



**Ms Vicki Rundle**  
General Manager  
Operations Division  
National Disability Insurance Agency  
GPO Box 700  
Canberra ACT 2601  
email: [vicki.rundle@ndis.gov.au](mailto:vicki.rundle@ndis.gov.au)

Dear Ms Rundle

Subject: **Early Intervention for autistic children**

Thank you for your letter (17/1/2017, ref. EC16-001302). A4's understanding is that your letter summarises aspects of the NDIA position on issues raised in our video meeting (12/12/2016). The focus of the video meeting was the NDIA's approach to early intervention (EI) for autistic children.

I understand that the video meeting resulted from A4's email to the NDIA on 17/11/2015. That email follows on from a series of previous emails expressing A4's concerns about [the NDIA's ECEI Approach](#), including:

- 6/10/2016 – see <http://a4.org.au/node/1299>
- 10/7/2016 – see <http://a4.org.au/node/1260>
- 12/4/2016 – see <http://a4.org.au/node/1209>

I also wrote on the subject (see <http://www.autismawareness.com.au/news-events/the-autism-post/asd/>).

A4's email (17/11/2016) included specific questions.

- “the complete list of the experts that the NDIA consults relating to the provision/delivery of the NDIS for autistic people”
- “explain how the Cooperative Research Centre for Living with Autism is a ‘stakeholder’ in the NDIS”

Neither the meeting nor your letter addressed these issues.

A4 expects the NDIA to answer our questions and recognise our concerns. Henceforth, A4 will interpret any unanswered questions however it chooses – in most cases, A4 will assume the lack of an answer from the NDIA means that the NDIA would be embarrassed or is unable to respond to the question. And A4 will deem/interpret failure/refusal to recognise a concern raised by A4 as meaning the NDIA dismisses/rejects the concern.

So please ensure that in future you (the NDIA) explicitly answer our questions and recognise/acknowledge our concerns if you feel our interpretation might not be what the NDIA intends.

In your letter, you

- mention “the right level of support, at the right time, for the right length of time”.

For over a decade [ASD experts have advised Australian governments](#) that best practice EI for ASD means 20+ hours per week comprehensive program of intensive individualised ASD-specific EI for at least 2 years.

The [latest review](#) (for the NDIA) includes recommendations showing “the right level of support” for autistic children.

Many NDIS planners resist/reject requests to include “the right level of support” (which means early intervention for ASD as recommended in the report/review) in NDIS plans for autistic children.

The [NDIA claims](#)

“The actual wording in the report ... was ‘20 hours of intervention’. It did not state that it had to be specialist; it actually went on to clearly indicate that that intervention should be, wherever possible, family and participatory based.”

This is incorrect and misleading (“alternative facts”); it is **not** “the actual wording” at all. The [report](#) says “children who have received a diagnosis of autism should receive 20 hours per week of early intervention that involves interaction with them” ... the “actual wording” describes a “comprehensive program” that “involves interaction with [the autistic child]” from service provider staff, which is in *addition* to normal family interaction. The advice states clearly that “staff to child ratios can vary between 1:1 and 1:3”; family are **not** staff. The advice does not say/mean “wherever possible, family and participatory based”.

The NDIA’s ECEI Approach is built on misunderstanding and false premises.

The [latest advice](#) expresses (albeit a bit obtusely) concern that providing “the right level of support” may not be feasible (I’m guessing, due to insufficient trained/qualified professionals/clinicians) in Australia today. A4 has yet to see the NDIA recognise this massive barrier to providing autistic children with *reasonable and necessary* early intervention.

- say your ECEI Approach results from work “with sector experts, evidence-based research has been used to design ECEI as a family-centred approach”.

The “sector experts” you refer to are not experts in the ASD sector. The “evidence-based research ... used to design ECEI as a family-centred approach” is not evidence relating to autistic children.

Previously, A4 [documented concerns](#) about the NDIA's "family-centred approach".

Parents do not have the years of tertiary training (and possibly not the aptitude) needed to supervise, administer and deliver effective early intervention for ASD. In relation to ASD, the NDIA's "family-centred approach" is like giving parents a basic first aid course then expecting/requiring them to do an appendectomy or brain surgery for their child on their kitchen table.

The NDIA has **not** shown any evidence that its "family-centred approach" benefits autistic children ... actually, we cannot discern what the performance benchmark/s are for your "family-centred approach" for autistic children. The NDIA really needs to show that its approach safely delivers expected outcomes including a level of "optimal" ([Fein et. al. 2013](#) or [here](#)) or "very positive" ([Anderson et. al. 2013](#)) outcomes like those described in the research literature. A4 is concerned that in the long-term the NDIA's ECEI Approach will make many parents, especially mothers, feel like failures because their best effort had sub-optimal results.

Your letter recognises that the NDIA's "family-centred approach" may not be appropriate for autistic children as "there are bodies of evidence that suggest targeted interventions for children with specific needs, such as ... Autism Spectrum Disorder, will be supportive of functional skill development". The NDIA's ECEI Approach omits/ignores these "targeted interventions" for children with ASD that ASD-sector experts describe as essential.

- say Early Childhood Partners (ECPs) "are experienced in supporting children with a developmental delay or disability". The DSM-5 says a diagnosis of "global developmental delay" should be resolved by age 5 years. But Michelle said in her video for the NDIA that her son, in the care of an NDIA ECP, still had DD diagnosis at age 12 years (see <http://a4.org.au/node/1299>). This raises major doubts about the service Michelle and her son receive from their ECP ... and the performance of other service providers (for example, [Thomas](#)).

Quite often, generic early childhood service providers have a history of excluding autistic children from their services for being "too difficult" or "uneconomic". The NDIA cannot just assume ECPs are experienced and competent in supporting severely autistic children. Nor should the NDIA just take the word of the service providers.

- say that "Early Childhood Partners must adhere to the National Guidelines on Best Practice in Early Childhood Intervention developed by Early Childhood Intervention Australia (ECIA)" ... but the essential "targeted interventions" mentioned above mean that those guidelines are irrelevant in the context of the substantial and complex needs of autistic children.
- say "the NDIA is working with a number of sector experts and specialist providers to support better outcomes for children and their families". This is an understatement that I will further discuss this in a separate letter.

- claim “Families have choice and control in choosing a provider to deliver early childhood intervention supports”. However, A4 observes that few NDIA plans for autistic children allow families to choose what they consider best-practice or evidence-based EI for their autistic child. And with the demise of the HCWA Autism Advisor scheme, a decreasing number of families are sufficiently informed about best-practice or evidence-based options for EI for ASD.
- acknowledge that “it is essential that early childhood intervention providers have the required expertise and experience ...”. A4 wants to know how the NDIA measures/assesses and maintains this requirement in relation to EI for autistic children.
- say that “The NDIA values all feedback in the continuous improvement of the delivery of early childhood intervention support” yet there is no sign that the NDIA has yet acted on any of A4’s feedback (acting on suggestions is essential in “continuous improvement” or *Kaizen*).

A4 does not know whether the NDIA

- a. simply cannot see/understand the substantial gap between ECIA’s view of (generic?) early intervention (via Inclusion and fixing broken parents, especially mothers) and expert advice on essential early intervention for ASD; or whether
- b. the NDIA just rejects the advice of the vast majority of ASD experts (that each autistic child needs a comprehensive program of intensive individualised ASD-specific early intervention).

Please understand that most autistic children are diagnosed after mainstream settings *fail* to include them. A child with clear clinical needs is unlikely to succeed through repeating previous failure (such as repeated attempts at inclusion in mainstream that is meant to *treat* their autistic behaviour).

It is also offensive/demeaning to simply assume that [the parents are the problem/inadequate](#) and cause or exacerbate ASD in their child/children; that is, suggesting/implying their parenting needs significant improvement (that the vast majority are not already the best parents they can be) and that “best practice” is making “better parents”. Similarly, it is unreasonable to expect/demand that parents meet personally the clinical needs of their children.

Discussions with other disability-specific peak bodies reveal that the EI needs of autistic children are very different from those of other disability types. Consequently, A4 regards the NDIA’s adoption of its one-size-fits-all ECEI Approach and the NDIA’s failure (or refusal) to recognise the distinct nature of ASD, particularly in relation to early intervention, as unacceptable.

*A4 recommends that the NDIA cease applying its “National Guidelines on Best Practice in Early Childhood Intervention” to autistic children. The NDIA needs a distinct and targeted description of best practice for autistic children.*

A4 remains concerned that the NDIA’s Early Childhood Partners cannot do the job that is expected of them for autistic children. A4 would like the NDIA to work with the ASD community to develop a distinct approach to early intervention for autistic children.

A4 would like the NDIA to acknowledge that many of its planners have insufficient knowledge or experience of ASD to be able to do their job properly for autistic NDIS participants. The NDIS could work with the ASD community to improve ASD training and awareness for NDIS planners.


A4 is also concerned that NDIS planners give incorrect information: apparently, planners tell NDIS participants that NDIS funding is capped for various items in an individual's NDIS plan. When this happened to me recently, I told the planner that the information she gave was incorrect. She apologised and said she meant that what she could approve is capped but that higher-level staff in the NDIA could approve higher funding levels. Reports from the community indicate this was not an isolated incident. If this is common or normal practice, it is a dishonest/reprehensible way for NDIA staff to conduct its business.

A4 would like the NDIA to acknowledge that LACs cannot help families properly when best-practice early intervention simply isn't available where they live (is not "feasible in Australia today"). Again, A4 would like the NDIA to work with the ASD community to develop solutions.

A4 is concerned and disappointed that the NDIA's public reporting does not separate its EI participants from its full/long-term participants. The NDIA does not report its EI measure and outcomes.

Thank you for your letter. Please feel free to contact me about any of the matters above, or any other systemic matters relating to autistic people.

Yours sincerely



Bob Buckley  
Convenor

email: [convenor@a4.org.au](mailto:convenor@a4.org.au)  
mobile: 0418 677 288

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cc: GUNN, Stephanie [Stephanie.GUNN@ndis.gov.au](mailto:Stephanie.GUNN@ndis.gov.au)  
FAULKNER, Chris [Chris.FAULKNER@ndis.gov.au](mailto:Chris.FAULKNER@ndis.gov.au)