

5-key questions response

for the NDIS Review

Action is the foundational key to all success.

Pablo Picasso



Autism Aspergers Advocacy Australia

4 September 2023



Preface

Autism Asperger Advocacy Australia, known as A4, appreciates the opportunity to respond to the NDIS Review's 5 key questions.

We sincerely hope this brief response will assist the NDIS Review.

A4 was created in 2002 as a national grassroots organisation to provide systemic advocacy for Autistic Australians and others affected by autism.

The Department of Social Services recognise A4 as a disability representative organisation (DRO) for autism on its [DRO webpage](#).

A4 is a member of:

- the Australian Federation of Disability Organisations (AFDO),
- the Disability Australian Consortium, and
- the Australian Autism Alliance (the Alliance).

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Autism Alliance

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The NDIS Review posed 5 key questions. Autism Asperger Advocacy Australia (A4), the disability representative organisation (DRO) for autistic Australians, offers the following responses ... followed by a broader discussion.

We hope the NDIS Review finds this input constructive and useful.

1. Why is the NDIS an oasis in a desert?

The NDIS is “an oasis in a desert” because that is how it was created.

Originally, the NDIS was described as having 3 Tiers.

When the NDIS started out, its staff scoured the finance landscape for all the disability funding at both state and federal levels.

Then the NDIS used almost all the funding to implement Tier 3. Tiers 1 & 2 were an afterthought; there was insufficient funding. They were renamed the ILC ... and were never adequately designed or implemented. And hived off to DSS, who also had insufficient funding for the job.

So, Tier 3, that is now the NDIS, is an oasis. And Tiers 1 & 2 are the desert that surrounds it.

The NDIS created the surrounding desert. That is why the NDIS is an oasis in a desert.

The challenge now is to rebuild effective Tiers 1 & 2.

And to consider the effect that the NDIS had on charities relating to disability.

2. What does reasonable and necessary mean?

A4 suggests that there are two parts to “reasonable and necessary”.

- ❖ Essential supports are “necessary”, but they should be delivered in reasonable ways. People with disability need transport – it is essential for their lives – but it is not reasonable for them to expect to always be driven in a Rolls Royce.
- ❖ Some supports are necessary for well-being or for a good life, but they must come at a reasonable cost.

3. Why are there many more children in the NDIS than expected?

While there are “many more children in the NDIS than expected”, there are not many more children than the autism sector expected. There are more children than the NDIS expected because the NDIS chose to ignore information and advice from the autism sector (and it continues to do).

The NDIS chose, from the very beginning, to ignore advice from the autism sector that their initial estimates were demonstrably wrong. The autism sector advised that:

- a. The initially estimated number of autistic participants expected in the NDIS was too low.
- b. Unlike other disability types, the number of people being diagnosed autistic was observed to be increasing significantly – the diagnosis was increasing, not stable or decreasing as is the case for other major disability types.

We invite the NDIS Review to consider the number of NDIS participants who are not autistic and consider whether a substantial part of the problem is that the NDIS and its designers chose to ignore advice about autism.

The creation of the Developmental Delay category in **Section 9** of the *NDIS Act 2013*. Also contributes to “unexpected” numbers in the 0-6 age range.

The NDIS may be interested in information that A4 provided to the National Autism Strategy that brings together data from a range of sources related to [Autism in Australia](#).

Diagnosis rates for children and young people are substantially lower than those observed among adults. The NDIS Review needs to better understand autistic diagnoses in the Australian population if it expects to improve the NDIS.

[A problem with definition](#)

Experienced teachers and pre-school staff tell A4 that they see far more “tricky kids” than before.

The early childhood sector, instead of providing help for tricky kids, sends them off for diagnosis and labelling ... rather than tackling the child’s trickiness immediately. A4 is not aware of data collection and reporting about tricky kids; nor are they formally recognised as a category or in need of consideration.

A4 is aware that access to diagnosis involves substantial delay.

Tricky kids just get trickier while they await the diagnosis/label.

Most of them need support by the time they get assessed ... so the process is creating more kids with labels. Most children in the 0–6-year age range getting support from the NDIS are labelled with Developmental Delay – see Annex B – NDIS participants 0-6 years, June 2023 below.

4. Why aren't NDIS markets working?

A4 cannot comment generally on NDIS markets, only on the market for autism supports.

The NDIS chose to ignore information and advice about evidence-based supports for autistic participants. Instead, the NDIS prefers to direct autistic participants towards generic disability supports that evidence shows *do not work* for autistic people. This is especially the case in relation to early intervention for the autistic children who are most affected by their autism, children whose diagnoses are very clear at earlier ages.

The NDIS does not trust autistic people or the informal supports to choose services and supports that they need. Even though very few NDIS officials have much understanding of autism, they still believe they know far more about the support needs of autistic people ... some with decades of experience.

The NDIS does not appreciate that people on the autism spectrum need a spectrum of services.

The NDIS needs to work with service providers to develop service models that are evidence-based and deliver measurable and cost-effective results.

5. How do we ensure that the NDIS is sustainable?

Autism is the most numerous primary disability type in the NDIS.

The NDIS will not be sustainable while it refuses to engage with the biggest primary disability type among its participants. The NDIS needs to understand autism. It needs to work with the whole autism sector.

More generally, the NDIS need to ...

- fix Tiers 1 & 2
- understand what evidence-based means
- collect good evidence and use it to improve outcomes and administration
- develop professional behaviour science supports for people with disability

The NDIS Review asked about 10 other issues. Frankly, they seem like distractions.

The Big picture

Evidence that the NDIS chooses to ignore the autism sector is very clear.

While autism is the biggest distinct disability in the NDIS, it is barely (if at all) represented on the NDIA Board or on the [NDIA's Independent Advisory Council](#) (IAC). The webpage shows that the IAC does not have a reference group for autism, which is the biggest primary disability type in the NDIS.

Many in the autism sector are extremely disappointed by the attack on autism¹ in the media from the Chair of the NDIA Board.

Annex A shows that A4's concerns to the IAC about the poor communication between the A4, the autism DRO and the IAC, fell on deaf ears.

The NDIA has an [Autism Advisory Group](#) that said it would publish a communique after each meeting ... but it published just two communiques: July 2018 and August 2019 (see the webpage). A4 is the DSS recognised DRO for autism, but the NDIA has always excluded A4 from the AAG.

Basic communication with the NDIA does not work. The NDIA has been informed repeatedly by multiple sources that the PEDI-CAT disability assessment tool gives very poor result for autistic children, basically it does not work². Yet the NDIA insists on continuing its use of the PEDI-CAT for autistic children.

The NDIS resists helping autistic children who most need supports – the NDIS sends autistic children with most need to the AAT to make their case. While AAT outcomes are often relatively successful³ for these children, the delay and consequent detriment caused to autistic children waiting to access essential supports, and the trauma inflicted on their families, are inexcusable. AAT outcomes are pretty random in these cases.

NDIS and government officials apparently believe that all parents of autistic children will want intensive early intervention for their child if it is seen to be at all accessible. A4 questions this prejudice.

A4 has not seen any data showing how many families are advised that their autistic child needs intensive early intervention, and how many families pursue those recommendations.

There must be a better, more informed approach than banishing the children who need the most support to the AAT. Instead of creating secret policies like the chronically discriminatory NDIS *OFFICIAL For Internal Use Only AAT Case Management Guide Applied Behavioural Analysis (ABA)*, the NDIA needs to work with representatives from across the whole autism spectrum to develop effective and affordable models of support.

People who lead the Autism CRC and the Disability Institute need to lead the research on effective supports for all the parts of the spectrum; they need to stop focusing on the average and properly address the spectrum. They need to better understand the autism landscape, how to better help people find where they fit and what supports work best for them.

¹ See <https://www.theaustralian.com.au/nation/ndis-diagnosis-of-autism-may-have-unforeseen-consequences-kurt-fearnley-warns/news-story/816a97ad53cc5e2275e86189b7b74577>

² NDIS even ignored advice it commissioned from the Autism CRC that even the PEDI-CAT (ASD) is unsuitable.

³ See <https://www.theguardian.com/australia-news/2023/aug/29/national-disability-insurance-agency-accused-of-failing-young-children-with-autism>

Historically, autism, Asperger's and PDD-NOS were separate islands (on continents). They were studied separately. Today, autistic people are all mixed together with one label – with many more autistic people included. Old research offers much information for the relevant parts of the landscape but does not help as much with the substantially expanded autism landscape of today.

There are few universal truths about autistic people. We all need to understand that different autistic people have different needs. We all need to appreciate that the families of autistic people who for whatever reason do not speak for themselves often need their families or individual supports who know them best to speak for them, not some official who does not know the individual's needs.

Everyone needs to appreciate that enraging proponents of different parts of the spectrum is especially unproductive. And the voices of all parts of the spectrum must be heard and respected.

The NDIS Review must recognise that the NDIS needs a new and comprehensive approach to the whole autism spectrum.

Annex A. IAC's response to A4's concerns

Subject:Re: EX Input to Special Meeting with the AAG re IAC Behaviour Support Briefing [SEC=UNOFFICIAL]

Date:Wed, 30 Aug 2023 01:30:24 +0000

From:Van Poppel, Leah <Leah.VanPoppel@ndis.gov.au>

To:Bob Buckley (Co-convenor) <convenor@a4.org.au>

CC:McKenzie, Corri <Corri.McKenzie@ndis.gov.au>, Falkingham, Rebecca <Rebecca.Falkingham@ndis.gov.au>, jenkaravolos@outlook.com <jenkaravolos@outlook.com>, Catherine Mcalpine <catherine.mcalpine@inclusionaustralia.org.au>, Sam Paior | The Growing Space <Sam@thegrowingspace.com.au>

Dear Bob,

There's clearly a deep difference in the way you and I communicate.

I'm going to be honest with you about how you're coming across to me, because I want to work collaboratively with you and the way you're communicating with me makes me feel - at best - really uncomfortable.

I felt disrespected and patronised by your last email. I also felt something more complicated: women are acculturated not to make men angry, and to fear - both through acculturation and actual life experience - what might happen if they do. Because your tone appeared angry I was also worried.

I am deliberately using language that talks about how I felt because I can't be sure that you meant to make me feel this way.

Please think about how you write back to this email, and how you might make me feel respected, valued and safe in the way you interact with me more broadly. I'd be happy to talk to you about what specifically would help, and I will definitely continue to be honest with you if you keep making me feel this way.

As a Board member at the Agency, I also have a duty of care to think about the welfare of Agency staff. I hope that you would never make anyone else feel the way I felt reading your last email. I'm really supportive of Agency staff having the same honest conversation we're having here if they feel uncomfortable in their interactions with you.

In terms of the issue at hand, I've asked you to go through AAG because you're a member of Autism Alliance, and they sit on AAG. You clearly believe that A4's contribution in this space is uniquely useful, but I genuinely don't think I've seen you describe why. You seem to be assuming I know what you do. What I want to hear about is why A4 is great - and unique amongst a range of very important voices that give us different perspectives.

Again, I'd be really happy to meet with you to talk this through - but only if I'm treated with kindness.

Leah

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From: Bob Buckley (Co-convenor) <convenor@a4.org.au>

Sent: Friday, August 25, 2023 2:03:26 PM

To: Van Poppel, Leah <Leah.VanPoppel@ndis.gov.au>

Cc: McKenzie, Corri <Corri.McKenzie@ndis.gov.au>; Falkingham, Rebecca

<Rebecca.Falkingham@ndis.gov.au>; jenkaravolos@outlook.com

<jenkaravolos@outlook.com>; Catherine Mcalpine

<catherine.mcalpine@inclusionaustralia.org.au>; Sam Paor | The Growing Space

<Sam@thegrowingspace.com.au>

Subject: Re: EX Input to Special Meeting with the AAG re IAC Behaviour Support Briefing [SEC=UNOFFICIAL]

Dear Ms van Poppel

I am disappointed that you do not find "constructive suggestions about the best steps going forward" in what I wrote below. If you need to hear then, rather than read them, you need to schedule I time to do that.

We have clearly established thoroughly that "it's best to put those suggestions through members of AAG" is not good advice.

Bob Buckley

Co-convenor, Autism Aspergers Advocacy Australia (A4)

website: <https://a4.org.au/>

Autism Aspergers Advocacy Australia, known as A4, is the national grassroots organisation advocating for autistic people, their families, carers and associates. A4 is internet based so that Australians anywhere can participate.

Recipients of correspondence from A4 are all subject to *Autism Aspergers Advocacy Australia's* policy on unanswered questions that is available at <https://a4.org.au/node/1419>.

A4 recognises and respects the traditional owners, elders past, present and emerging, of lands in Australia. Sovereignty was never ceded.

“The first step in solving any problem is recognising there is one.” Jeff Daniels as Will McEvoy in *The Newsroom*.

On 21/07/2023 3:42 pm, Van Poppel, Leah wrote:

Dear Bob,

Thanks for your email outlining your concerns. As you'll see from the trail below your original email went to an old address of mine - please use this one in future if you'd like to reach out.

I agree that the Independent Advisory Council could have done a better job of including expertise on autism during this advice development process, and

I've made that acknowledgement to AAG. It may not be the ideal solution for anyone to do so this late in the piece, but the connection with AAG on this - and on discussing better ways to engage longer term to ensure autistic voices are heard - is being undertaken in good faith with the aim of learning and doing better in future.

If you have constructive suggestions about the best steps going forward, I'd be keen to hear them. Noting that you're not a member of AAG I think that it's best to put those suggestions through members of AAG, in particular Autism Alliance, who I note have invited you to be engaged in this piece of feedback.

Kind regards,

Leah

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From: Sam Paior | The Growing Space Sam@thegrowingspace.com.au
Sent: Thursday, July 20, 2023 9:19 pm
To: Van Poppel, Leah Leah.VanPoppel@ndis.gov.au
Subject: FW: EX Input to Special Meeting with the AAG re IAC Behaviour Support Briefing

Was sent to an old email address of yours!

From: Bob Buckley (Co-convenor) convenor@a4.org.au
Sent: Wednesday, July 19, 2023 10:38 AM
To: Catherine McAlpine catherine.mcalpine@inclusionaustralia.org.au; Leah Van Poppel leah.vanpoppel@wdv.org.au; Sam Paior | The Growing Space Sam@thegrowingspace.com.au
Subject: Fwd: EX Input to Special Meeting with the AAG re IAC Behaviour Support Briefing

FYI - I am extremely disappointed.

Bob

----- Forwarded Message -----

Subject: Re: Input to Special Meeting with the AAG re IAC Behaviour Support Briefing
Date: Wed, 19 Jul 2023 09:13:26 +1000
From: Bob Buckley (Co-convenor) convenor@a4.org.au
Organisation: Autism Aspergers Advocacy Australia (A4)
To: Jenny Karavolos jenkaravolos@outlook.com, Chris Varney chris@icannetwork.com.au
CC: ...

Hi Jenny

Thank you for sharing that information.

However, I have to say that I am utterly outraged by it.

The *DRAFT Enhancing behaviour support in the NDIA* document appears to be written for NDIS participants with Intellectual Disability. Apparently, it was created by the

IDRG for the IAC. From what I can see, it was created with little or no consultation with the autistic NDIS participants or their representatives. It is unclear what data and information this "advice" is based on. How many of the people in the NDIS with a funded behaviour support plan (BSP) have "autism" as their primary disability, compared to other primary disability types? How many of those BSPs include reportable Restrictive Practices? Is it appropriate that voices for autism were excluded from the development of this advice? How credible is the advice when it makes no mention, neither positive, negative nor neutral of behaviour science or behaviour analysis?

Clearly, this briefing for the NDIA's so-called Autism Advisory Group (AAG), which is *not* a reference group for the IAC, is a belated afterthought (not just an afterthought).

This might have been OK were it a policy just for people who only have Intellectual Disability. But behaviour support is a central issue in supporting many autistic NDIS participants. Behaviour support needs for autistic people can be quite different from those relating to intellectual disability (though such a distinction may not be clear for undiagnosed autistic adults).

I am extremely disappointed that the IAC would countenance this. This must mean that the IAC does not understand the significance of behaviour and behaviour support for many autistic NDIS participants. Perhaps they have not noticed that autism is the biggest primary disability in the NDIS. Do they think that there are few or no autistic people who would benefit from well-implemented behaviour supports? Or do they think that autism representatives have no role in developing or enhancing behaviour support in the NDIS - that they just need the AAG to rubber-stamp their work? Note: the NDIA's deliberately and persistently excludes a DSS-recognised DRO for autism from its membership.

The predecessor to this draft advice, [the National Action Plan Developing the NDIS Specialist Behaviour Support Market](#) (December 2020), also had very little input in relation to autistic NDIS participants.

I am disappointed that representatives of other disability types regard what has happened here as acceptable, and even participate in it. I believe that the autism sector consistently promotes the practice of ensuring the voices of people affected by advice and policy development are heard in the process. But others in the sector have not reciprocated.

These documents are about positive behaviour support (PBS); they ignore behaviour science and ABA. It seems most people involved, IAC, IDRG, NDIS and Q&SC, regard PBS and ABA as very different things. But they do not explain why. It is apparent that understanding of PBS, ABA and the relationship between them is lacking.

ABA and PBS as very closely related: research literature is unclear about the difference.

There cannot be a meaningful discussion of this topic when there is so much confusion. The result is uninformed "advice" and policy.

It is incredible (literally) that so much can be written on behaviour supports without a single reference to the international Behaviour Analysis Certification Board and the people registered with them who practice in Australia.

Have any of the people involved had to deal with failing behaviour support plans or had to argue for increased behaviour support in the AAT? Where are the voices of autistic people most affected by this policy?

The confusion and ignorance indicates that the people coming up with these policies are simply not sufficiently informed to do so, at least in relation to autistic NDIS participants.

I object strongly to the creation of a general NDIS behaviour support policy that is not considerate of and informed by a full range of autistic representation - or with input from specialist practising clinicians and from the people most affected or their families and representatives.

Bob Buckley

Co-convenor, Autism Aspergers Advocacy Australia (A4)

website: <https://a4.org.au/>

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Note for politicians and bureaucrats – *Autism Aspergers Advocacy Australia's* policy on unanswered questions is available at <https://a4.org.au/node/1419>.

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“The first step in solving any problem is recognising there is one.” Jeff Daniels as Will McEvoy in *The Newsroom*.

On 18/07/2023 1:22 pm, Jenny Karavolos wrote:

Good Afternoon Alliance Colleagues,

I mentioned at the last Alliance meeting that:

- the Chair of the NDIA Independent Advisory Council (IAC) was invited to the Autism Advisory Group (AAG) to present activities that they were undertaking
- During the briefing, the Chair mentioned that the IAC were presenting advice to the NDIA, as requested by the NDIA, on Behaviour Support
- Given the issues that we had raised regarding Behaviour Support with the NDIA, our 1:1 session with the NDIS Q&S Commissioner and submission to the Joint Standing Committee on the Capability and Culture of the NDIA, among other forums I requested (and was supported by Emma Goodall and the other AAG members) to be able to input into this advice.

A briefing paper (attached) was provided to the Alliance yesterday for a special meeting scheduled for tomorrow afternoon with the AAG. Please respect the channel this has been provided from and hence is not to be circulated further.

I have also attached, as a reminder, the response received earlier in the year from the NDIS Commissioner to the concerns we raised at the 1:1 Alliance meeting session late last year re Behaviour Support.

A summary of my quick reading of the document is there is some good advice, however, areas for further consideration go-toare:

1. I don't believe market stewardship of providers goes far enough
2. There is little, if any, recognition of the Autistic community being a significant stakeholder regarding PBS. I make mention of this as ID is called up and various minority groups.
3. The recommendations for co-design make no specific mention of the Autistic and autism community as a contributor (revert to point in Item 2 above)
4. Stronger emphasis is needed on when PBS should not be utilised (as in my opinion appears to be a "go to" solution at times instead of therapy or education of other stakeholders)
5. A heavier emphasis is needed on recommendations that cover the "development of PBS plans". Currently, there is a perceived emphasis predominantly on "implementation of PBS plans"
6. There is Under Consideration 4: Pricing on page 9 for "funding a Support Coordinator or other designated actor to perform critical tasks of BSP implementation, training, monitoring and review". I am not convinced this is the right authority to be able to execute "what good looks like".
7. There is Under Consideration 5: Planner, LAC and ECI practice for skills/ training/ experience in trauma-informed practice, PBS, and training for planners/ LACs and ECI. While some is valid in my mind there is a need to ensure it is clear what the purpose of this is and where this fits in the roles and responsibilities of these stakeholders so that valid advice from quality practitioners and endorsed guidelines is not diluted/replaced/ overruled.

I would appreciate your thoughts on the points above and the paper I am likely to have missed valid points, including from my AAG colleagues - Chris Varney, Jim Mullen, Pam Macrossan, Katharine Annear and Andrew Davies.

Thanks in advance.

Kind regards
Jenny

Jenny Karavolos (she/her)
Co-Chair, Australian Autism Alliance

M: 0401 988 186 | E: jenkaravolos@outlook.com | chair@australianautismalliance.org.au

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Annex B – NDIS participants 0-6 years, June 2023

NDIS - Age 0 to 6 years									
Row Labels	ACT	NSW	NT	QLD	SA	TAS	VIC	WA	ALL
Autism	233	7,396	141	3,926	1,625	435	4,477	1,603	19,828
Developmental delay	847	15,900	658	13,277	3,661	911	19,571	2,904	57,721
Global developmental delay	113	4,368	122	1,981	1,374	162	2,156	808	11,084
Intellectual Disability	-	688	47	424	133	44	558	201	2,119
ALL	1,342	31,045	1,026	21,693	7,334	1,736	28,875	6,347	99,395
Autism	17.4%	23.8%	13.7%	18.1%	22.2%	25.1%	15.5%	25.3%	19.9%
Developmental delay	63.1%	51.2%	64.1%	61.2%	49.9%	52.5%	67.8%	45.8%	58.1%
Global developmental delay	8.4%	14.1%	11.9%	9.1%	18.7%	9.3%	7.5%	12.7%	11.2%
Intellectual Disability	0.0%	2.2%	4.6%	2.0%	1.8%	2.5%	1.9%	3.2%	2.1%
Row Labels	ACT	NSW	NT	QLD	SA	TAS	VIC	WA	ALL
Autism	\$ 30,000	\$ 28,000	\$ 28,000	\$ 29,000	\$ 30,000	\$ 25,000	\$ 32,000	\$ 31,000	\$ 29,000
Developmental delay	\$ 20,000	\$ 21,000	\$ 24,000	\$ 20,000	\$ 23,000	\$ 20,000	\$ 22,000	\$ 25,000	\$ 21,000
Down Syndrome	\$ 30,000	\$ 31,000	\$ 34,000	\$ 31,000	\$ 40,000	\$ 30,000	\$ 38,000	\$ 35,000	\$ 34,000
Global developmental delay	\$ 24,000	\$ 24,000	\$ 33,000	\$ 26,000	\$ 25,000	\$ 25,000	\$ 27,000	\$ 32,000	\$ 26,000
Intellectual Disability	\$ 74,000	\$ 50,000	\$ 45,000	\$ 53,000	\$ 42,000	\$ 52,000	\$ 54,000	\$ 84,000	\$ 55,000
ALL	\$ 25,000	\$ 24,000	\$ 28,000	\$ 24,000	\$ 26,000	\$ 24,000	\$ 25,000	\$ 33,000	\$ 25,000