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Senator the Hon Linda Reynolds

Minister for the National Disability Insurance Scheme
Parliament House
Canberra ACT 2600

Dear Senator the Hon Linda Reynolds,

Subject: creating trust and respect between the NDIA and the autism community

Currently, you and the NDIA seem to want a simple process to rebuild the trust of the disability sector in the government and the NDIA. You seem to believe this is in the hands of the disability sector; that we can have a bit of a chat, tick a few boxes, and leave all that behind.

Frankly, creating trust and respect between the NDIA and the autism community will take far longer than you and the NDIA seem to appreciate ... or are prepared to recognise.

Before getting into issues of trust and integrity, please understand that the Autistic community is united in wanting an effective, affordable, and sustainable NDIS. Prior to the NDIS, the Autistic community had a good relationship with government around John Howard's *Helping Children with Autism* (HCWA) package and the ALP's [Autism Specific Early Learning and Child Care Centres \(ASELCC\)](#).

Regrettably, the NDIA chose to squander the trust of much of the autistic community from the outset.

Our impression is that you and the NDIA feel trust was lost over the recent so-called Independent Assessment fiasco. Be assured that matter is just the tip of the distrust iceberg. Even the broader matter of draft legislative changes to the NDIS Act are just the latest aspects of the rift in relations. The NDIA's CEO wrote to the community claiming, "The tools have been designed to assess the capability of people with disability and used all over the world for many years". This claim is false: there is no such tool in relation to autism. The NDIA ignored [A4's objection](#) to such the CEO's widely-distributed incorrect claim. It's not just that we did not want the so-called IAs, it's the frequent misinformation and secrecy that is how the NDIA does its business. Clearly, we *can* trust the NDIA to refuse to consider our concerns.

The NDIA's disrespect for A4, an established and DSS-recognised national DRO, is prodigious. The NDIA's contempt and disregard for Autistic representation and interests including families, academics, and clinicians is inexcusable when autism is the biggest distinct disability type in the NDIS and a significant secondary disability type for many.

Some specific examples follow.

1. The NDIA ignored [warnings from the Autism community](#) that its initial estimates of the numbers of Autistic NDIS participants were insufficient. This resulted in temporary [shutdown of NDIS roll-out](#) in South Australia and the Australian Capital Territory when the autism community were proven correct, though government never acknowledge that the autism community had advised accurately.
2. The NDIA ignore [advice form the autism community](#) about eligibility criteria. They refuse to recognise there are two severity ratings in a DSM-5 ASD diagnosis. Senior NDIS officials agreed to fix the criteria but then reneged on their commitment.
3. In a major attack on the Autistic community, the NDIA tried to [exclude “autism Level 2” from the NDIS eligibility criteria](#). Their claim that this was a “mistake” is simply not credible.
4. Note that the NDIA excludes children diagnosed with “autism Level 1”, yet these same children could be labelled with either Developmental Delay or Global Developmental Delay and would be eligible for NDIS. A government agency that behaves like this cannot be trusted.
5. In less than a week after the NDIS autism Level 2 fiasco, [the NDIA broke the Minister’s subsequent promise](#) to consult before making any changes.
6. The NDIA dismissed a series of expert reports on early intervention for autistic children while creating its ECEI Approach.
7. The NDIA keeps its whole TSP completely secret repudiating its transparency claim in its [Service Charter](#). This conduct shows that the NDIA is untrustworthy.
8. The Joint Standing Committee on the NDIS advised that using the PEDI-CAT assessment tool with Autistic children was inappropriate, yet the NDIA persisted with this unacceptable practice. It seems that the NDIA now compares previous PEDI-CAT assessment results for autistic NDIS participants with more recent functional assessments. Results from these comparisons are extremely unreliable.
9. NDIA officials [told the Senate Community Affairs Legislation Committee on 1/6/2019](#) that they expected to get autism numbers in the NDIS down to just 20% of the NDIS by full roll-out. This means that the NDIA either intended to kick 1 in 3 Autistic NDIS participants off the NDIS or allow very few, if any, further Autistic NDIS participants into the Scheme irrespective of their disability.
10. The NDIA ignores A4’s concerns that NDIA staff claim falsely to families of newly diagnosed Autistic children that the NDIS does not fund evidence-based early intervention, or that evidence-based early intervention for autism does not work. The AAT has ruled that the NDIS will fund reasonable and necessary evidence-based intervention and numerous AAT matters were settled with funding for EIBI/ABA for young autistic NDIS participants. Many NDIA representative and planners advise or promote cheaper early intervention of a type that evidence shows to be ineffective, and is not value for money.
11. Both [the NDIA and the IAC ignored A4’s concerns about IAC’s advice](#) to the NDIA on early intervention including its basically uninformed views on early intervention for young Autistic NDIS participants. Nor did the NDIA live up to its Service Charter in how it handled A4’s concerns.

12. The NDIA excluded A4 from its CEO Forums for years. A4 and DeafBlind Australia have finally been included in the new and larger group presumably, so the NDIA can now claim to be more “consultative” in the aftermath of its so-called IAs fiasco.
13. The NDIA’s Independent Advisory Council rarely includes autistic expertise or representation (see <https://a4.org.au/node/1512>).
14. The NDIA excludes A4 from its Autism Advisory Group (AAG). And it keeps AAG business secret. It doesn’t share its agenda with the community or even provide post-meeting communiques that it promised.
15. Many NDIA staff and representatives have a deep distrust of or prejudice against everyone associated with autism. NDIA staff culture is to believe parents of autistic children want:
 - a. their family income reduced by \$35K per year on average,
 - b. to spend their lives fighting the NDIA over funding, and
 - c. their child:
 - i. spending hours every week in therapy,
 - ii. having tantrums in supermarkets,
 - iii. failing in their education,
 - iv. having poor health and mental health with a high risk of suicide,
 - v. being perpetually unemployed, and
 - vi. not living independently as an adult.

NDIA culture has a profound disregard for parents of autistic children. They have a similar low regard for clinicians.

... etc.

Even if the NDIA embarks on a credible co-design process that includes representatives of the Autistic community, we could not trust the NDIA to stick to a co-designed outcome. Historically, they break any promise of that kind.

The proposal to develop a co-design agreement between the disability sector and the NDIA is alarmingly offensive. Clearly, the NDIA just ignores any such agreement. The proposal treats the disability community as excessively naïve, though some in the sector would sigh through pathological politeness. There is no justification for the NDIA wanting a written agreement from disability sector leaders.

Creating trust and respect between the NDIA and the autism community will take much more than a couple of workshops and a broken agreement. It will take a long time and a lot more work than the current exercise recognises. We eagerly await the first signs of the process starting. Trust may emerge through action; it will not come from talk or signed agreement.

Yours sincerely

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Bob Buckley
Convenor

16/09/2021