

The Members of the Committee
c/- Committee Secretariat
Joint Standing Committee on the National Disability Insurance Scheme
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Dear Committee member,

Autism Aspergers Advocacy Australia (known as A4) appreciates that your report on the NDIS and early intervention is imminent. Sadly, A4 has growing concerns over the operation of the NDIS in regard to early intervention for autistic children^{1[1]}. A4 received reliable reports about the NDIS's approach.

1. In the NDIS planning process, many NDIS planners (and NDIS decision-making “delegates”) with no discernible expertise or relevant training in ASD overrule or ignore needs assessments and support recommendations from specialist clinicians on specific early intervention needs of individual autistic children. In relation to ASD, planners and/or delegates have ignored multiple consistent recommendations for individual children from independent specialist clinicians.
2. Some NDIS planners tell families that an NDIS plan of over about \$16K cannot be approved. When a family or their advocate questions this statement the planner backs down, and explains that a planner cannot approve a larger plan, that is up to a “delegate” who has to approve a larger plan. This is also misleading if *all* plans have to be approved by an “NDIS delegate”. Clearly, this tactic aims to avoid having the NDIS fund good practice early intervention for autistic children.
3. Some NDIS planners tell families of autistic children simply that Applied Behaviour Analysis (ABA) “doesn’t work” which is contrary to advice the Government publish that says ABA or Early Intensive Behavioural Intervention (EIBI) for ASD often works and is the only approach to early intervention that can be described as “evidence-based” (which means there is published evidence that it works a significant amount of the time or for a significant proportion of autistic children) ... other approaches rate as having “emerging evidence”^{2[2]}. Clearly, NDIS planners who say “ABA doesn’t work” seek to mislead/misinform families.
4. Some NDIS planners tell families that “the NDIS does not fund ABA”. This clearly a lie as the NDIS funds some ABA for some families. The NDIS is meant to provide “choice and control” for participants over reasonable and necessary supports. The NDIS has admitted in AAT proceedings that ABA may be reasonable and necessary for an autistic child, though a dispute remains as to how many hours of early

^{1[1]} “autistic children” are children who are diagnosed with *autism spectrum disorder* (ASD) using [criteria from the DSM-5](#) ... or with a *Pervasive Developmental Disorder* using criteria in the ICD-10.

^{2[2]} A4 advocates for families being able to make *informed choices* about their child’s early intervention.

intervention the NDIS needs to fund and how much clinical intervention the NDIS requires the family to deliver.

5. When it does fund part of a child's early intervention, the NDIS typically requires families, who are usually not clinically qualified/trained and may not have the capacity or be suited to a clinical role, to deliver most of the necessary clinical supports for their autistic child. The resulting stress on a family often leads to mental illness, especially in mothers.
6. Some NDIS planners tell families that their draft plan will be sent directly to the NDIA's "ABA panel" for review if they want the NDIS to fund ABA early intervention. They are told the "ABA panel" process takes at least 6 months.
7. Some NDIA planners tell families that if they ask for an NDIS internal review of a plan or a planning decision, most likely such a review will decrease funding for their plan.
8. The NDIA delays some internal reviews that families request for extended periods or possibly indefinitely. This practice makes a mockery of the appeal process via the Administrative Appeals Tribunal (AAT) ... apparently, families cannot raise their issues with the AAT until the NDIS completes its internal review and makes a "reviewable decision".
9. Clinicians and families are concerned that some NDIS planners rely on PEDI-CAT assessments of autistic children when there is wide recognition that the PEDI-CAT is inaccurate for autistic children^{3[3]}.

The NDIS claims to have introduced "typical support packages". These appear to be secret NDIA business: they are hidden from participants and disability representatives. Their development was not discussed with disability stakeholders. There is no information available on how planners use them in planning and decision processes. The NDIA won't tell us what distinct categories of NDIS participants have "typical support packages".

This practice is contrary to the aims of the NDIS which is meant to meet individual needs rather than be centred on "typical support packages".

The NDIA now admits that "higher than expected number of children approaching the Scheme". The ASD community warned the NDIA that its initial estimates were too low but the NDIA chose to ignore advice from the ASD community, just as it ignores advice about good practice early intervention for autistic children.

The NDIA created its "Early Childhood Early Intervention (ECEI) gateway which aims to support children within mainstream services and the community"^{4[4]}. The NDIA's ECEI Approach is a clear and deliberate barrier meant to divert autistic children into "mainstream

^{3[3]} For this very reason, the authors of the PEDI-CAT have a PEDI-CAT ASD in development intended to address "the unique characteristics of children with autism" – see <https://www.pedicat.com/pedi-cat-asd>

^{4[4]} See <https://ndis.gov.au/medias/documents/h91/hbc/8805559468062/Report-to-the-COAG-Disability-Reform-Council-for-Q1-of-Y5.pdf>

services” that simply do not meet their needs. The NDIA’s strategy excludes autistic children and denies them access to effective early intervention.

The NDIA should provide separate figures on the mean and variance of plan/package costs for the different aspects of the NDIS: at the very least, separate figures should be reported for pre-school, school age and post-school NDIS participants, separated by primary disability. It would help if these were also reported separately for each state/territory.

Yours sincerely