A4 Autism Aspergers Advocacy Australia

PO Box 4016
Ainslie ACT 2602

ACN: 623 372 047

email: convenor@a4.org.au
web: https://a4.org.au

Dear Senator McAllister

I was disappointed to read your announcement of a new disability assessment tool for the NDIS is paywalled media: https://www.smh.com.au/politics/federal/family-doctors-out-government-assessments-in-to-determine-ndis-support-20250924-p5mxiv.html.

I understand from the article (and the subsequent article on the NDIS website) that your government chose the I-CAN disability assessment tool – https://cds.org.au/clinical-services/i-can/ - for use in the NDIS, and that it made this decision without consulting Disability Representative Organisations (DROs) or Disability Representative and Carer Organisations (DRCOs), and especially without consulting the autism sector. This is the same strategy that delayed progress in Closing the Gap for years.

The NDIS and the government have an unfortunate history with their efforts to impose independent assessments and assessment tools. Previous attempts to impose so-called Independent Assessments were fraught. A4 regards this latest approach, avoiding even basic discussion, as disingenuous and a breach of trust. It discredits Labor's basic ideology.

There are also major issues relating to the choice of assessment tools. For example, the NDIS continues to use the PEDI-CAT assessment tool with younger autistic children despite research and parliamentary inquiries finding consistently that the PEDI-CAT is inappropriate for assessing autistic children. The PEDI-CAT authors recognised the problem and sought to create an autism-specific version called the PEDI-CAT ASD. The NDIS commissioned research to evaluate the autism-specific PEDI-CAT ASD … but that assessment tool was also found to be unsatisfactory – see https://www.autismcrc.com.au/knowledge-centre/publications/reliability-validity-and-acceptability-pedi-cat

As yet, the autism sector is not aware of a properly validated assessment tool for assessing support needs for autistic people. Possibly, the autism spectrum is too diverse to be assessed this way – it is possible that a practical tool for the autism spectrum is too complicated to be viable – and the practical solution is what the NDIS originally promised, that autistic individuals would have their individual needs assess individually.

The NDIS has enormous difficulty with autistic NDIS participants who are the largest (most numerous) primary disability type in the scheme. The NDIS legislation omits the triad of autistic impairments, social, communication, and behavioural impairment, from the legislation's core list of impairments (repeated 3 time in the Act) … thereby ignoring autism as a disability. This makes it difficult (if not impossible) for the NDIS to legally support autistic NDIS participants since supports for an individual are legally tied to the individual's recognised impairment(s).

On the positive side and from the little information available about the I-CAN tool, A4 sees that the domains it considers include 5. Communication and 10. Behaviours of Concern. Items 4 & 9 might address "social" impairment … so possibly I-CAN might recognise keys aspects of autistic support needs.

Autism Aspergers Advocacy Australia acknowledges the traditional owners and custodians of the lands on which we live and work. We respect past, present and emerging elders. We recognise their continuing connection to lands, waters, and cultures. Sovereignty over the lands was never ceded.

Addressees are subject to A4's policy on unanswered questions: see https://a4.org.au/node/1419

A4 is very interested to see how I-CAN has been (or will be) validated for the full diversity of the autism spectrum. Already, it is apparent that there are many issues with the tools and associated processes that needs to be addressed.

There are many questions starting with …

- Does I-CAN produce substantially different results from those the ABS has reported from its SDAC series?
- The I-CAN was designed to be used by our clinicians. Why does the government believe that our own treating clinicians cannot administer and report using I-CAN?
- The example on the I-CAN website gives an example of breaking the Mobility domain into 4 sub-domains. It is unclear how it would assess a severely autistic person who cannot leave home, who cannot drive or use public transport alone, would be assessed.
- Only "behaviours of concern" are mentioned. Why are other absent or dysfunctional behavioural issues ignored?
- The I-CAN considers health issues. Will those be omitted from the NDIS version since health issues are not NDIS responsibility?
- How was I-CAN validated for Australia's current autistic population?

A4 agrees that the limited information that the NDIS records for autistic NDIS participants does not meet the Agency's planning needs. From the outset, A4 has advise the Agency repeatedly that it should at least collect the full functional assessment information that is part of every properly described DSM-5 (or DSM-5-TR) diagnosis report for an ASD diagnosis. But the Agency refuses to do that. Health (former DSS bureaucrats) who oversee the NDIS also reject this advice.

A4 also agrees that information included in the full DSM-5 diagnosis report is still insufficient for NDIS planning purposes. So, the planning process would benefit from additional information. We doubt that anyone really has the answer at this stage, so this must be the subject of immediate research.

A4 believes that the Agency could get the information it needs for proper planning from a participant's treating clinicians. We disagree with the Agency's belief that every clinician, except those the Agency uses as IMEs in AAT/ART matters, is corrupt or incompetent. We do not agree with the Agency's view that professionally registered clinicians who are required to maintain professional standards are likely to be corrupt … or incompetent.

We feel that if the Agency has standard questions that it needs answered for planning purposes, then it should simply ask those questions of the applicant's or participant's treating clinicians. And it should recognise the answers given and use them in planning. The Agency must have a systematic process for administering questions arising and recording and processing responses.

Please understand the clear lesson from Closing the Gap that successful government programs are designed and implemented in conjunction with the people who are affected. Autistic Australians and their representatives must be included in the design and implementation of the NDIS and other disability programs.

Yours sincerely

26/09/2025