

Response to NDIA consultation on its Early Childhood Reset

This brief response to the NDIA ECEI Reset is from *Autism Asperger Advocacy Australia*, known as A4.

We know that writing this response is pointless. The NDIA ignores input from A4, and it will certainly ignore what follows. This response is provided simply for the record.

The NDIA has a solid track record of dismissing expert advice on early intervention for autistic children, not just from A4. It misinterprets advice on early intervention for autistic children, claiming the evidence supports its preferred “family-centred” service model. There is no prospect of the NDIA developing an early childhood approach that is best or evidence-based practice for autistic children.

The *Early Childhood Early Intervention (ECEI) Implementation Reset Project Consultation Report* claims the NDIA’s ECI focus should be on *prevention*. A4 doubts that, other than eugenics or sterilisation, there are prevention strategies for ASD (or for other developmental delays like intellectual disability).

The Papers talk about the NDIA’s “family-centred approach”. The NDIA claims that children with disability, especially children with “developmental delay” (including autistic children and children with intellectual disability), mostly need better parents. Research is clear that this approach does not work for autistic children, but the NDIA rejects research relating to autistic children.

The NDIA’s disrespectful and misguided approach was discredited decades ago when those who demeaning parents, mothers especially, realised that many autistic children have able siblings who are raised by the same parents in the same environment. They observed that most parents of autistic children are effective parents for non-autistic children. In fact, to this day support for autistic children falls back onto parents when all else fails (childcare, school, etc.) – in most cases only parents cope when everyone else fails.

Parents always want to be better parents. The NDIA’s approach of telling parents that they are not good enough and they just need more basic instruction does more damage than good; it undermines parent resilience and self-confidence.

Researchers realised a long time ago that autism is not due to bad or poor parenting, and better outcomes are achieved through intensive work to help autistic children learn more functional skills and to apply them in varied settings.

Further, when an autistic child does not learn skills or generalise them across varied environments, then there are usually a smaller set of skills combined with environmental adjustments that allow an autistic child to function more effectively in a smaller number of environments. Best practice involves the family but may not make the family responsible for everything.

The NDIA is unable to recognise that its ECEI Approach that dumps an autistic child back in the environment where their autism was observed as disordered behaviour and expecting a different outcome is generally not regarded as best practice. It is unlikely to succeed and should be judged accordingly.

There is a plethora of reviews that found Early Intensive Behavioural Intervention (EIBI – sometimes called Applied Behaviour Analysis, ABA) has or is among the best evidence of improvement or

outcomes for autistic children. NDIA staff tell parents “the NDIS does not fund ABA” despite several AAT decisions that require it to do so: clearly, NDIA staff tell lies to families of autistic children. If families want evidence-based or best practice early intervention for autistic children, they may have to get the AAT to review NDIA decisions. The NDIA appears to want to make this even more difficult.

Not all parents want EIBI (or ABA) for their autistic children. This is their choice. A4 hopes they are well informed in making such a choice.

The NDIA refers to a report on early intervention from the IAC. It fails to mention or acknowledge criticisms of the report in relation to autistic children.

Basically, people outside the NDIA will need to inform parents of autistic children of the pathway to evidence-based early intervention for autistic via formal diagnosis and the AAT if that is what they want for their children.

Regrettably, the NDIA will remain a complex, difficult and unreasonable bureaucracy for young autistic children and their parents.