causes uncertainty and anxiety for families. It also builds inefficiency into the NDIS which is seriously challenging Provider organisations' resources and practices.

Case Study: A waitlisted family experience:

During their planning interview in June 2020 with their Early Childhood Early Intervention (ECEI) planner, the family requested that their child attend AEIOU Foundation's service. However there would not be a placement available at AEIOU until January 2021. So, the family asked for a 6 or 9 month plan to be written to align with a January 2021 start. The planner advised they firstly had to check with their team lead, if they could write plans of this length, as typically plans are for 12 months. The advice was that it had to be a 12 month plan and without a place being currently available they could not write an intensive plan. The family were then locked into 12 months, on a low value plan.

This outcome occurred despite the planner acknowledging the complexity the family would endure in attempting to convert a typical low value support package to an intensive plan. The planner recognised that with a 12 month Plan, a review would have to occur at about the 6 month mark, which would cause the family difficulties. Their review time frame would fall beyond the first 100 days – the approved timeline a family may make this request based on being dissatisfied with their current plan. It would also fall outside the last 100 days of a plan - when an early review is more easily actioned. So, any review would have to be a Change of Circumstance Review. The parents would have to provide evidence of this Change (most likely in the form of a report from their current provider).

Problematically, this kind of situation sits outside the scope of what one could reasonably claim a Change in Circumstance – which is defined as involving:

- *Changes to your disability needs*
- *Significant changes in your care or support provided by family or friends*
- *Changes to your living arrangements such as where you live, if you live with new people, if you move overseas or into an aged care or residential facility.*
- *Changes to your job or that you're looking for a job; or*
- *If you receive or claim compensation for an accident or illness related to your disability.*

The reality for this family is:

- *The initial Plan was inappropriate and insufficient and was driven by rules (requiring instant availability of a placement at AEIOU, and not allowing a temporary period of support i.e. six*

to nine months duration), which is leading to known poor outcomes and stress for the family.

- *The process governing allocation of such an inappropriate Plan was not only manifestly inflexible, it was followed despite the knowledge of the difficulties that would inevitably follow regarding achieving a review.*
- *The rules governing reviews are such that in this case the possibility of achieving a review of any sort is greatly diminished for no good reason, other than the consequences of timing.*
- *Further, the rules for achieving a Change of Circumstance Review are also clearly written with adults in mind. They are simply a poor fit for children and families.*

This is not planning with flexibility for newly diagnosed children and their families who are in the early learning stages of understanding their child's disability and the supports they need. AEIOU would request an improvement to this system, where plans have more flexibility in their length e.g. three, six, nine, and 12 months, before extending to two years, with associated funding.

Other challenges with unscheduled reviews include that this process is now managed by a National Review Team. This arrangement has had negative consequences for parents and Providers in comparison with the prior situation where Partner organisations could liaise with local delegates. Not only does the National Review Team lack important **local** knowledge, the Partner no longer has a direct connection with the process, and the parent and Provider must accept ignorance of the progress status of the process.

- **factors affecting specific markets or market segments, including in rural and remote areas**

Overall, the scheme is built on insurance principles, with a mandate to reduce costs over time and using an actuarial approach. This produces a conflict with the stewardship of the NDIS, which needs to be responsive and efficient. It is apparent where needs are not being met, for example, the six and seven year old market. The ECEI presents non-flexibility for families receiving their first plan, and during the review process if they seek an alternative level of source of care.

Further, by failing to invest in this area, there is further impact on an already thin market of providers, with only a select few who can afford private services. This does not encourage innovation or the establishment of an adequate number of good practice services for growing children.

Childhood sector vs adult sector rules

Children aged under seven are often experiencing delays when accessing appropriate levels of support. The review process presents delays, the time taken to access a correct plan is excessive. Adult rules affect this – parents need to have the flexibility to change their child's plan as they learn more about their child's disability and what they need. A diagnosis does not mean a family knows what the child needs straight away. There is an assumption that parents are equally capable regardless of how new the diagnosis is, how equipped the parent and how educated the parent is. When measuring a child's functional capacity, the family's capacity must also be assessed, meeting their needs in these early years. There is little support to families to receive additional training, respite or support. This immediately changes once a child turns seven based on different criteria.

Rural market

Children and families living in rural areas are greatly disadvantaged based on their ability to access specialist support. Market stewardship is essential. While a child may receive a plan with rural prices, there are typically no local services that can provide the required supports. For example, since July 2020, AEIOU has enrolled four children from Alice Springs – two have commenced in Townsville, Queensland, and one in Adelaide, South Australia. This is not uncommon. Families move from and commute from areas all over

Australia in order to access regional and metropolitan sites operated by AEIOU. In this recent example, the children in question did receive a higher value of funded plans, but there was no market in the area to provide the support: so, the family needed to relocate away from family and friends and community supports, in order to access the intervention their children needed.

The families are also subject to paying for their relocation costs and the need to re-establish employment and new community connections.

- **options for improved policies and measures to ensure the NDIS market meets the needs of participants now and in the future.**

Recommendations

- That the NDIS partners with all registered providers, to ensure families have true choice of where their children may receive supports.
- A market where families can have access to planners or autism advisors to provide guidance in the early years of an autism diagnosis, with expert, unbiased advice.
- Ensure early childhood plans have more flexibility in their length e.g. three, six, nine, and 12 months, before extending to two years, with associated funding.
- Establish greater understanding of support needs during early childhood learning, including the first years of school utilising a collaborative approach between governments.
- 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.
- Guaranteed funding for early childhood supports and into their first years of school, truly up to the age of seven as per the Scheme's age provision with a collaborative approach between the NDIS and State Government to provide the best supports to the child and invest in their future. Failing to do so discourages growth, impeding any school's ability to foster genuine, true inclusion where children with autism can stay and succeed in a mainstream environment.
- Further market solution would enable external services to provide specialised supports to assist schools and education providers to ensure these children are able to access education in an inclusive environment where their needs are respected and understood, and their skill development is fostered. The child spends most of their time at school, this should be where they are encouraged to engage, connect and be part of their immediate community, which is impossible if they are not supported to learn or access their education over a lifetime, starting in their foundation years of primary school.
- Reinstate small-group intervention price guide line-item in the 2020-2021 iteration of the NDIS Price Guide in the ECEI space.

Conclusion

AEIOU Foundation recognises the challenges of establishing a major reform such as the NDIS and commends the Australian Government and State Governments for the progress made to date. However, there are systemic challenges which need to be addressed to ensure the futures of young children are not disadvantaged, family units do not experience distress, including financial and emotional burdens, and organisations delivering good practice early intervention, therapy and care remain viable.

While the challenges do not all sit within the scope of the Queensland Government to directly address, there is opportunity for partnership in some areas, most particularly in relation to supporting young children in the early years of their primary school education. This should not be the full and entire responsibility of the state, and should be consistent across the country, demonstrating a genuine desire to insure against future academic and communication exclusion for these children.