Productivity Commission Review of National Disability Insurance Scheme

About this submission

As chairman of AEIOU Foundation and the father of an adolescent child with severe autism, I welcome the opportunity to provide a submission to the Australian Government Productivity Commission's review into the costs of the National Disability Insurance Scheme.

My son was diagnosed with severe autism spectrum disorder (ASD) in 2001 at the age of 2. He is now 17, attends a special school, is training for entry to the workforce, is verbal and independent, and has exceeded all our expectations as to who he is and what he can do.

Our experiences in the early years led us as to a family to invest significant personal and financial capital to establish AEIOU. The AEIOU program started in 2005 with the aim of providing families with children with moderate and severe ASD (representing a severe to profound disability) with affordable access to high quality evidence based intervention. Over the subsequent decade we have opened 10 such centres with the organization currently employing 160 skilled ASD professionals supporting 250 pre-school children with moderate and severe ASD. Prospective studies have demonstrated highly significant gains in age adjusted scores for expressive and receptive language and reduction in autism symptoms and behaviours. Nearly all children are toilet trained at 3 months, 90% have functional communication at 12 months, and consistently over the last decade 70-80% of these children have successfully transitioned into mainstream school settings (against an expectation of around 20% based on entry scores). Outcomes achieved are independent of a child's social or financial circumstances with over 35% families having total household incomes below $40 000pa.We have developed Australia's first early childhood curriculum for children with moderate and severe ASD and are at the time of writing launching a unique and extensive on line training package.

We have participated with Synergies Economics in evaluating the cost of ASD ($10B pa) and assessing the benefit cost ratio for high quality early intervention meeting the Department of Social Services evidence based guidelines for young children with moderate and severe ASD (B:C ratio 11.3 based on a 2 year investment of $100 000 2012 AUS).

This submission outlines national and global rates of increased diagnosis of ASD with significant challenges to the National Disability Insurance Scheme (NDIS), particularly in the area of early intervention funding and delivery.

Key learnings, international research and economic forecasting underpin this submission, which proposes a process of objective diagnosis and ascertainment linked to tiered early intervention pathways and provides preliminary cost modelling and workforce recommendations.

Autism diagnosis and ascertainment

The last 20 years have seen a large increase in ASD diagnosis rates nationally and internationally. Whilst diagnostic pressures have been raised (e.g. Carer Allowance, Helping Children with Autism package, school classroom resourcing) it is clear that change in diagnostic patterns, including reclassifying children with intellectual impairment (Girirajan et al, 2015) and increased diagnosis of children with less severe behavioural symptoms (Whitehouse et al, 2017) has occurred.

Currently ASD 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 made by a Paediatrician or Paediatric Psychiatrist. Personal communications indicate considerable pressure at times being applied by the education system on medical services to provide a diagnosis to facilitate increased support in the classroom for children with challenging behaviours. While there are objective tools that can be used to assist in diagnosis and ascertain severity these have not been widely used or funded in Australia to this point.

The Productivity Commission, in establishing guidelines for the NDIS, recommended the use of tools that could be broadly applied and the establishment of tool kits that could be nationally applied. In 2014 AEIOU submitted a paper to the NDIS (Appendix 1) outlining a possible such tool kit for young children with ASD to both verify diagnosis and ascertain severity, linking severity to early intervention supports. The provision of an objective assessment toolkit can be costed and capacity can be developed such that these can be routinely applied as part of the assessment linked to NDIS early intervention pathways and packages, with serial evaluation being included in ongoing assessment, outcome reporting, research, and package allocation.

Early Intervention

There is a large body of evidence establishing the benefits of intensive behaviour-based early intervention for young children with ASD. These are summarised in the Department of Social Security's Guidelines for Good Practice. These guidelines were initially developed by the Commonwealth Department of Health and Ageing in 2007, and updated in 2012 by the Department of Social Security. The guidelines recommend individualised programming based on a detailed assessment of a child's strengths and weaknesses, with early intervention starting as early as possible and continuing as long as required, and including 15-25 hours per week, autism specific therapy, delivered by autism-trained professionals with a majority having a minimum of two years'

experience as part of a multi-disciplinary team, and with a staff-to-child ratio of a minimum of one staff member to every three children (Figure 1). It is important to note that the children enrolled in these studies were diagnosed with ASD during the 1990s and early 2000s and represented children at the moderate and severe end of the spectrum.

Figure 1

Structure

- Individualised Programming: based strengths and weaknesses
- Highly supportive environment: predictability, routine
- Autism specific curriculum
  - Attention, Compliance, Imitation, Language, Social Skills
  - Functional Approach to Behaviour
  - Visual Support
- Family involvement
- Transition support
- Evaluation, Review, Adjustment
- Research

Timing

- Early as possible, long as needed
- 15-25 hours, 2 years

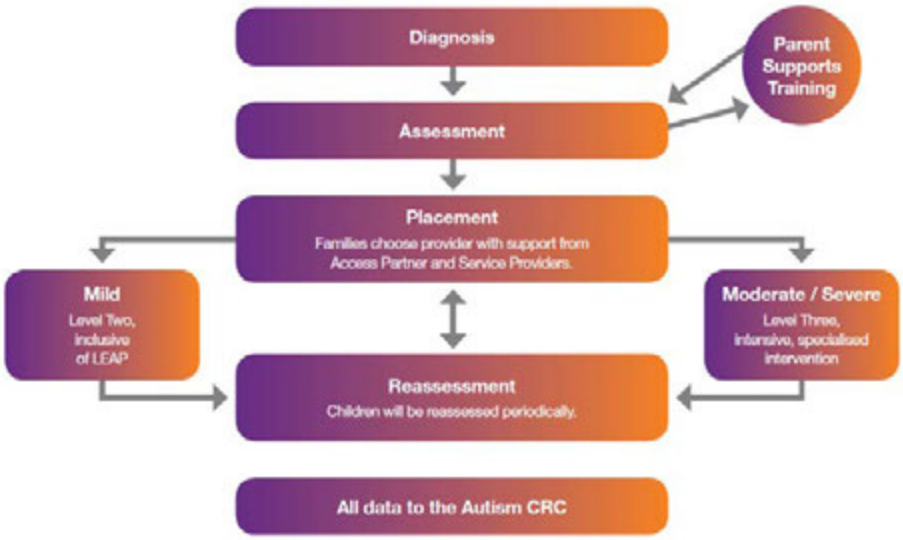
Staffing

- Multi-disciplinary collaborative team
- Autism trained, majority 2 or more years of experience
- Continuing Personal Development
- Ratio not less than 2 adults per 6 children

Preliminary versions of the NDIS Early Childhood Early Intervention (ECEI) policy focused on delivery of support in an inclusive setting and the home, with the onus on parents being responsible for delivery of early intervention. Positive outcomes in mainstream settings have been limited to children with mild/high functioning ASD with no improvements for children with moderate and severe ASD (Fernell et al, 2011, Strain et al, 2011). A Cochrane Review found parent training programs failed to produce gains in primary outcomes for children with ASD, although improvement in parent-child interactions was strong and statistically significant (Oono et al, 2013) emphasizing importance as component of but not a replacement for evidence based early intervention.

This paper proposes an interconnected 2 tier model for delivery of NDIS ECEI for children with a confirmed diagnosis of ASD (Figure 2).

Figure 2 Connected Universal Service Model for Children with ASD



Tier 1 (Intensive ASD Specific) will be for children ascertained with moderate/severe ASD and will benchmark the Guidelines for Good Practice (2012). Tier 2 (Mainstream ASD Supported) will provide multidisciplinary therapy (behavioural/speech/OT) support to mainstream placements (childcare, kindergarten, Prep) for children ascertained with mild ASD. The tiers are connected in such a way that children who improve in the intensive model and develop appropriate skills can transition in a continuous manner between the tiers, while children who struggle in the mainstream tier, generally due to behavioural issues, can transition into the more intensive tier for such a period of time as necessary to develop the skills required for a mainstream setting (see appendix 2, real world case studies).

In all cases, children will be assessed objectively at six monthly intervals with associated package reviews based on progress achieved. It is anticipated that in general children who are ascertained as moderate/severe will spend two years in Tier 1 programs. Agency assessments could be incorporated into individual program reviews at these six monthly updates, with consideration to additional needs families may require to build family capacity and support inclusion of their child in society addressed.

Tier 2 packages would attract additional support through existing kindy and childcare inclusion support schemes (up to $25 000pa). Alignment of NDIS funding and Inclusion Support Schemes should be considered.

Costing

Modelling has been based on an ASD prevalence of 1/100 (100:10000) with moderate/severe 1/250 (40:10000, Parner et al, 2011) and mild 1/160 (60:10000). A second model is presented based on more recent ASD prevalence estimates of 1/66 (150:10000) and assumes the majority of new diagnoses are children with milder features (moderate/severe 1/200, mild 1/100) with reduced costs of early intervention in the second tier ($10000 pa) reflecting milder spectrum features.

The tier related costs are based on the NDIS price guide:

- Tier 1: item 15_039_0118_1_3 group based intervention of 1 adult to a maximum of 4 children ($58.53/hr, 20 hours per week, 48 weeks pa, 5 public holidays): $55 000pa.
- Tier 2: item 15_040_0118_1_3 individual specialist interventions ($175.57/hr, 1-2 hours per week): $8500 - $17000 pa.

Assessment of Economic Benefits are based on work performed by Synergy Economics (2013) which found lifetime benefits following intensive intervention for children with severe ($1.3M), moderate ($1.2M) and mild ASD ($0.75M) adjusted to 2017 values. A key observation of this work is that the greatest economic benefit was associated with minor behavioural improvements for children with severe ASD.

Table 1a: ASD Prevalence 1/100 (100/10000)

	New Cases	Packages	Cost/Package	Total Cost	Benefit
Profound	600	1200	55000	$66M	$858M
Severe	600	1200	55000	$66M	$792M
Mild	1800	3600	12000*	$43M*	$1440M*
Total	3000	6000		$175M*	$3090M*

Table 1b: ASD Prevalence 1/66 (150/10000)

	New Cases	Packages	Cost/Package	Total Cost	Benefit
Profound	900	1800	$55000	$99M	$1287M
Severe	600	1200	$55000	$66M	$792M
Mild	3000	6000	$10000	$60M*	$2400M*
Total	4500	9000		$225M*	$4479M*

**: does not include funding costs associated with Childcare and Kindergarten based Inclusion Support Schemes ($15 000 - $ 25000 pa).*

We have estimated the cost of the assessment toolkit at $1200 applied to 1:66 children at annual cost of $5.4Mpa with 6 monthly updates limited to Tier 1 packages ($7.2Mpa), total cost of $12.6M.

Workforce Issues

The provision of National Tier 1 and Tier 2 ASD specific early intervention services will require a workforce of ASD specialised behaviour therapists, speech therapists, occupational therapists, early childhood teachers and learning facilitators. While there are sufficient training placements for speech therapy, occupational therapy and early childhood teaching, specific skills to work with young children on the autism spectrum are limited and targeted learning modules and accredited masters programs should be developed.

There are no behavioural training pathways in Australia with the current limited workforce trained in the United States, Europe or New Zealand. Need for these services extends beyond early intervention to the school system and is substantial. Universities should be encouraged and supported to provide behavioural training pathways for existing and future teachers and therapists. Behavioural training programs require considerable supervised training time by a registered behavioural therapist with NDIS ECEI Intensive ASD Specific (Tier 1) services ideally placed to provide such in partnership with accredited university programs. This should be considered in funding design.

Specific Questions February 2017 Issues Paper

In the early childhood area there are 2 main drivers for demand exceeding expectations: increased diagnosis of childhood ASD and inclusion of children with developmental delay. As this paper outlines diagnosis of childhood ASD has broadened to include many children with “milder” features of the condition. These children by and large would not have been diagnosed in previous times when many of the studies that provide the evidence for specialized early intervention were recruiting. The previous PC review and subsequent NDIS guidelines for tier 3 services targeted “a much smaller group of people with significant care and support needs related to a permanent disability”. For the early intervention component it was recommended that there be “good evidence that the intervention is safe, significantly improves outcomes and is cost effective”. The NDIA has chosen to broaden criteria for support beyond those children with a severe/profound disability to include children with developmental delay, and has removed specificity around diagnosis and associated evidence based early intervention. Furthermore, existing Childcare and Kindergarten

based schemes for supporting children with a disability have not been considered in the overall scheme design and assessment of comparative total costs of different models of service delivery.

For children with moderate and severe autism there are evidence based Commonwealth Government Guidelines for Good Practice in early intervention. It is problematic that these guidelines exist but the NDIA through its assessors are not universally providing plans or funding that recognize such. Our experience in Adelaide and Townsville is that the current subjective assessment process is resulting in widely different package allocation for children not as a result of differences in need or symptom severity but rather based on the ability of their parents to advocate and the post code in which live.

For children with ASD this paper proposes a formal objective assessment process with the application of this tool kit confirming diagnosis, ascertaining severity, identifying personal strengths and weaknesses and guiding fair and targeted package allocation: intensive behaviourally based early intervention for children with moderate and severe ASD as per the government's evidence based guidelines and a mainstream ECEI package that interacts with existing childcare and kindergarten inclusion support schemes for children with mild ASD. The assessment process as attached is valid, reliable, accurate and cost efficient. It provides baseline and subsequent follow up data for the agency and long term follow up studies and can be used to diagnose and ascertain children with ASD. Such objective processes will be vastly more targeted in producing the best outcomes for children according to their needs than the current subjective and highly variable approach with current assessment processes.

The proposed early intervention tiers are interlinked in such a manner that children can move between tiers based on subjective and objective assessment of progress (performed as part of their individual plan) with linked transition packages. Illustrative real world cases are provided in the appendix. An objective diagnosis of moderate or severe ASD would result in an appropriate NDIS package to access programs providing services in accordance with the Government Guidelines for Good Practice with additional needs to be determined by an assessment process. Based on existing item 15_039_0118_1_3 for group based intervention maximum of 1 adult to 4 children ($58.53/hr) and the Guidelines for Good Practice (15-25 hours per week, ratio of adults to children 1:3: 20 hours per week, 48 weeks pa, 5 public holidays), base funding package of $55 000pa is recommended. On average this will be required for 2 years with a long term savings (predominantly to the agency in

terms of reduced costs of care) of $12.30 for each $1 spent. A child with an objectively confirmed and ascertained diagnosis of moderate to severe ASD should not require an assessment by a planner to receive such a package. Planner involvement should be around the other things that a family / carer requires which can be determined in partnership with the early intervention provider to support the child's inclusion and participation in society and ideally would be reviewed in parallel with a child's Individual Planning Meetings (reviewed 6 monthly and as required as per Guidelines for Good Practice).

Conclusion

The NDIS represents a key opportunity to develop coordinated pathways to provide appropriate early intervention for children on the autism spectrum. The development of such pathways will require an objective diagnostic process and ascertainment, a process of continued subjective and objective assessment monitoring linked to passage through early intervention from specialised programs to inclusive mainstream placements, will cost in the vicinity of $200,000,000 per annum or approximately 1% of the NDIS budget, with annual lifetime savings to the Australian community estimated to exceed $3 billion per annum.

Yours sincerely

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