

Mr Kurt Fearnley
Chair of the Board
National Disability Insurance Agency
GPO Box 700
Canberra ACT 2601

Dear Mr Fearnley

The following responds to your [article in The Australian](#), *NDIS diagnosis of autism may have 'unforeseen consequences'*, Kurt Fearnley warns (1/5/2023). The NDIA Board Chair's article opens with the paragraph:

The need for a diagnosis of autism early in a child's life to secure NDIS support may have "unforeseen consequences" as they face the long-term stigma of being labelled disabled, National Disability Insurance Agency chair Kurt Fearnley says.

Autism is the most frequent primary diagnosis for children (and teenagers up to 18 years of age) who are participants in the NDIS. Australia has an Autism CRC, a Melbourne Disability Institute, the UNSW Disability Innovation Institute, La Trobe University's Olga Tennison Autism Research Centre (OTARC), Sydney University's Brain and Mind Centre (Autism clinic), ASfAR, and many more. Claiming that autism diagnosis may have *unforeseen* consequences accuses all these organisations of not doing their job properly or of doing their job very poorly. I doubt Mr Fearnley is personally able to justify such a claim.

The article refers repeatedly to *stigma*.

Mr Fearnley fails to appreciate that while the stigma from being labelled autistic or disabled has unnecessary negative outcome, a person without their ASD diagnosis misses having their needs recognised and addressed with possibly worse consequences. ASD diagnosis is complex: and there are positives and negatives on both sides. And there are more options than yes or no to diagnosis: you can get a diagnosis and then choose when to disclose it.

Mr Fearnley is ill-informed; was given overly simplistic misinformation or worse about autism in his role as NDIA Board Chair.

The article says:

But with anxious parents [presumably, meaning parents of autistic children] understandably pursuing what they believe is the best for their child, the NDIS can feel like the only pathway open for them, Mr Fearnley said.

Mr Fearnley and the NDIA Board need to appreciate that "what they believe is the best for their child" is mostly based on:

- a. what they were advised by reputable clinicians (that NDIA officials distrust and denigrate)
- b. experience with the various early intervention approaches that have been tried with their autistic child,
- c. their knowledge and observation specifically of their own child, and
- d. often, some amount of their own reading of relevant research literature (that NDIA officials ignore).

Most, parents' beliefs in this respect are solidly grounded. It is disrespectful and demeaning for the NDIA's Board Chair to claim that the beliefs these parents hold are not well-founded. A4's observation is that most parents of newly diagnosed autistic children immediately seek to understand to the best of their (considerable) ability their child's ASD diagnosis and consequent needs. Mr Fearnley offers no evidence to the contrary.

Some clinicians advise parents, based on strong research evidence, that evidence-based early intervention for their child's autism is best for their child. The NDIA has another view; it often ignores advice about early intervention for autism and rejects requests for evidence-based early intervention for autistic children. The NDIA fights hard for its unevidenced position in the AAT, even though it repeatedly and routinely loses.

Of course, parents believe that the NDIS is "the only pathway" open for their autistic child; their "belief that (the NDIS) is the only lifeboat in the sea" is based on solid evidence. The NDIS and state & federal governments shutdown *all* the other supports for autistic people when they started the NDIS. Mr Fearnley fails to mention any other pathway, or anywhere else to find a "lifeboat" for autistic people in Australia.

The NDIS was designed with a Tier 2, but that was never delivered. A4 questions the current plans that governments have for disability supports beyond the NDIS.

What does Mr Fearnley expect when he says, "the participant is engaging with the scheme longer than predicted"? The DSM-5-TR (2022), the diagnostic manual that provides the current (medical) diagnostic criteria for Autism Spectrum Disorder (ASD), says¹:

Only a minority of individuals with autism spectrum disorder live and work independently in adulthood; those who do tend to have superior language and intellectual abilities and are able to find a niche that matches their special interests and skills. In general, individuals with lower levels of impairment may be better able to function independently. However, even these individuals may remain socially naive and vulnerable, have difficulties organizing practical demands without aid, and are prone to anxiety and depression.

What prediction is Mr Fearnley referring to? What has the NDIA told him about its predictions and expectations for autistic children? And what does the NDIA base its predictions on?

All we know, all we are told, is that the NDIA repeatedly and consistently gets its participant number and budget predictions wrong.

The article reports that Mr Fearnley "said parents worried about their young child having a developmental delay enter a "complicated world of disability". It is unclear how this relates to autistic children. The term, Developmental Delay, is defined in **Section 9 Definitions** of the *NDIS Act 2013*. *Developmental Delay* is a diagnosis created in Australian legislation in 2013.

Possibly every child who is up to 6 years of age and diagnosed autistic, as well as children showing early signs of intellectual disability, some genetic disorder, and a range of other *differences*, could also be described as meeting the NDIS Act criteria for Developmental Delay. That means that all those children are eligible to participate in the NDIS. As eligible NDIS participants, the law says they must receive an individualised NDIS plan including a Statement of Supports that *meets* the individual's needs. The law requires that autistic children have their autism-related needs met.

¹ See <https://a4.org.au/dsm5-asd>

A4 agrees that people with disability are stigmatised, however it is not clear that stigma is due significantly to diagnosis. The stigma may be another source. One might argue that when a person's disability is not immediately visible, then the stigma they experience is may be due in part to their diagnosis making their disability more visible. However, I doubt that is what really happens.

Mr Fearnley's "difference"² is visibly apparent pretty quickly. I note that his difference is far less of a disability than people would assume when they first see him – as is clear from his many achievements. His achievements far exceed those of most people without any disability.

People, if they think about it, might appreciate that the difficulties autistic people experience are from their difference, not their diagnosis. Try watching *Love on The Spectrum* and similar vignettes into some versions of autistic life, then think about whether the challenges for autistic people are due to their diagnosis on a piece of paper, or perhaps more due to their clearly different behaviour that people see without having even seen their diagnosis.

It is true that children who are diagnosed autistic are stigmatised: due to their diagnoses, they are likely to be denied effective education and are burdened with unacceptable low expectations that deny them good outcomes. The problem here is that Australia's education systems respond badly to an ASD diagnosis. But the diagnosis is not the problem; the problem is how education systems respond to it. A good response to the diagnosis would deliver access to much more effective education for autistic children in Australia.

Education systems in Australia are simply *not inclusive* of autistic students.

For years, the Australian Bureau of Statistics (ABS) [Survey of Disability, Ageing and Carers \(SDAC\) reports](#) has reported poor education outcomes, and particularly poor at tertiary levels, for autistic students. Poor education outcomes drive poor employment outcomes for autistic adults.

There are equally challenging issues in health, employment, disability support, and Australia's injustice systems.

The stigma and poor outcomes are not due to the diagnosis, they are due more to absent and inappropriate response to an ASD diagnosis across many government sectors.

The NDIA is badly misinformed about autism, see Annex A below, and about early intervention for autism, see Annex B below.

Autism is a major challenge for governments in Australia and elsewhere in the world. The NDIA and governments in Australia are not going to fix the problem by pretending it does not exist. Or by blaming parents for acting appropriately to the information and advice available to them. Instead, The NDIA and governments in Australia need to work with the autistic and autism communities to understand what is happening and how best to tackle the challenges.

And most people with other disabilities need to appreciate that their lived experience is not with autism; most likely, they have no more understanding or experience of autism than members of the general public.

The government initiated the development of a National Autism Strategy. Unfortunately, the NDIA has yet to engage with the National Autism Strategy and its development. The NDIA and its Board

² Respecting that his difference is substantially less "disabling" for him than most people would expect when they first see him.

Chair think autism is the problem. You are escalating *their War on Autism*³. Your *War on Autism* must end now.

Sincerely

A handwritten signature in blue ink that reads "R Buckley". The signature is written in a cursive style with a large, stylized 'R' and 'B'.

Bob Buckley
A4 Co-convenor.

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16/5/2023

Cc: Ms R. Falkingham, NDIA CEO
The Hon. Bill Shorten, Minister
NDIS Review

³ See <https://a4.org.au/node/2243>

Annex A. NDIS and autism

Table 1.1 in [the Productivity Commission's initial NDIS report](#) indicated that for Australian “people who have a profound core activity limitation” and are under 65 years of age, 9%⁴ were autistic. Box 1.2 suggests that estimates needed to expand to include some (or all) people under 65 years of age with severe disability; this means including more autistic people. The issue of whether an expanding eligibility for the NDIS to include about half the people with severe disability increased the expected proportion of autistic NDIS participants was not discussed.

We understand that the Productivity Commission and the NDIA based their autism estimates on data from state and territory governments. It appears that no validity checks were done.

When the NDIS started, members of the autism community especially from A4, the ACT and SA told NDIA officials that they had underestimated the likely number of autistic NDIS participants, and that the proportion of diagnosed autistic people in the Australian population was increasing. The proportion of autism in the community was not static, as the Productivity Commission appeared to assume.

Unsurprisingly (in either foresight or hindsight), the initial estimates were wrong.

By June 2018, autistic NDIS participants were 29% of the NDIS but senior management expected to cut that back to just 20%. In Estimates, they said ...

Senator WATT: Does the NDIA have concerns about the number of people with autism entering the scheme?

Mr De Luca : Does it have any concerns with it? Our focus is to make sure that those eligible for the scheme get into the scheme. At the moment, 29 per cent of our active participants have a primary disability of autism. The Productivity Commission's expectation at full scheme was around 20 per cent. So it's not materially different to what the Productivity Commission's expectations were.

And shortly after that:

Senator WATT: What does your actuarial evidence say, Mr De Luca, about the cost impact on the scheme if the levels of entry to the scheme for autism go on the way they are?

Mr De Luca: I'm trying to understand the question. What do our actuarial insights tell us if the current trajectory of those with autism get into the scheme?

Senator WATT: Correct—if that continues into the future.

Mr De Luca: In terms of being at 29 per cent versus 20 per cent [autistic]?

Senator WATT: Yes. Let's start with: would you anticipate further growth beyond 29 per cent over the next five or 10 years if changes aren't made?

Mr De Luca: Obviously, estimates are estimates, and the Productivity Commission did some work on the estimates of the scheme. But everything that we've been seeing to date broadly supports those estimates and the PC's recent review acknowledged that, basically, in terms of the cost view that we had, based on our current experience of the scheme, the 2020 estimates is the best estimates that exist. Therefore, there's nothing materially different, at

⁴ based on data from the ABS SDAC 2012.

this point in time, based on experience, that gives us concern. Obviously, as Ms Rundle and Mr Lye alluded to, it's an insurance scheme, and an insurance scheme allows us then to look at and monitor experiences and recognise whether there are other interventions that are required at any point in time. Where we sit today, the 2020 estimate for the scheme is that that the Productivity Commission put in play, based on our experience.

From Community Affairs Legislation Committee, 01/06/2018, Estimates, Social Services Portfolio, Department of Social Services,
<https://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;db=COMMITTEES;id=committees%2Festimate%2Fc0730a81-3382-47c0-9bce-8920288dad41%2F0002;query=autism;>

The statement that “there's nothing materially different, at this point in time, based on experience, that gives us concern” showed that the NDIA maintained its expectation that the NDIS, on reaching full roll-out, would have 20% autistic participants – that is, not *materially different* from expectations/predictions. NDIA officials expected that around 1 in 3 autistic NDIS participants were not eligible for the NDIS.

The NDIA's expectation by 2018 about autism were still very wrong.

The proportion of autistic NDIS participants continues to increase; it has not stabilised or started to decrease. The Q2 Year 10 (Dec 2022) NDIS Quarterly Table E.10 shows 35% of NDIS participants had “autism” as their primary disability (just more than double the next highest primary disability type, intellectual disability, at 17%).

The NDIA leadership's answers in the same session to questions about their attempt to exclude “autism level 2” from the NDIS were simply unbelievable.

The autism sector has been subject to numerous other attacks from the NDIA.

- The NDIA's ongoing use of the PEDI-CAT assessment tool on autistic NDIS participants is inexcusable.
- The attempt to reign in autism through so-called “independent assessments” was rejected by the entire disability sector.
- The initial omission of evidence-based early intervention for autistic children from the most recent price-guide was inexcusable.
- The NDIA's refusal to require and collect complete diagnostic reports based on DSM-5 requirements is a broken promise to the autism sector.
- The dysfunctional and invisible operation of the NDIA's so-called Autism Advisory Group and its manicured membership are despicable.
- The absent or minimal autism representation on the NDIA Board and the IAC, when 35% of NDIA participants are autistic, is discriminatory.

The NDIA excludes A4, a recognised DRO specialised in autism, from its Autism Advisory Group (AAG). The NDIA says A4 can contribute to the AAG via the Australian Autism Alliance who are members of the AAG. However, the operations of the AAG are secret: the Alliance cannot share the conduct of the AAG with its members so A4 cannot participate in the AAG. The NDIA committed that the AAG would publish regular communiques, but there have only ever been 2 of them, the last is dated August 2019.

Annex B. NDIS and early intervention for autism

Since it started, the NDIA commissioned Robert's & Williams and the Autism CRC to report on research and evidence relating to early intervention for autistic children. The resulting reports try to supersede previous reports; however, the conclusions of the new reports were largely unchanged; those later reviews did not deliver the outcomes that the NDIA wanted, so the NDIA and its officials ignore evidence describing good/best practice early intervention for autistic children.

[The NDIA's initial ECEI Approach document](#) (Feb 2016) said "Three key research pieces form the basis of the ECEI approach", and relegated review material from its chosen autism experts to "also informed". Since then, the NDIA dropped the reference to evidence relating to autism when describing early intervention for children. It's current [early childhood approach web page](#) (December 2022) implores us to "Read the latest update on how we're progressing with the ECEI reset" but does not seem to provide a link to that information. It links to an NDIS web page on [Early childhood approach](#) (June 2022) that does not mention autism.

The NDIA's initial ECEI Approach document cites first a KPMG report⁵. However, in an AAT review⁶ of two autistic children's NDIS Plans (Statements of Supports), the NDIA objected to the KPMG report as evidence, claiming that report is not reliable evidence.

In relation to autism, the KPMG report cites research describing outcomes for Aspect's *Building Blocks* early intervention for autism. The results of that research found the home-based program of *Building Blocks* made fewer gains than the control group. But the NDIA's ECEI Approach document claims "the common theme in these research pieces is a family-centred practice ...".

The underlying principle of "family-centred practice" is the belief that fixing the parents is key to fixing the child's disability; that their parenting contributes to their child's disability. While most parents seek to improve their parenting skills, in most cases it is grossly unfair to burden them with (impose on them) a belief that their parenting contributes significantly to their child's disability. Too often, parents are left feel inadequate when they cannot find answers that simply don't exist. The approach is known to stigmatise and/or traumatise some parents.

An updated [NDIS Early childhood approach \(June 2022\)](#) only mentions autism once⁷ in the whole document. It says:

Best practice not only takes into account broad early childhood intervention research, but also evidence relating to the needs of children with a specific diagnosis, such as autism spectrum disorder or cerebral palsy.

This says best practice for autistic children is described in research that is specific to autism, but it provides no reference ... nor guidance on how to find that evidence. This means the NDIS's early childhood approach documents omit essential information and guidance about early intervention for autistic NDIS participants.

Planners write NDIS Plans for autistic participants that fail to recognise the autism-specific needs of autistic children. Recent NDIS Plans for autistic children have responded to multiple goals such as "[Child's parents] would like [child] to develop his receptive and expressive communication skills so

⁵ KPMG (2011), *Reviewing the evidence on the effectiveness of early childhood intervention*, Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA)

⁶ Specifically, **2022/0757 and 2022/0754 - VXGN & HHRQ and National Disability Insurance Agency**

⁷ in a paragraph copied (unacknowledged/plagiarised) from [the ECIA guidelines](#) also only mention autism once.

he can effectively communicate with others” with a section under the heading “How I will be supported” that says:

[The autistic NDIS participant] will be provided with opportunities at home, at school and in the community to practice skills and strategies to support the goal.

Given the diagnostic criteria for ASD, such NDIS Plans are equivalent to saying:

- turn on the lights when a blind person enters a room/space, so the blind person has an equal opportunity to see; or
- deliver a person who is wheelchair dependent to the bottom of the staircase at the front of a courtroom, so the person has equal access legal processes and protections.

In over 40 AAT matters, an A4 member, who voluntarily helped autistic families in those matters, has *never* seen a NDIS plan reviewer refer to either of the NDIA’s documents on early intervention for ASD in their list of review reference documents. Instead, they refer to NDIA’s ECEI documents that themselves say they are irrelevant in relation to autism.

The NDIA made numerous attempts to develop an appropriate approach for autism in the NDIS. They have all failed. Possibly, that is because the NDIA refuses to consult or co-design with then full autism community.

Apparently, the NDIA is conducting an Early Childhood Taskforce⁸. Hopefully, this time there will be a meaningful outcome.

Parents of autistic children need choice and control about early intervention. Experts on autism advise that the parents are the preeminent experts on their autistic child. But the NDIA insists that their planners know more about individual autistic children than the parents despite the NDIA’s planners never have met, or even seen, the autistic child.

NDIS Planners seek to impose their preferred early intervention styles on autistic children and their families, especially in s24D AAT decisions.

Apparently, many NDIS Planners oppose the use of Behavioural Science and early intensive behavioural intervention (EIBI) (often called Applied Behaviour Analysis (ABA)). They often deny funding for specific requests for ABA and seek to prevent flexible use of funds for ABA in young autistic children’s NDIS Plans⁹. In essence, this means that they oppose the use of science in toilet training children, especially autistic children. Their attitude is contrary to the rights of children to effective education ... when careful clinical approaches are required to teach them skills that other children learn more readily.

Note that **Applied behavioural analysis (ABA) or early intensive behavioural intervention (EIBI)** is the only early intervention approach rated as “ER = Eligible based on established research evidence”¹⁰ in Prior & Roberts (2011)¹¹. The HCWA report rated several other approaches to EI for

⁸ A search of the NDIS website finds no reference to this Taskforce.

⁹ The term, Early Intensive Behaviour Intervention (EIBI) is a more specific (preferred?) name for EI using ABA for young autistic children.

¹⁰ The review and the Early Intervention Table are available from <https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/research-and-evaluation>

¹¹ 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.*

autistic children as “EE = Eligible based on emerging or best practice evidence”, that is not yet rated as evidence-based.

The NDIA’s preferred approach for early intervention for autistic children, that it calls the “key worker model”, is not evidence-based for autistic children¹². The NDIA’s “key worker model” is not even mentioned in reviews of evidence for early intervention for autistic children¹³.

When it comes to EIBI/ABA, NDIA planners deny parents “choice and control” of their child’s early intervention, even when parents/families produce solid evidence of efficacy ... and evidence that therapy approaches that NDIA officials prefer were ineffective for the specific autistic child. It should be illegal under the *NDIS Act 2013* for a NDIS planner to include therapy in a child’s NDIA Plan that has been previously found ineffective for that child ... but there is no penalty to the NDIS or its planners for such action.

The NDIA should support families to make the best choices for their autistic children. Parents/families must be able to choose, within reason, early intervention approaches that they have established are effective for their child, or to trial approaches that they have good reason to believe might be effective in their search for improved outcomes for their autistic child. The test for the NDIA is “reasonable and necessary”; these choices are not matters for unreasonable NDIA officials to dictate.

As indicated above, parents of autistic children are the experts in their child. Choice of early intervention should be theirs unless there are exceptional circumstances. Also, enabling people to “exercise choice and control” is prescribed in subsection (e) of **Section 3 Objects of Act** of the *NDIS Act 2013*. The NDIA should not seek to deny parents’ choice and control of their autistic child’s early intervention.

A4 recently established that senior management in the NDIA were mistaken or being misinformed about people’s requests for ABA early intervention. Investigation¹⁴ revealed that families and service providers rarely if ever request 40 hours per week of ABA intervention as a senior NDIA official claimed. The senior NDIA official’s claim to A4 was false.

¹² A4 suggest that you try search [PubMed](#) for “key worker model” or “autism and ‘key worker model’” to see how little evidence there is in the research literature.

¹³ Such as Prior & Roberts (2011), Roberts & Williams (2016), or the Autism CRC’s *National Guideline For supporting the learning, participation, and wellbeing of autistic children and their families in Australia* (Dec 2022).

¹⁴ Email thread between Bob Buckley, A4 Convenor and Ms Falkingham, NDIA CEO subject: **Re: claims of request for 40 hours of EIBI/ABA [SEC=OFFICIAL]**, 22/11/2022.