

5 August 2015

Joint Standing Committee on the National Disability Insurance Scheme
PO Box 6100
Parliament House
Canberra ACT 2600

The Members of the Joint Standing Committee on the National Disability Insurance Scheme

NDIS and Proposed Funding of Early Intervention for Children with Autistic Disorder

Following the media coverage in the Australian regarding the greater than expected applicants to the NDIS in the trial sites for people with Autism Spectrum Disorder and the concerns raised over affordability to the scheme. We wish to again highlight the raising of these issues by AEIOU to the Committee last year and reinforced at the Committee hearing last year.

We wish to reinforce the urgent need for policy development in this area around proper objective assessment to determine the reasonable and necessary supports for the individual. The estimate of need for intensive early intervention is in the region of 2,500 scheme participants each year across the country. Appropriate investment in early intervention will ultimately provide a return on investment by a factor of 11:1.

Estimate of need provided in previous submission:

Children with autistic disorder represent a subgroup of children on the autism spectrum. Most recent reports suggest prevalence of around 40/10000 (compared with 60-100/100000 for autism spectrum). Providing an average of 2 years of funding at \$34 000 for autism intensive early intervention as compared to the \$16000 2 hour trans-disciplinary support item will require incremental funding of \$43-\$54M pa (or <0.25% of the NDIS funding umbrella).

**\$34 000 pa based on data from the Olga Tennyson Centre and the AEIOU Foundation and represents the additional costs of early intervention (staffing, additional floor space, additional materials) over and above the cost of providing childcare in these service models.*

40/10000 of 300 000 births pa = 1200 new diagnoses, average 2 years = 2400 packages. Model 2400-3000 packages, incremental cost of \$18 000 (difference \$34 000 and current \$16 000): total incremental cost \$43M-\$54M (0.2-0.25%).

AEIOU has provided recommendation to the NDIS on suggested objective assessment and a copy of this is attached.

Detailed below is an extract from our previous submission to the committee. The recommendations on investment in line with the Good Practice Guidelines remain accurate and we implore the Committee to support these recommendations and advise the NDIA accordingly.

Funding Levels Identified for Early Intervention Supports

- a. Research around adequate funding support was limited to generic disability providers in the Barwon area with no tension around the outcomes that they produce. Autism disability support*

providers were not consulted when researching reasonable and necessary supports for children with autism spectrum disorder. Limiting high level funding support to \$16,000 per annum does not provide the individual with the ability to purchase supports that meet the Commonwealth recommended Good Practice Guidelines of 20 hours per week of intensive therapy support.

- b. The NDIS has ignored the Commonwealth Department of Health and Ageing / DOSS evidence based guidelines. NDIS officers have stated that quality is more important than quantity (guidelines state both are important), that the NDIS has evidence that the same outcomes can be achieved with less cost (no such evidence when challenged), and that the evidence for intensive intervention is not strong enough to fund (despite 2 detailed reviews by leading academics with consequent guidelines developed, and contrasted with the NDIS proposed model for which a recent Cochrane review concludes no evidence of benefit in any of the primary outcomes for a child with autism: see 2c below).*
- c. The proposed rewriting of the Good Practice Guidelines by the NDIS is of great concern to the autism community as the guidelines have undergone 2 previous reviews and they currently provide consistency with those in most other western countries. This will be viewed by the autism community with scepticism and fear, and carries great potential to damage the NDIS brand.*

Funding

- a. Currently the funding offered to a child is insufficient to deliver quality early intervention that meets the guidelines for good practice. The funding required is \$34 000 pa (based on Olga Tennyson Centre Early Start Denver, AEIOU data).*
- b. Inadequate duration: funding should continue from diagnosis to school age whilst objective benefit is derived.*
- c. Poorly applied:
 - i. Proposed trans-disciplinary support item, up to \$16 000pa for 2 years, is expected to provide a therapy based program to build capacity of the family to deliver early intervention. Based on therapy charges and travel component under the NDIS of \$164/hr it is likely that this package will provide 2 hours or less early intervention (against guidelines 20 hours) directed at building family capacity (a component of but not a replacement for good practice) with recent Cochrane review (Ooho et al) indicating that there is no evidence for effectiveness of such processes for any of the primary outcomes of autism. Similarly the "Building Blocks" program cited by the NDIS as evidenced based showed no differences in outcomes compared with the control group not attending the program (ie the only evidence was for ineffectiveness).**

- ii. *The NDIS currently places the responsibility for delivering early intervention with the family or carer irrespective of their needs. This negates the opportunity for families to participate in the workforce, to participate in the lives of their other children, enjoy social opportunities others take for granted) and the capacity of single mother/parent families are placed at a social disadvantage. The NDIS officers state “that the primary responsibility of the family is to provide for their child with disability, including early intervention, and they state that where they don’t have the capacity the child can attend a playgroup”. It is ironic that the NDIS seeks to build workforce capacity for the disabled but does not respect the rights of the family of a child with a disability to participate in the workforce or the lives of their other children, and supports playgroups for which there is no evidence of effectiveness.*
- iii. *For the majority of children and their families this model will be ineffective, a waste of tax payer money, and a lost opportunity for the child and their family.*
- d. *Nonsensical: as proposed maximum investment on EI over a child’s lifetime (\$16000pa for 2 years = \$32000 lifetime) is less than the average annual package for an adult with a disability. Surely an insurance scheme would focus on building ability wherever possible to mitigate the costs of long term disability.*

Assessment Process

- a. *Funding provided is currently based on subjective and generic assessment of a child’s disability and severity rather than their specific early intervention needs and the potential for gain that can be achieved. Attached – Appendix 1 is a proposal that was forwarded to the NDIS around a recommended framework of assessment. The NDIS has thus far shown no interest in a more structured and objective assessment procedure.*
- b. *AEIOU has within the assessment recommendation provided advice around ongoing objective assessment that can potentially inform the NDIS when an Early Intervention transition point is reached and the child is ready for a reduced level of support – therefore potentially saving the scheme significant investment in Early Intervention supports that the child no longer requires.*

If you require any further clarification we would be happy to meet with you for further discussion.

Yours sincerely

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Appendix 1 – AEIOU Recommended Assessment tools for children with Autism Spectrum Disorder