



Submission to  
Joint Standing Committee on  
the National Disability Insurance Scheme

Inquiry into  
Provision of services under  
the NDIS Early Childhood Early Intervention Approach

10<sup>th</sup> August 2017

## Summary response to terms of reference

Following is brief response to each item in the terms of reference. After that, there are detailed discussions of NDIS ECEI Approach.

- a. *the eligibility criteria for determining access to the ECEI pathway;*  
The NDIS eligibility criteria for people with autism spectrum disorder are gobbledygook. The NDIA refuses to even discuss the matter with ASD stakeholders.
- b. *the service needs of NDIS participants receiving support under the ECEI pathway;*  
The NDIA asked for an update to two previous documents that describe the service needs of autistic children. Apparently, the result was not what the NDIA wanted. The NDIA chose to ignore expert advice that it received.
- c. *the timeframe in receiving services under the ECEI pathway;*  
There is no apparent difference in the timeframes experienced between the NDIA and the *Helping Children with Autism* package that preceded the NDIS.
- d. *the adequacy of funding for services under the ECEI pathway;*  
People in the disability sector have been told by various Ministers that NDIS funding, including ECEI funding, is uncapped. We are concerned that this question is even being asked.  
A4 understands that the NDIA's funding estimates for early intervention for autistic children may have been severely underestimated. This may result in cost pressure on the NDIA. A4 feels that this results from inadequate consultation/engagement with the ASD community.
- e. *the costs associated with ECEI services, including costs in relation to initial diagnosis and testing for potential ECEI participants;*  
ASD diagnosis services run by state/territory governments are slow (long waiting lists) and are often considered too unreliable. The cost of private ASD diagnosis is high and not covered by private health insurance.  
The diagnosis process for ASD is currently under review.
- f. *the evidence of the effectiveness of the ECEI Approach;*  
The report following provides numerous references showing why A4 expects the NDIS ECEI Approach will be largely ineffective for autistic children.

- g. the robustness of the data required to identify and deliver services to participants under the ECEI;*

The submission following describes how the NDIA refuses to include reasonable and necessary early intervention services for autistic children in their NDIS plans.

- h. the adequacy of information for potential ECEI participants and other stakeholders;*

In relation to autistic children, the NDIA has received sufficient information. The NDIA chose to ignore or misinterpret the information about ASD that it was given.

- i. the accessibility of the ECEI Approach, including in rural and remote areas;*

The [ANAO report](#) on the *Helping Children with Autism* package showed autistic children in rural and remote settings were not accessing services as needed. A4 cannot discern any effort from the NDIA to improve service access in the regions.

- j. the principle of choice of ECEI providers;*

As we understand it, the NDIA assigns an NDIS Access Partner to each applicant. Applicants have no choice and control over which NDIS Access Partner they are assigned to. And in the ACT, there is only one NDIS Access Partner so there is no choice.

- k. the application of current research and innovation in the identification of conditions covered by the ECEI Approach, and in the delivery of ECEI services; and*

The NDIA ignored advice relating to “current research and innovation” about early intervention for ASD in developing its NDIS ECEI Approach.

- l. any other related matters.*

A4 is focussed on early intervention in this submission.

## **About Autism Aspergers Advocacy Australia**

*Autism Aspergers Advocacy Australia*, known as A4, is the national advocacy group advocating for autistic people (or people with autism spectrum disorder), their families, carers and associates. From its origin in 2002, A4 had strong autistic representation in its management. Some A4 members are clinicians.

A4 is a member of the Australian Federation of Disability Organisations (AFDO), Disability Australia and the Australian Autism Alliance (AAA).

A4 gets no Government funding contribution toward its operating costs.

## the NDIS and early intervention for autistic children

Increasingly, families report that NDIS planners deny/refuse their request for an NDIS plan providing reasonable and necessary service in the form of best practice early intervention for autistic children.

The NDIA created its [Early Childhood Early Intervention \(ECEI\) Approach](#) and published it on 26<sup>th</sup> February 2016. The document can be downloaded from [a link](#) found on [the NDIS Information, publications and reports page](#) below the heading **Early childhood early intervention research**.

According to the NDIS website, the ECEI Approach first refers a child with disability to an NDIS Access Partner. Apparently, the NDIA assigns a child to an Access Partner: contrary to NDIS policy, the child and the child's family do not have "choice and control" over the Access Partner that they are assigned.

For a child with permanent and severe disability, the NDIS Access Partner may refer the child to a "NDIS access" process that is meant to lead to more intensive EI for the child. The NDIS assesses the child and decides whether the child will be granted NDIS access.

The NDIS webpage headed [Evidence of your disability: What to provide with your Access Request](#) says

To allow the National Disability Insurance Agency to determine whether you meet the disability or early intervention access requirements, you may need to provide us with evidence of your disability.

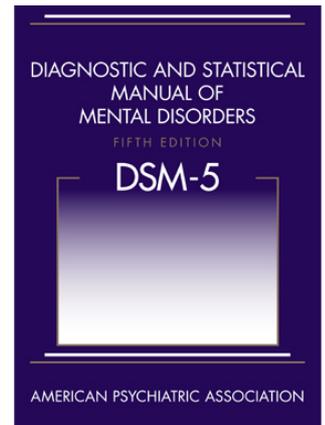
Further down the page, under the heading *Permanent impairment/functional capacity – no further assessment required*, the document says:

1. **Autism** diagnosed by a specialist multi-disciplinary team, pediatrician, psychiatrist or clinical psychologist experienced in the assessment of Pervasive Developmental Disorders, and assessed using the current Diagnostic and Statistical Manual of Mental Disorders (DSM-V) diagnostic criteria as having severity of Level 2 (Requiring substantial support) or Level 3 (Requiring very substantial support)

Since the NDIA first published these eligibility conditions, A4 has repeatedly informed the NDIA that these eligibility/access requirements are *gobbledygook* (for example, see <http://a4.org.au/node/794>).

The NDIA's eligibility conditions cause confusion because:

1. A DSM-5 diagnosis should be "autism spectrum disorder", not "Autism". Nor was it called "autism" under the previous DSM-IV.
2. The wording is ambiguous over whether all of "a specialist multi-disciplinary team, pediatrician, psychiatrist or clinical psychologist" or just a "clinical psychologist" needs to be "experienced".
3. The term "experienced" is spectacularly vague.
4. "Pervasive Developmental Disorders" comes from the DSM-IV; the DSM-5 classifies ASD as a "Neurodevelopmental Disorder".
5. The current manual is the DSM-5 ... A4 does not know what the DSM-V is, we just assume it means the DSM-5.
6. A DSM-5 diagnosis provides two severity levels for two aspects of the diagnosis; it does not deliver a singular (just one) severity level.



The NDIA's eligibility for "Autism" suggests that the NDIA subjects an autistic child with severity of Level 1 (that is severity below Level 2 or Level 3) to further assessment to determine the child's eligibility to become an NDIS participant and to receive an NDIS plan. A4 is concerned that the type of and criteria for this further assessment, nor the skill and experience of people conducting this further assessment, was never discussed with ASD stakeholders.

The [NDIS COAG Disability Reform Council Quarterly Report, Version 1 2017](#) indicates (to A4) that 98.8% of NDIS applicants who say they have "autism" are accepted as NDIS participants (see Table 2-12, on page 56 ... "autism" is only exceeded by Cerebral Palsy with 99.1% of applicants given NDIS access). There appears to be very little justification for reviewing severity of Level 1 "autism" diagnoses. And delaying access to the NDIS is inconsistent with the goal of supporting children based on their disability rather than diagnosis.

There seems to be some confusion over who is involved in developing the child's funding plan: it could be the Access Partner or it could be an NDIS planner.

In relation to autistic children (that is, children who are diagnosed with autism spectrum disorder), many families request that their child's plan provides best practice evidence-based early intervention for their autistic child. These families of autistic children ask for ASD-specific early intervention; these families want their child's individual needs to be met. The families of autistic children *rarely* ask for early intervention that is aimed at children with "developmental delay or (unspecified) disability".

The NDIA's ECEI Approach document itself does not contain a reference section. Instead, the NDIA cites three documents.

Three key research pieces form the basis of the ECEI approach:

- KPMG (2011), *Reviewing the evidence on the effectiveness of early childhood intervention*, Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA)
- Family & Community Services, NSW Government (2015), *Strengthening supports for children and families 0-8 years: Now and into the future*
- Department of Education and Early Childhood Development (DEECD), Victorian Government (2009), *DEECD Early Childhood Intervention Reform Project: Literature review*.

The common theme in these research pieces is a family-centred practice and timely, well integrated early intervention does promote optimal individual outcomes.

A report on Autism Spectrum Disorder (ASD) – *Autism Spectrum Disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers*, which the NDIA commissioned, also informed the ECEI approach.

The report highlights the need to match early childhood programs and services to the child's natural settings. It also notes parents need support to give their child an opportunity to gain and use the functional skills they need to participate meaningfully in key environments in their life.

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The three documents given are not “research pieces”. They are meant to be research reviews but they are reviews that were not conducted by researchers; nor do they use recognised research review protocols.

In adopting “a common theme” view, the NDIA chose a “one style suits all” approach. This approach, preferred by bureaucrats, diminished any person-centred planning that is meant to be a foundation for the NDIS.

A4 asks agencies including the NDIA to recognise and respect the distinct nature of ASD. But the NDIA's “common theme” view, ignores the distinct nature of ASD (and possibly other types of disability). If the NDIA cannot recognise the distinct nature of a condition like ASD, there is little or no prospect for the NDIS delivering person-centred services and supports for young autistic children.

In relation to autistic children, research does **not** support “family-centred practice” over individualised service and support directed clearly at the autistic child. For autistic children, it would be better to recognise that helping a child's family *usually* improves outcomes for the child.

Research outcomes suggest there is little or no benefit from providing generic early intervention for autistic children, so it is unlikely that the ECEI Approach that provides generic EI is cost effective for autistic NDIS participants.

Links to the three foundation documents for the NDIS ECEI Approach are:

- [KPMG 2011 document - https://www.dss.gov.au/sites/default/files/documents/05\\_2012/childhood\\_int\\_effectiveness\\_report\\_0.pdf](https://www.dss.gov.au/sites/default/files/documents/05_2012/childhood_int_effectiveness_report_0.pdf)
- FACS, NSW (2015) [http://www.adhc.nsw.gov.au/\\_data/assets/file/0018/330741/Strengthening-supports-for-children-and-their-families-0-to-8-years-Now-and-into-the-future.pdf](http://www.adhc.nsw.gov.au/_data/assets/file/0018/330741/Strengthening-supports-for-children-and-their-families-0-to-8-years-Now-and-into-the-future.pdf)
- DEECD Vic (2008) - <http://www.education.vic.gov.au/Documents/childhood/providers/needs/ecislitreviewsept2009.pdf>

The first of these reports, KPMG 2011, is written by Consultants with no discernible knowledge of ASD.

Its opening remarks say “there is a significant body of evidence on the effectiveness of ECI for children with specific types of disability or underlying condition (such as autism spectrum disorder, cerebral palsy), and the focus of this project has been to review the evidence from a broader perspective – that is, the effectiveness of ECI for children with a developmental disability or developmental delay regardless of underlying cause or condition”.

The report also says “while aspects of this report will have broad relevance for a range of ECI services, the focus of this report is on the Better Start initiative”. It says that the focus is **not** on the *Helping Children with Autism* initiative. It says “the conclusions outlined in this report are intended to be read in relation to [the Better Start] initiative only”. It makes this point repeatedly.

Clearly, the KPMG 2011 report **does not** address the specific needs of autistic children. Remarkably, the report shows that autistic children are a high proportion, a larger group, of EI recipients than those who can access the *Better Start* initiative for select non-autistic children.

Interestingly, the report summarises [research](#) into an Australian ECI approach, Aspect’s Building Blocks program, for specifically autistic children (the primary authors of the paper cited are also the authors of the ASD update that the NDIA mentioned above). This research article found that centre-based EI for autistic children was most effective. Subjects in the wait list (WL) ( “non-treatment” or control group) did better than those in the home-based (or family-centred) version. This contradicts the NDIA’s claims in its ECEI Approach that “family-centred” or home-based, at least for autistic children, is evidence-based best practice.

The article says “A potential influence on outcomes for parents in the [home-based/family-centred] group generally is the more severe nature of their child’s disability in terms of ASD diagnosis and cognitive ability

reflected in baseline data (despite randomisation between the [centre-based] & [home-based] groups).”

The article says “In reviews of interventions for children with autism (Dawson & Osterling, 1997; NRC, 2001<sup>1</sup>; Roberts & Prior, 2006) there is considerable variation of the optimal amount of intervention (intensity) that is recommended, ranging from 15 to 25 h per week.” The article fails to mention explicitly that the Aspect’s *Building Blocks* program falls well short of intervention intensity recommended in the reviews cited. Despite citing these reviews, the article does not identify outcome benchmarks and measure outcome relative to such benchmarks. Aspect’s Building Blocks programs cannot be considered “best practice”, and the KPMG 2011 report fails to recognise the issue.

The authors of the FACS 2015 report and the DEECD 2008 report have no discernible expertise in EI for autistic children. These report shows little or no awareness of the distinct nature of ASD. Their conclusions do not apply for autistic children.

These three documents do not provide any basis for the NDIA to claim that “family-centred practice and timely, well integrated early intervention does promote optimal individual outcomes” is best practice or evidence-based for autistic children. None of the three documents even looks for research or review articles about “optimal individual outcomes” for autistic children. The first article contradicts the NDIA’s claim as it relates to autistic children.

The NDIA’s ECEI Approach appears to be based mostly on the document [ECIA National Guidelines for Best Practice](#); A4 cannot now find a clear statement on the NDIS website of the role of this document in the NDIA’s ECEI Approach though there is an indirect link to the document on [the NDIS Information, publications and reports page](#) (see the final entry below the heading **Early childhood early intervention research**).

In relation to autism or ASD, all this document says is ...

#### **The role of direct intervention by specific professionals**

In addition to the body of evidence for the ECI sector there are also other bodies of evidence that suggest specific intervention for children with specific needs, such as cerebral palsy and autism spectrum disorder that lead to improvement in childhood development and skill development. This is particularly evident in disability-specific evidence. This evidence should be taken into

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<sup>1</sup> National Research Council. (2001). *Educating Children with Autism*. Committee on Educational Interventions for Children with Autism. Washington DC: National Academy Press.

While this major review is cited in the article being discussed, Roberts & Prior omitted this key review from their 2006 and subsequent research reviews/updates (more below).

account when providing services to young children. However, any specific intervention with young children should always be provided through the context of family centred principles, inclusive of coaching, and incorporated into everyday routines and settings. Therefore, providing ECI does not exclude the provision of specific targeted interventions, it is the way in which these interventions are provided and supported which is critical (ECIA, NSW Chapter, 2014).

The document cited (ECIA NSW, 2014, *Early Intervention Best Practice discussion paper*) does not support ECIA's claim, that "specific intervention with young children should always be provided through the context of family centred principles" since it does not address the specific needs of autistic children. ECIA's expectation that EI should "always" be family-centred (apparently, for *all* autistic children) is contrary to actual evidence.

A4 is disappointed that ECIA made this unsupported claim and that the NDIA accepted it in the face of extensive contrary evidence for its ECEI Approach for autistic children.

A4 believes the relevant evidence suggests that family context should be considered and included appropriately, rather than exclusively, in EI programs for autistic children. Similarly, naturalistic settings have important and valuable roles but evidence shows that they are not appropriate as an *exclusive* setting in provision/delivery of EI for autistic children.

A4 is not aware of any NDIA document that warns its planners that it's ECEI Approach is not applicable to autistic children. Nor is it aware that any planners have sufficient knowledge or training to reach this conclusion on their own.

In addition to ECIA's "guidelines", the NDIA commissioned an update to the Government's on-going review of research into early intervention for ASD. The previous parts of this developing report are:

- Roberts, J. M. A., & Prior, M. (2006). *A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders*. Australian Government Department of Health and Ageing, Australia.  
<http://a4.org.au/sites/default/files/2006RobertsPriorreport.pdf>
- Prior, M., Roberts, J. M.A., Rodger, S., Williams, K. & Sutherland, R. (2011). *A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders*. Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, Australia.  
<http://a4.org.au/sites/default/files/2012ASfARreport.pdf>

The update is limited. It is called *Autism Spectrum Disorder (ASD) – Autism Spectrum Disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers* ([PDF](#) or [MS Word](#), again from [the NDIS Information, publications](#)

[and reports page](#) below the heading **Early childhood early intervention research**).

Its title downgrades it to “good practice” rather than “best practice” and includes “evidence-informed” materials as well as “evidence-based”. It is about “supports” rather than “early intervention”. And its content examines a very narrow timeframe; it says “As this was an update of the Prior, Roberts, Williams, Rodger and Sutherland (2011) review, searches [for review articles] were limited to the period 2011–February 2015”.

These ASD-specific reviews have conclusions that differ substantially from the NDIS ECEI Approach.

It is hard to see how this latest update/advice “informed the ECEI approach” (as the NDIA claims in the NDIS ECEI Approach document); rather than understand the report’s content, the NDIA carefully “filterer” the report and re-interpreted phrases to suit the NDIA’s ECEI Approach. For example, the NDIA re-interpreted reports of evidence that an autistic student *may* benefit from some programming of appropriate intervention for a child in his/her natural settings to mean *all EI* for every autistic child should be delivered entirely/exclusively in “the child’s natural settings” (often before an autistic child is adequately prepared for a natural setting). The NDIA has misinterpreted and misrepresented the advice it received about early intervention for autistic children: an examination of all occurrences of terms “natural” or “naturalistic” in the ASD update shows *none* of them “highlights the need to match early childhood programs and services to the child’s natural settings” contrary to the claim made in the NDIS ECEI Approach (quote above).

The NDIS ECEI Approach document says “parents need support to give their child an opportunity to gain and use the functional skills”. In other words, the NDIA expects that parents are responsible for giving “their child an opportunity to gain and use the functional skills”, but that parents may need some support in doing so. Many NDIS planners and allied health clinician who are registered with the NDIA believe that parents of autistic children who are both under-trained and under-resourced are responsible for providing all or most of the intensive specialised clinical intervention that their autistic child needs.

There are several issues here.

1. Article 23 Section 1 of the [Convention on the Rights of the Child](#) says the state, not the parents/family, is responsible for ensuring an autistic child, as “a mentally or physically disabled child”, has the right to appropriate and effective early intervention (or “conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community”). Section 2 of the same article says explicitly that “State parties recognize the right of the disabled child to special care and shall ... ensure the extension ... to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to

- the child's condition ...". So, when parents apply (to the NDIS) for best-practice (appropriate) early intervention for their autistic child, the Australian Government should ensure best-practice early intervention is provided (the state shall "ensure the extension").
2. The evidence-base does not indicate that making parents responsible for program/service provision for an autistic child is best-practice ... or is even good, effective or appropriate practice. The authors of the research reviews discussed above apparently also missed eminent reviews<sup>2</sup>. Making parents responsible for delivering 20+ hours per week per child of intense clinical intervention is completely unreasonable and usually unsuccessful.
  3. By all accounts, experts regard comprehensive intensive ASD-specific early intervention as necessary ... and reasonable. Current practice under the NDIA's ECEI Approach denies autistic children EI for their ASD that is "reasonable and necessary".

Note that the original report and the subsequent ASD updates are not proper research reviews. The latest only includes "systematic reviews and evidence based guidelines that had been published after the evidence summary prepared for FaHCSIA in 2011". Substantial research into EI systems for children was completed before 2011.

Instead of simply updating the previous analyses with articles and reviews since 2011, it seeks to answer three questions.

### Question 1

What is evidence-based/evidence-informed good practice for supports provided to children with autism and their families/usual carers — with a focus on the autism-specific elements?

### Question 2

What characteristics or other factors would assist in deciding individualised levels of early childhood intervention support needed for a child with autism?

### Question 3

What factors, including intervention outcomes would indicate a need for a modification, for example an increase or decrease to intensity and/or type of intervention, once an early intervention program has been in place and the recommended timeframe for review of outcomes?

The answers the ASD update gives for these questions are unclear.

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<sup>2</sup> Oono IP, Honey EJ, McConachie H. *Parent-mediated early intervention for young children with autism spectrum disorders (ASD)*. Cochrane Database of Systematic Reviews 2013, Issue 4. Art. No.: CD009774.DOI: 10.1002/14651858.CD009774.pub2.

<http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD009774.pub2/epdf>

The *Summary and Recommendations* section (page 35) says ...

We therefore recommend that children who have received a diagnosis of autism receive 20 hours per week of early intervention that involves interaction with them (focus on social communication), with review of this level of support after the first 12 months, or sooner if they fail to progress or make rapid progress. Review of progress should be more frequent (see Q 3) but review of the level of support is not needed more than 12 monthly unless otherwise indicated. In addition a package to support the child's family (for example, counselling or respite) be provided.

While the research evidence answers questions 1 & 2 above saying an autistic child needs a comprehensive program of 20+ (probably 25+) hours per week of intense individualised ASD-specific EI for at least 2 years, it does not answer these questions to support diminished EI as the NDIA apparently would like.

The advice on EI for ASD given to Government omitted articles that compared comprehensive behavioural EI programs with multi- or transdisciplinary (previously called “eclectic”) programs<sup>3</sup>. The research indicates that behavioural programs are usually more effective than eclectic or trans-disciplinary programs.

The ASD update fails to mention that there has been increasing discussion of “optimal outcomes”<sup>4</sup> or “very positive outcomes”<sup>5</sup> in recent literature. The reports describe a small number of children who receive best practice

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<sup>3</sup> Howarth, et. al. *A comparison of intensive behavior analytic and eclectic treatments for young children with autism*, Res Dev Disabil. 2005 Jul-Aug; 26(4):359-83, see <https://www.ncbi.nlm.nih.gov/pubmed/15766629> or Eikseth, et.al. *Intensive behavioral treatment at school for 4- to 7-year-old children with autism. A 1-year comparison controlled study*, Behav Modif. 2002 Jan;26(1):49-68, see <https://www.ncbi.nlm.nih.gov/pubmed/11799654>

<sup>4</sup> E. Troyb, et.al. *Academic Abilities in Children and Adolescents with a History of Autism Spectrum Disorders Who Have Achieved Optimal Outcomes*, Autism. 2014 Apr; 18(3): 233–243.  
See <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4481875/>  
and D. Fein, et. al., *Optimal Outcome in Individuals with a History of Autism*, J Child Psychol Psychiatry. 2013 Feb; 54(2): 195–205. doi: 10.1111/jcpp.12037  
See <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3547539/>

<sup>5</sup> Anderson DK1, Liang JW, Lord C., *Predicting young adult outcome among more and less cognitively able individuals with autism spectrum disorders* J Child Psychol Psychiatry. 2014 May;55(5):485-94. doi: 10.1111/jcpp.12178.  
See <https://www.ncbi.nlm.nih.gov/pubmed/24313878>

early intervention then no longer meet the diagnostic criteria for ASD ... or proceed through school without support for ASD.

The report fails to consider or discuss how a family might choose an early intervention method that suits an autistic child.

Unfortunately for the NDIA, there are many difficult questions that remain unanswered, like: how much to spend on EI for each child, what the EI outcomes will be for each child, etc.

The NDIA's ECEI Approach fails to recognise that an autistic child needs a *comprehensive* EI program so best outcomes are likely for the child. The ASD update mentions ABA/EIBI programs and "eclectic comprehensive programs".

Few, if any, EI service providers in Australia offer "eclectic comprehensive programs" for autistic children. A4 believes this is because a) few graduates are taught how to deliver "eclectic comprehensive programs", b) graduates are (correctly) advised that getting families to fund 20+ hours per week is detrimental for most families, and c) Governments in Australia do not fund best practice evidence-based early intervention for autistic children. It seems the NDIS does **not** intend to tackle any of these barriers.

[A4 raised concerns](#) that the NDIA does not understand advice it was provided about the specific needs of autistic children or whether it chose to ignore the expert advice it received. The NDIA responded (see [here](#)), that "the NDIS acknowledges the evidence and research that supports targeted interventions for some children with specific needs such as Cerebral Palsy and Autism Spectrum Disorder" ... though A4 is so far unable to identify any impact of the NDIA having "targeted interventions" for autistic children.

There are further concerns.

- When a NDIS participant is an autistic child and the family wants best practice EI in the child's NDIS plan, the NDIS planner often asks the family for extensive (and expensive) evidence/proof that EI works for the individual child. This process limits accessing best practice EI for ASD to relatively wealthy NDIS participants.
- The NDIS appears to taking "choice and control" away from autistic NDIS participants ... contrary to NDIS objects. NDIS planners and delegates are making decision for the families; denying the family choice and control. Families should get EI funding approved as part of their plan, then it is up to the family to choose a provider (and the EI approach).
- NDIS planners do not approve best practice EI for autistic children. The decision may be passed on to a "delegate" ... the process and its criteria are a mystery.

- The NDIA wants to see (and expects families to fund) “outcome measures” that the Government has completely failed to deliver for its existing EI for ASD programs.
- The NDIA cuts off access to early intervention after age six years. This is a bureaucratic decision with little or no evidence base.
- Fewer than 1/3<sup>rd</sup> of autistic children are diagnosed by age six years, in time to access any early intervention.
- Graduates in Australia are not taught to deliver best practice EI for ASD, that is comprehensive evidence-based programs for 20+ hours per week.

### **Other issues**

A4 does not understand how NDIS eligibility work for severity Level 1 ASD. Are these applicants sent for further assessment? If so, by who does the assessments and what are the criteria? Is further assessment useful given that the NDIA reports a very high acceptance rate?

While most reports say Applied Behaviour Analysis (ABA) or Early Intensive Behavioural Intervention (EIBI) have the best evidence of positive intervention outcomes for ASD, most EI funding in Australia goes to speech therapy<sup>6</sup>.

HCWA rules required funds pay for face-to-face intervention, which prevented the use of early intervention funding to train people for and to supervise delivery of best practice early intervention. The NDIA’s approach seems no better.

It appears that the Government has only sought advice on best/good practice EI for ASD. Why is this?

There is no discernible attempt to develop a cost/benefit analysis for early intervention.

### **Conclusions**

The NDIA ECEI Approach when applied to autistic children is contrary to the advice that the NDIA received about the needs of autistic children. Apart from the ASD-specific advice in the NDIA’s ASD update (discussed above), advice that the NDIA received about early intervention is not relevant for autistic children.

The NDIA’s current practice is to deny reasonable and necessary services and supports in the form of best practice evidence-based early intervention for autistic children.

There is no evidence that NDIS planners understand the needs of young autistic children. There is no apparent indication that NDIS planners receive relevant training or can access clear information that describes the detailed needs of young autistic children yet they are required to issue plans for autistic children.

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<sup>6</sup> see [http://a4.org.au/sites/default/files/ANAO\\_Report\\_2015-16\\_24a.pdf](http://a4.org.au/sites/default/files/ANAO_Report_2015-16_24a.pdf)

## **Annex A: the NDIS entry process for a possibly autistic child under 7 years of age**

NDIS documents apparently suggest:

1. The child's family make an NDIS application to the NDIA for access to the NDIS.
2. The NDIA refers/assign the child to an NDIS Access Partner. NDIS Access Partners are not expected or required to have knowledge or skills in EI for autistic children so families may be dealing with an NDIS Access Partner with little or no actual knowledge of their autistic child's disability.
3. If the NDIS Access Partner feels the child may need NDIS support, the child is referred back to the NDIA to determine eligibility.

If the child has an ASD diagnosis with severity Level 1, then the child is meant to be further assessed for eligibility. According the NDIS reporting, most children are eligible.

A4 cannot discern from NDIS documents what is meant to happen for a child who has not been assessed for ASD.

If the child has an ASD diagnosis with severity Level 2 or 3 or if the child is deemed "eligible" (98.8% are), then the child is assigned an NDIS planner.

4. The NDIA required that families very quickly become expert in their autistic child's EI needs. This is very difficult because the NDIA annihilated the impartial Autism Advisor service that was set up for this purpose. Instead, families have to try to navigate the quagmire of misinformation from self-interested and essentially untrained service providers.
5. The NDIA denies requests from families of autistic children for best practice evidence-based EI for their autistic child; instead, they are assigned an allocation of generic EI with no known benefit for an autistic child.
6. After a period, the NDIA reviews an EI participant's "eligibility". Presumably, the same eligibility criteria apply.