

intensive therapy for autistic children

In Sep 2022, the Acting NDIS CEO, Ms Studdart, raised the issue of families with autistic children wanting 40 hours of intensive therapy with A4. A4 expressed scepticism and in an email exchange with NDIS CEOs acknowledged that there was only one request for 40 hours (please see the associated email thread).

Subsequently in conversation, the NDIA CEO said that autistic children don't need intensive intervention for their ASD; but instead, autistic "kids just need the chance to be kids".

This shows a particularly poor understanding of young autistic children, especially the severely and profoundly¹ autistic children who are diagnosed when they are very young. Young children are diagnosed autistic typically because they don't know how to "be a kid". They do not communicate effectively or interact with most others. They do not engage in play or imagination; they are very delayed in the developmental milestones. Some severely or profoundly autistic children can be taught how to "be a child", how to communicate, play and learn but research indicates that they usually require investment in intense ASD-specific individualised therapy.

So, giving an autistic child the *opportunity* to "be a kid" is like turning on the light in a dark room so that a blind child has an equal opportunity to see, or delivering a person with quadriplegia (using a wheelchair) to the bottom of a staircase so they have an equal opportunity to walk up them.

Severely and profoundly Autistic children get little benefit from being left to practise autistic dysfunction. Typically, it is quite detrimental. They need neuro-affirming guidance to develop and improve functional skills for life.

In his [speech to the Press Club](#) (7/12/2023), Mr Shorten said,

"We don't want kids enduring childhoods of 40 hours of weekly therapy where there is no evidence of it being beneficial.

"Kids deserve the chance to be kids."

And in [the subsequent questions](#), he said:

"There's no point in saying to a child, or family of a child, oh yeah, we'll just give him 40 hours a week when that's not beneficial."

¹ The Australian Bureau of Statistics (ABS) reporting on its Survey of Disability, Ageing and Carers (SDAC) classifies disability into 'mild', 'moderate', 'severe' and 'profound'. This document uses the same technical terminology. The 2018 report described 68.9% of autistic Australians and having severe or profound disability – autism is typically not mild or moderate as many people believe.

The FoI section in DSS confirmed (FOI LEX 49105, 11/1/2024) that “no documents exist” that record advice on requests for 40 hours per week of therapy being provided to the Minister.

It is likely that the Minister's “40 hours” remark arises from misunderstanding of early autism research (Lovaas, 1987) that reported on positive outcomes for intensive intervention for autistic children. PubMed indicates that this article has 461 citations².

It is important to recognise some key issues.

1. Lovaas and others³ provided evidence that intensive (~40 hours per week for years) early intervention substantially improved outcomes for ~50% of autistic children (about 15% did not benefit measurably from the therapy) while less intensity (~10 hours per week) was ineffective – it is incorrect to say that “there is no evidence of it being beneficial”.
2. The “autism” label has a much broader meaning today.
3. For a range of reasons, few autistic children today are regarded as needing 40 hours of intervention per week. There are numerous recommendations discussed below based on further research and experience.

Changes relating to autistic children since 1987 include:

- Autistic children no longer need to appear “normal” to enrol in mainstream school - so the goal of intervention is less demanding
- “Autism” is no longer rare and is less severe on average - the autistic population has changed significantly; severe/profound cases still exist but there are more cases of less severe autistic presentations now.
- Autism is recognised as neuro-developmental where the associated neurology does not imply dysfunction ... and the broad spectrum was combined under the ASD label. In the DSM-IV, Asperger’s disorder and PDD-NOS were separate diagnoses.

The consequence of no longer needing to appear “normal” to attend mainstream school means that fewer (in absolute terms) autistic children need such intense programs. In its *Educating Children with Autism* (2001) review, the National Research Council (USA) advised:

The committee recommends that educational services begin as soon as a child is suspected of having an autistic spectrum disorder. Those services should include a minimum of 25 hours a week, 12 months a year, in which the child is engaged in systematically planned, and developmentally appropriate educational activity toward identified objectives.

This means that a child suspected of being autistic (in the sense of DSM-IV Autistic Disorder - which did not include DSM-IV Asperger’s disorder or PDD-NOS) should not wait years for a diagnosis (as often happens in Australia) then, if the child is one of those advised clinically to access EIBI, spend more

² For comparison, the paper describing the popular [PECS intervention](#) for autistic children (Bondy, Frost, 1998) has 24 citations.

³ For example <https://www.sciencedirect.com/science/article/abs/pii/S0270468485800057>

years in the AAT arguing the case with the NDIS (due to [the NDIA's cruel policy](#) that targets Australia's most vulnerable autistic children).

In Australia, a series of reviews⁴ advised government that

- “no one intervention will meet the needs of all children with autism”, and
- some autistic children (DSM-IV Autistic Disorder) need a comprehensive program comprising 15 to 25 hours per week of intensive ASD-specific individualised early intervention. Just prior to the HCWA roll-out, the autism sector had its 1000 hours (20 hours per week for 50 weeks a year) campaign. The [Prior, Roberts, et.al. \(2011\)](#) review for HCWA found that EIBI was the only EE rated intervention.

The Autism CRC's more recent “umbrella” review⁵ for the NDIS, like Sandbank's work that it references heavily, concludes that later research has less definitive results. These reviews fail to mention/recognise that more recent results relate to DSM-5 ASD ... rather than DSM-IV Autistic disorder in previous research. Hence their comparisons are unsound as they fail to appreciate that the results are for substantially different “autistic” cohorts.

The NDIS commissioned further work⁶. Its key conclusion said:

“Behaviourally based interventions are efficacious for key outcomes in children on the autism spectrum compared with children who undergo treatment as usual or non-behavioural interventions, but the pooled effect sizes are small (about 30% of a standard deviation) and vary considerably across studies.

Even for equivalent hours of clinician-delivered intervention, there is evidence for added benefit of behaviourally based intervention above that of treatment as usual (i.e., standard care or community based intervention) or non-behaviourally based intervention.”

This review did not go in the direction the NDIA wanted, so they dropped it before publication. That is quite dishonest; the autism sector cannot trust the NDIA and the government.

So, the sector has progressed since the initial evidence indicated positive outcomes for autistic children from 40 hours of intervention. Today, very few families ask for 40 hours per week, and very few clinicians advise that amount of therapy unless there are strong individual reasons for doing so. It is unclear why the Minister and his Agency continue to misrepresent a part of the sector in this way.

In most AAT matters about accessing EIBI/ABA for young autistic children, the AAT has decided to fund “ABA” for young autistic NDIS participants - the issue needing decision is the “intensity” of ABA to be funded.

⁴ See [Prior & Roberts \(2006\)](#), [Prior, Roberts, et. al. \(2011\)](#), [Roberts & Williams \(2016\)](#) and the associated booklets (for a less technical audience) - links available via <https://a4.org.au/node/965>

⁵ See <https://ndis.gov.au/about-us/research-and-evaluation/early-interventions-and-high-volume-cohorts/evidence-review-early-interventions-children-autism> or <https://www.autismcrc.com.au/interventions-evidence>

⁶ See <https://a4.org.au/node/2599>

Relatively few families of autistic children request EIBI (or NDBI) for their autistic child. The cases Mr Buckley has helped are profoundly or severely disabled by their autism - they are autistic children with the highest support needs. The NDIS makes families of autistic children with the highest needs fight the hardest for the support they need.

Many of those that do request EIBI or NDBI (the NDIS calls the therapies ABA) for their severely autistic child are sent to the complex and adversarial AAT for a decision. This is cruel and discriminatory.

Note: ABS SDAC data shows autistic Australians experience high levels of severe and profound disability - in 2018, the ABS reported 68.9% of autistic Australians have severe and profound disability. Even in the NDIS's severity terms there are fewer "low" severity (which is still within the severe and profound category) than the other severity ratings. A4 expects a significant proportion of the "low" severity ratings result from PEDI-CAT assessments where the NDIS has been advised *repeatedly* that the PEDI-CAT is inappropriate for autistic participants as it seriously under-states disability for this cohort. Autism is not usually mild as some people like to believe.

Persistent and wilful misinformation about autism and autistic participants pervades the NDIS. NDIA staff denigrate parents of autistic children (who are often neurodivergent themselves) and specialist clinical staff. The NDIS tolerates, even promotes, and maintains, a strong anti-autism culture. The NDIS *war on autism* must end.

25/02/2024