

## **Another battle in the NDIA’s war on autistic Australians**

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The NDIA’s Independent Advisory Council (IAC) published a report to the NDIA titled **Promoting best practice in early childhood early intervention** (March 2020) Paper, herein referred to as the IAC’s Advice. The website says the IAC gave this advice to the NDIA Board.

Recognising the preference<sup>1</sup> of autistic people, we use identify-first language in the following document except in direct quotations that use person- first language. The IAC’s Advice uses person-first language for autistic people, contrary to their preference.

*Autism Aspergers Advocacy Australia (A4)*, a Disability Representative Organisation specifically representing the autism community and recognised on [the DSS web page](#), offers the following commentary on the IAC’s Advice because we are extremely concerned by its content.

The IAC’s Advice says:

The paper will address key questions of:

- the nature of best practice and ways to harmonise best practice guidance for all children in the ECEI Pathway
- whether the ECEI as currently operating provides a framework for best practice Early Childhood Intervention (ECI) in ways that are sustainable for the NDIS
- whether there has been an erosion of best practice under the NDIS; and
- what best practice would look like in participant planning and budget.

It then goes on to reject expert advice about the “nature of best practice” early intervention (EI) for autistic children. It simply assumes best practice for autistic children in not sustainable; it is not clear what it regards as “sustainable”.

To consider whether there has been “erosion of best practice”, it would need to show there was best practice for autistic children in the NDIA’s ECEI Approach that could be eroded – but the IAC’s Advice does not do that because the NDIA denies young autistic children evidence-based (best practice) early intervention whenever it can.

It is unclear what the IAC means by best practice in participant planning and budget: does “best practice” relate to ECI delivery and outcomes, or to planning practice and budget/accounting practice (irrespective of EI outcomes).

In any case, the real purpose of the document is to support the NDIA’s war on autistic NDIS participants.

The IAC’s Advice is that Australian recognised experts in early intervention for ASD are completely wrong, that the NDIA should *reject* advice from expert clinicians and

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<sup>1</sup> See <https://www.afdo.org.au/news/language-guide/> or <https://www.amaze.org.au/2019/04/excuse-you-mind-your-language/>

researchers, including ASfAR representative, and take advice instead from the NDIA's "Independent Advisor Committee" that has little or no discernible knowledge or experience of early intervention for autistic children. The IAC's advice is that the NDIA should deny autistic children best practice early intervention for their ASD; instead, the IAC's Advice says the NDIA should provide generic (or "broader") early intervention for Australia's autistic children, the same that has been shown repeatedly to be ineffective for the control groups throughout the research literature.

Since 2006, the Australian Government published advice<sup>2</sup>, three successive research reviews about early intervention for young autistic children. Respected Australian autism researchers and clinicians wrote these reviews for the Government. The latter two reviews are cited in the IAC's references.

The reviews say best or good practice early intervention for autistic children is:

1. *Intensive* – for 20+ hour per week of therapy for at least 2 years
2. *individualised* – adapted for the specific needs of each individual child and their family
3. *ASD-specific* – research provides a range of effective techniques for teaching individual autistic children

In addition, the only approach that they rate as "evidence-based" provided a *comprehensive* program for each individual autistic child that is supervised by an experienced program supervisor and clinician.

Views about the advice vary in the ASD community, but it has been generally accepted across much of the ASD community. Basically, the ASD community view can largely agree that families should be fully and accurately informed about the research evidence and should be free to choose early intervention options that they believe meet their child's needs.

However, the NDIA rejects this advice and prefers to get its own advice selectively about early intervention for autistic children.

Apparently, the NDIA *expects* that substandard (i.e. not even "good practice") early intervention for autistic children will improve functional assessment results after their early intervention sufficiently so that they no longer need (or are eligible) to be an NDIS participant. The IAC and the NDIA reject [the DSM-5 where it says](#):

... Only a minority of individuals with autism spectrum disorder live and work independently in adulthood; those who do tend to have superior language and intellectual abilities and are able to find a niche that matches their special interests and skills. In general, individuals with lower levels of impairment may be better able to function independently. However, even these individuals may remain socially naive and vulnerable, have difficulties organizing practical demands without aid, and are prone to anxiety and depression. Many adults report using compensation strategies and coping mechanisms to mask their difficulties in public but suffer from the stress and effort of maintaining a socially acceptable facade.

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<sup>2</sup> They are:

1. Roberts & Prior (2006) the original was [a review](#) and [a booklet](#). They were available originally on the Health Department website but they were removed. They are still available from [an A4 web page](#).
2. Prior, Roberts, et. al. (2011) again, a report and a booklet are available from <https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/research-and-evaluation>
3. Roberts & Williams (2016) *Autism spectrum disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers* - download from <https://www.ndis.gov.au/about-us/publications#early-childhood-early-intervention-research-ecei>

The research literature is quite clear that the NDIA's expected spectacular outcomes, where substantially fewer autistic children become NDIS participants as a result of not-even-good practice early intervention for autistic children is fanciful: it simply will not happen.

The IAC's Advice says:

## 2. HARMONISING BEST PRACTICE FOR ALL CHILDREN IN ECEI

### Synopsis

*This section summarises the elements of early intervention that deliver optimal outcomes for children outlining:*

- *the tension between general ECI practice guidance and that for children with ASD*
- *contemporary evidence in relation to delivering optimal outcomes in ECI*
- *contemporary evidence in relation to good practice in ECI for children with ASD in Australia and comparing it with contemporary evidence in NZ, UK, Scotland and US*
- *a comparison of broader ECI guidelines with those of ECI for children with ASD.*

“Harmonising best practice for all children” means not recognising that autistic children have needs specific to their ASD; it means denying they have ASD-related needs that are distinct from needs arising from other types of disability. Apparently, the IAC's Advice is that the EI needs of autistic children are not distinct or significantly different from the general needs of other children with disability. The IAC's Advice treats ASD diagnoses as functionally meaningless; it denies that autism is a distinct disability with distinct needs.

Does the IAC's Advice intend that children with vision impairment are *not* taught Braille, that children with hearing impairment do *not* learn Auslan? Hopefully, it does not intend to “harmonise” (eliminate) those disability-specific supports as well. But the IAC's Advice indicates that the specific needs of autistic children should be ignored ... because the child is autistic but not vision, hearing, physically or intellectually impaired.

The IAC's claim is that the young autistic child belongs in the same childcare or pre-school setting as all other children whether or not they are ready for such a setting. So, when the children are told “be like a tree” and they all stand and wave their hands around, but the autistic child does not; so, the autistic child is seen as dysfunctional – probably non-compliant. It does not matter that the child has hardly ever seen a tree wave about vigorously. An astute early childhood teacher/worker might realise that the “be like a tree” instruction really meant “be like a tree waving about in a strong wind”; the instruction was confusing for an autistic child. Giving the full instruction is impractical (too long-winded).

Next week, she says to the children “do this” and stands waving her arms about. The autistic child still does not get it ... because yesterday “this” meant “stand on one leg”, and the day before “this” meant “put your hands on your head”. The meaning of “this” can be extremely confusing for an autistic child. Even an expert Speech Therapist may not be able to explain pronouns to a 5-year old autistic child.

The autistic child is being taught that whatever he is asked to do, he gets it wrong. In a few years, when he goes to school, he may be labelled with Pathological Demand Avoidance or Oppositional Defiance Disorder.

Many autistic children of pre-school age do not imitate naturally. They may not just pick up that skill the way non-autistic children do. Many pre-school staff are unable to teach an autistic child imitation, or they lack the capacity (or required resources) to deliver the intensive instruction needed. An autistic child who does not imitate gets very little benefit from a mainstream pre-school setting and falls further behind their age peers. Putting these children in mainstream pre-school before they are ready is like including a student with no knowledge of algebra in a class on calculus; it is detrimental for everyone.

The IAC does not explain how general or broader ECI, that is ECI of a type that the IAC prefers, differs from what children receive when they are in an autism research control group. Notoriously, research reports that generic or broader ECI achieves very little for autistic children. Somehow, the IAC missed (or chose to ignore) this vital conclusion of the research literature. Typically, young children are diagnosed with ASD when they fail in their natural settings or general ECI. So, it is very disappointing that the AIC thinks that returning autistic children to the “natural settings”, where they already failed, will somehow succeed next time around: the strategy of doing the same thing and expecting a different result is rightly held in contempt.

Of course, the IAC will say “that isn’t what we meant”. The problem is they do not explain what they mean, and the recommendations are being made to NDIA bureaucrats whose job is to interpret the IAC’s Advice in the most dysfunctional way possible.

The IAC’s Advice talks quite a lot about “delivering optimal outcomes” but fails to say what that is for autistic children. We can be certain that the IAC’s use of “optimal outcomes” in relation to autistic children is entirely different from how the term is used in the autism research literature.

In relation to autism research, the term “optimal outcomes” in association with “autism” appears first in [Pubmed](#) at

Stevens MC, Fein DA, Dunn M, Allen D, Waterhouse LH, Feinstein C, Rapin I. *Subgroups of children with autism by cluster analysis: a longitudinal examination.* J Am Acad Child Adolesc Psychiatry. 2000 Mar;39(3):346-52. doi: 10.1097/00004583-200003000-00017. PMID: 10714055.

Pubmed finds 22 papers: 16 of them have D. Fein as an author. Fein, et. al (2013)<sup>3</sup> wrote in relation to “optimal outcomes” for children who were diagnosed autistic:

... [Mundy \(1993\)](#) pointed out that normal IQ and functioning in regular education is possible in high-functioning autism and does not by itself constitute ‘recovery’. He also noted that even if an individual no longer meets criteria for ASD, he or she might manifest traits reflecting persistent core features of ASD, comorbidities, or non-autism problems requiring intervention. We agree with Mundy that normal IQ and mainstream classroom placement are insufficient for a claim of ‘optimal outcome’, and that absence of autism symptoms must also be documented. In our definition of ‘optimal outcome’, we require that the individual be without any significant autism symptoms and function within the normal intellectual range; however, other difficulties such as weaknesses in executive functioning or vulnerability to anxiety and depression may still exist.

We would be inclined to regard successfully attending a mainstream school with relatively little support and achieving a good education outcome, followed by

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<sup>3</sup> See <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3547539/>

successful employment and social participation, to be an “optimal outcome” for an autistic child who was diagnosed with ASD before entering or while at school.

In our view, the Pubmed list of papers contain “contemporary evidence” in relation to ECI outcomes for autistic children, especially in relation to “optimal outcomes” for autistic children. A Turkish study<sup>4</sup> recently reported findings comparable to Fein’s in respect of (previously) autistic children with “optimal outcomes”.

Note that the only early intervention with credible reports of achieving such an “optimal outcome” for a significant number of autistic children diagnosed before school age is ABA/EIBI. This appears to be the reason that the Government’s [HCWA Early Intervention Table](#) (2011) lists ABA/EIBI as the *only* eligible intervention “based on established research evidence”. As yet, none of the approaches rated back then as “Eligible based on emerging or best practice evidence” have published results that could lift their rating to “evidence-based”.

The IAC’s Advice is not clear about what the performance benchmarks for early intervention for autistic children are or should be. It seems that the NDIA expects high levels of Fein’s “optimal outcome” will be achieved as a result of generic or broader early intervention – an outcome that we have never seen reported in the research literature.

Different disability types have different needs. And different autistic children usually have needs that differ from each other. The differences between autistic individuals is so significant that the name used for the disorder in both the DSM-5 and the ICD-11 includes the word “spectrum”.

The IAC’s Advice shows an extremely poor understanding of evidence-based early intervention for autistic children. Under the heading “the voice of adults with autism” (p16-17), the IAC’s Advice cites just one organisation, Reframing Autism, that has the particular view of EI for autistic children that the NDIA also supports – they “reject the use of ABA and EIBI treatments”.

There are several issues with this:

- the IAC’s Advice rejects the only intervention for ASD that Government advice rates as “established based” and being capable of delivering “optimal outcomes” for autistic children, the only approach that by most standards would be regarded as “best practice for autistic children”;
- Reframing Autism (RA) is a particular group with its particular view about autism. RA is not the only group representing autistic adults in Australia; there are several autistic representative organisations in the Australian Autism Alliance, and Reframing Autism is not among them. RA’s view is selective: it does not represent the range of views of autistic adults or the ASD community. RA’s view contradicts that of other well-known autistic adults, for example Temple Grandin.
- The IAC did not contact or consult the recognised DRO for autism on the DSS website (which is A4) or other groups like Autism Awareness, ABAA, ABIA, the NDIA’s Autism Advisory Group, the Australian Autism Alliance.

We know that whenever possible the NDIA rejects the choices of families who request NDIS support for ABA/EIBI for their autistic child because many families report that their LACs and planners (if a family is in touch with their child’s NDIS planner) say “the NDIS does not fund ABA”. This is a lie; the AAT decisions in [FRCT vs NDIA](#) and [WKZQ vs NDIA](#) show the NDIS funds ABA/EIBI programs for autistic children if families are prepared to take their case to the AAT, the independent adjudicator. Few

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<sup>4</sup> See <https://pubmed.ncbi.nlm.nih.gov/27862704/>

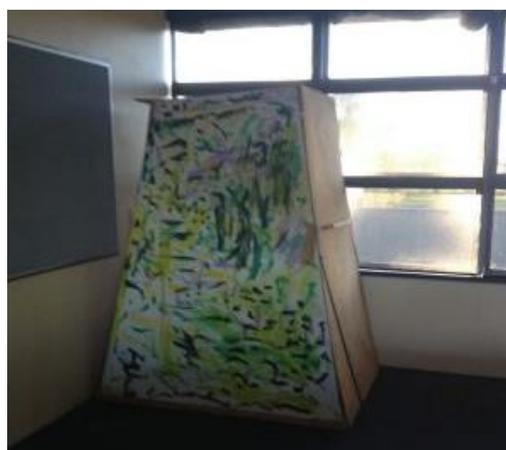
families are willing or able to challenge a government agency in the legal system: this limiting access to evidence based early intervention is extremely inequitable.

The NDIA pretends it is concerned about inequitable access to supports, yet they are the ones that annihilated family's access to impartial Autism Advisers who are essential to informed choice, and force the inequity of a requiring families to battle them in the AAT if they want evidence-based early intervention for autistic children.

*Autism Aspergers Advocacy Australia* (A4), the recognised DRO for autistic people, has raised this issue with the NDIA repeatedly but the NDIA refuses to even discuss it.

Some people claim A4 promotes only ABA/EIBI for autistic children. A4 promotes a person or their family's using informed choice and having ready access to evidence-based supports of their choice, without having to fight government agencies for their choice through the legal system. Whether or not a person or family chooses behavioural interventions, or other approaches, should be a fully informed choice, and not dictated or limited by the bigotry of NDIA officials. A4 also opposes misinformation and prejudice (such as the IAC's Advice on EI for autistic children), and defends the human rights of autistic people, their families and associates (such as their right to appropriate effective education and best practice treatments).

ABA clinical practice is not limited in application to early intervention for autistic children; ABA is essential for evidence-based behaviour management. Examples of infamous consequences of rejecting ABA, of not applying clinical behavioural science, are visible in the following images from Australian media showing use of inappropriate restraint when clinical behaviour management is lacking.



Behaviour science is a very powerful tool. As with many things, there is good, mediocre and bad practice; for example, behaviour science is used to addict people to gambling. As with any clinical method, there are risks so it is essential that its application has strong ethical management.

In relation to supporting people with distressed, frustrated or perceived challenging behaviour, the alternative to ABA (sometimes rebranded as PBS) is restraint ... usually escalating restraint. Opponents of ABA refuse to recognise that the alternative to applied behaviour science in this circumstance is restraint that is extremely detrimental for autistic people, including autistic children.

These matters are being discussed currently in the Disability Royal Commission.

While individuals who reject ABA may not “intend” such consequences, governments in Australia have been repeatedly informed that their failure/refusal to ensure autistic Australians can access safe behaviour support denies vulnerable people many crucial human rights.

Currently, the NDIS promotes, encourages and funds thousands of people and organisations with little or no training, qualifications, clinical experience or professional standards (or oversight) in behaviour management to offer behaviour support to NDIS participants. There have been [thousands of complaints](#), some of them specifically about behaviour management, and just one small fine unrelated to behaviour support, over a South Australian woman who was killed by abusive support (see [here](#)).

The IAC’s Advice emphasises Family-Centred and Strength-Based Practice. The Advice says “the way forward” should, instead of supporting the individual, “ensure planning is family-centred, strengths-based, builds the capacity of the family”, making the family into a child’s long-term safety net rather than meeting the state responsibilities to autistic children.

The IAC’s Advice heavily emphasises family-centred practice and misrepresents the family’s role in evidence-based practice for autistic children. This misrepresentation of the role of families in evidence-based early intervention for autistic children has been a feature of advice about early intervention for autistic children in Australia for some time.

Typically, the family-centred approach means that parents are required to deliver most of their child’s therapy. Parents, especially mothers are made responsible for their child’s outcomes. Apart from the evidence that parent-mediated therapy rarely delivers optimal outcomes for autistic children, it leaves parents of the many children who do not achieve optimal outcomes with life-long guilt over their less-than-ideal outcome. This is unfair and very cruel. It is especially unfair for single mothers with multiple autistic children.

A review<sup>5</sup> of parent-mediated autism early intervention (which is pretty much an autism-specific version of the IAC’s family-centred approach) only found “some evidence for the effectiveness of parent-mediated interventions”; this review found that parent-mediated EI for autistic children does *not* deliver “optimal outcomes”.

People think because the advice previously provided by the Australian Government about best practice early intervention for autistic children classified ABA/EIBI as the *only* “evidence-based” approach, that the authors and their reports were pro-ABA. But that is not the case. Their advice promoted approaches with “emerging evidence” as “best practice” instead of approaches with evidence of “optimal outcomes”. The authors opposed ABA/EIBI and preferred TEACCH, The Eclectic Model and perhaps

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<sup>5</sup> See <https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD009774.pub2/full#CD009774-sec1-0001>

ESDM. However, these approaches are yet to deliver evidence of “optimal outcomes” as most people hopes they will; we want more evidence-based options.

The Eclectic Approach had some unfortunate research results, so exponents rebranded it the Multi-disciplinary Approach. It was poorly defined. In the field, implementation was erratic and typically its uncoordinated outcomes were poor (not known to deliver any “optimal outcomes”). Proponents revised their description, adding the expectation of better coordination and rebranded it the Trans-disciplinary Approach. Sometimes the NDIS refers to it as the Key-worker Approach. Increasingly, the approach comprises evidence-based techniques from across the ABA repertoire with some coordination. The approach still lacks the teamwork and record keeping cultures that contribute to ABA’s stronger evidence of outcomes.

The tension between differing communities of practice are described in Freeman’s *Science for Sale in the Autism Wars* (2003), SKF Books, Langley.

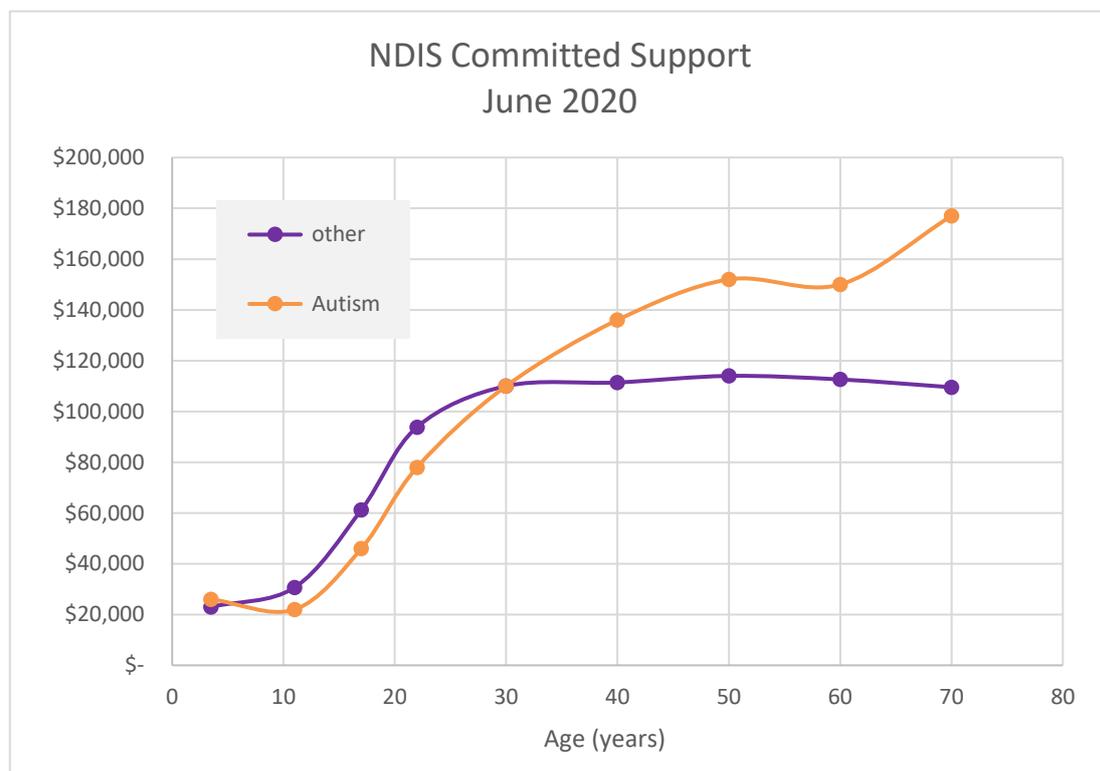
A key issue is that the family-centred models in the various autism-specific approaches are not as similar as either Roberts & Prior or the IAC’s Advice claim.

Roberts & Prior together with the NDIS seem to start from the incorrect premise that intensive EI is too expensive; that the only way 20+ hour per week of intervention is possible is if you get the family, usually the mother (or parents), to do it. Otherwise it is simply unaffordable.

This assumption is incorrect:

- All 50 states in the USA have legislated that the cost of intensive early intervention for autistic children is covered by private health insurance. To our knowledge, no US private health insurer has gone broke paying for EI for ASD.
- The Productivity Commission concluded that it was unaffordable to not properly fund early intervention.

Data from the NDIS shows the average cost of plans for autistic participants.



These data indicate that plans for autistic children under 10 years of age are not more expensive than the cost of an average NDIS plan for that age group. The lifetime average cost for autistic NDIS participants is over \$6 million.

Effective early intervention will “flatten the curve” for autism, especially the part of the curve relating to autistic NDIS participants who are over 30 years of age. Given the shape of the curve, any spending in the 0 to 10 years age range that reduces support needs in adult life will be value for money. Cutting the cost of early intervention is a false economy. The cost of early intervention for autistic NDIS participants is not a significant risk to the NDIS.

The far bigger risk for the NDIS is the government’s failure to understand (refusal to recognise) how ASD diagnosis rates are changing and the implications of chronic under-diagnosis of autistic adults and delayed diagnosis for autistic children.

The nub of the IAC’s Advice is one sentence.

*The IAC recommends the development of new practice guidelines for children with ASD to support best practice in ways that are sustainable for the NDIS.*

Most likely, the ASD community feels the NDIS need to develop guidelines for NDIS Planners who write NDIS plans for young autistic children. These will be “new” (by definition) since NDIS Planners apparently do not have at present any guidelines relevant to autistic children – certainly, the NDIS has not shown ASD representatives any guidance it gives its planners about NDIS planning for autistic children.

The major danger is that the NDIS will develop new guidelines based on the IAC’s Advice and other misinformation. NDIS avoids consulting anyone with knowledge and/or experience in evidence based EI for autistic children. It has no basis for creating guidelines for EI for autistic children.

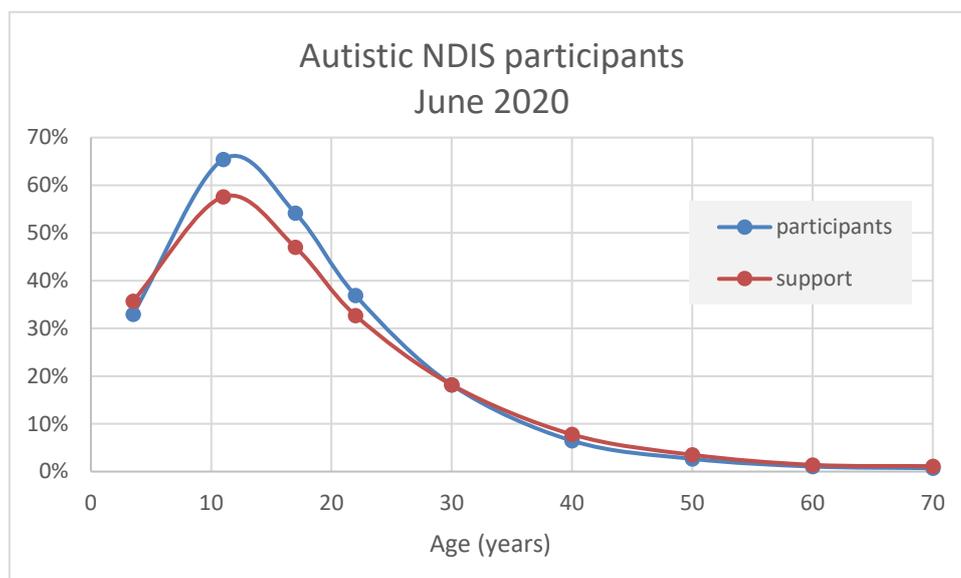
Ideally, such guidance for NDIS planners would support evidence based (best) practice, though what the IAC, whose members have no discernible knowledge or experience of evidence-based early intervention for autistic children, regard as “best practice” for autistic children is very different from autism clinicians, researchers, most advocates, members of the ASD community and qualified service providers regard as best practice early intervention for autistic children. Most people with experience and knowledge of ASD regard generic or “broader” ECI, as the IAC Advises, to be completely substandard for autistic children.

The NDIS is meant to give people with disability, including autistic children, “choice and control. The IAC’s Advice seeks to deny the families of young autistic children choice and control in relation to good practice early intervention for autistic children. It does recognise that others said ...

... in the early stages, parents are not sufficiently well informed or have a clear enough understanding of the needs of the child and family to make good choices. They proposed a range of conditions needed for parents to make productive choices including access to unbiased and accurate information and support from an experienced and skilled planner, neither of which could be guaranteed in the current operation of the ECEI Approach

The NDIA and the IAC cannot justify their belief that the NDIS is “unsustainable” for autistic children. Currently, over 31% of NDIS participants have autism as their primary disability. The NDIA wants to get this figure down to 20% of NDIS participants are autistic because that what their initial modelling predicted. They misunderstand “modelling”: modelling is used when there is little or no data available. Now that the NDIA has data, it must use the data. It must move on from its early modelling, possibly using the actual data to refine its future modelling.

Modelling does not provide performance benchmarks, as the NDIA appears to believe. This is misuse of modelling.



While 31% of NDIS participants have autism as their primary disability, the June 2020 cost of committed supports for autistic NDIS participants in 17<sup>3</sup>/<sub>4</sub>% of the total. This is below the average cost of 20% of participants. It is very hard to see how these figure show autism in the NDIS is “unsustainable”.

The IAC and the NDIA need to explain why they regard the autistic 31% of NDIS participants who account for 17<sup>3</sup>/<sub>4</sub>% of the NDIS’s committed participant support is not sustainable.

[The original NDIS ECEI approach](#) was based on “Three key research pieces”. Only one mentions early intervention for autistic children: KPMG (2011), *Reviewing the evidence on the effectiveness of early childhood intervention*, Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSia) – links are [PDF](#) and [RTF](#) formats. KPMG’s report cites Australian research<sup>6</sup> that described the outcomes of Aspect’s *Building Blocks* programs:

The results found that there were statistically significant improvements in all three groups on the communication scale of the *Vineland Adaptive Behaviour Scales*. Children in the centre-based program had the largest improved (78.4 after the program compared to 64.4 before the program) followed by the waiting list (74.2 after the program compared to 68.5 before the program), the home-based group had the smallest increase (68.4 after the program compared to 64.4 before the program). No other changes were statistically significant.

“Statistically significant improvements” are well short of “optimal outcomes”. The waitlist group gets the type of early intervention that the IAC Advice recommends while the parent directed natural setting group does worst (possibly random assignment disadvantaged this group in the study).

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<sup>6</sup> Jacqueline Roberts, Katrina Williams, Mark Carter, David Evans Trevor Parmenter, Natalie Silove, Trevor Clark and Anthony Warren, “A Randomised Controlled Trail of Two Early Intervention Programs For Young Children with Autism: Centre-Based with Parent Program and Home-Based”, *Research in Autism Spectrum Disorders*, Volume 5, 2011, pp. 1553-1566

This research does not support the IAC's Advice. Despite the lesser outcomes for the generic (waitlist) and natural settings (home-based) groups, the NDIA and the IAC prefer that the NDIS provide EI that delivers worse outcomes for autistic children. This is very poor advice.

The family-centred approach sends families a message that their child will be less autistic if they are better parents. This is a variation on the long-refuted "refrigerator mother" hypothesis of autism. The IAC's advice fails to describe the serious risk to families, especially to mothers, that the family-centred approach will leave them feeling guilty or traumatised if their child does not achieve an optimal outcome.

The IAC and the NDIS seem to think that current practice in ABA consists largely or entirely of therapy sessions delivered by clinicians in clinics, and that little or none of it is delivered in "natural settings". This could not be further from the truth.

ABA/EIBI early intervention has always involved the family as much as possible. Most ABA/EIBI clinicians expect families to continue their child's program as much as possible in all the child's settings. The family is heavily involved in development of each child's program and is trained to support the child and their program through all their natural settings. Optimal outcomes simply cannot be achieved without the generalisation of a child's skills in their natural environment. For some skill, the natural environment is too distracting for initial learning of some skills, so an effective program depends on an effective balance between clinical (segregated?) and natural settings.

The IAC and NDIS's insistence on conducting early intervention *only* in "natural settings" is sub-optimal for most autistic children.

The IAC and NDIS's belief that ABA/EIBI programs do not involve appropriate use of natural settings is seriously misguided. The observed outcomes could not be achieved without extensive use of natural settings. The use of natural settings in EI for autistic children was pioneered in ABA/EIBI and evidence of its benefits comes from those programs.

A substantial body of research shows that less intense early intervention for autistic children provides little or no benefit; the influential Lovaas (1987) research described results for 3 groups and the groups who received <10 hours of intervention showed no benefit. The Government's advice about EI for autistic children has repeatedly advised 20+ hours per week of therapy is essential to achieving good outcomes.

The IAC's recommendation for using general or broader ECI for autistic children is not suggesting a change. Currently, young autistic NDIS participants get \$23K committed support per year on average, similar to \$22K which is the average committed support for all NDIS participants in this age group. Most young autistic NDIS participants get services that are not ASD-specific; providers are not delivering evidence-based or best practice EI for autistic children – certainly not with that funding level. Their interventions are not being delivered in specialised setting ... presumably they are already being delivered mostly by family members in "naturalistic settings". The system is already delivering what the IAC's Advice suggests.

Clearly, delivery of EI as the IAC advises does not deliver the outcomes that the NDIA expects for autistic children.

The IAC's Advice offers no reason, no evidence, to expect it would achieve the improved outcomes they expect in order that more autistic children function well enough to *not* progress to being NDIS participants. In fact, available evidence indicates that there is little or no benefit or prospect of success (see *Building Blocks* research, above).

The IAC's Advice about evidence-based or best practice EI for autistic children, that is EI that achieves "optimal outcomes" for autistic children, is incorrect. The IAC's Advice says:

1. *There is significant similarity between general practice guidance for ECI and that for children with ASD.*
  - a. *Similarities relate to the importance of family-centred practice that is culturally appropriate, strengths-based, capacity building and outcomes-focused and delivered via a collaborative team approach*
  - b. *Differences relate to the individualised nature and weight given to specialist versus capacity building focuses.*

The IAC's lack of knowledge and experience with EI for autistic children limits their ability to make comparisons "between general practice guidance for ECI and that for children with ASD" or to draw conclusions. The IAC's Advice shows extremely poor understanding of best practice EI for autistic children. Of course, there are similarities, for example both approaches apparently aim to reduce long-term support needs and primarily use the child's first language, but the IAC does not make its case adequately that outcomes are sufficiently similar that the ASD-specific EI is unnecessary.

Experts (apparently recognised by the Australian Government because the Government published their research reviews and advice about early intervention for autistic children) describe evidence-based best practice and good practice based on emerging evidence as:

1. Intensive meaning at least 20 hour of clinically supervised therapy per week for at least 2 years,
2. Individualised meanings adapted to the needs of the individual child in the child's environments and settings,
3. ASD-specific meaning using teaching and therapy techniques/methods where the evidence shows they work for autistic children and where there are no contra-indications for the particular child,
4. Comprehensive meaning the child's program includes a complete set of elements needed to achieve an optimal (best possible) outcome for the individual child.

The IAC mentions a few perceived differences and appears to imply that it has preferences. The IAC's Advice mentions "the individualised nature" however it is unclear what difference it sees in this regard. The recommendations of ASD experts is that EI for autistic children needs to be highly individualised so presumably, since the IAC sees this as a difference, it expects that general ECI is *not* individualised. The IAC's Advice to adopt non-individualised general ECI goes against the original intent of the NDIS.

The crucial difference, that the IAC does not mention, is the evidence describing achievement of "optimal outcomes". It is this difference that drives the substantial body of published research that highlights the substantial differences "between general practice guidance for ECI and that for children with ASD".

Evidence about the value of family-centred approaches varies in EI autism research, but most researchers and clinicians strongly prefer that families be heavily involved in their child's program, especially when it comes to generalising the skills an autistic child learns into the child's natural environment. Most researchers and clinicians describe "optimal outcomes" as unlikely without full family engagement with the program.

The role of the family in optimal outcomes for autistic children varies; it is in addition to the essential aspects of EI for autistic children described above, it is not the foundation element of best practice early intervention for autistic children that the IAC's Advice suggests.

*Evidence based* is usually more important for autistic children than "strength based". Successful learning for autistic children depends on their responses to situations and events in their life being functional and effective (self-reinforcing). This might be perceived as "strength-based", however it is crucial that functional solutions also address "deficits" and barriers to independence in order to achieve optimal outcomes.

Most parents of autistic children want to build their capacity and ability for parenting: they all want to be better parents. They vigorously seek information and advice about how to be better parents. However, most of them are already spectacular parents through necessity. Anyone who doubts this should think about why preschools, kindergartens and schools [send children in huge numbers home to their parents](#) in ridiculous numbers when the faeces are spread around (often literally), that is when the experts in the children's "natural settings" cannot properly support autistic children. Clearly, the people on the ground already regard the parents as being best for the child.

So, it is irresponsible for the IAC to advise that "capacity building" programs should undermine parents and get people who cannot support autistic children adequately telling parents their parenting should improve. This approach blames parents for their child's autism: it is a variant on the cruel and discredited "refrigerator mother" hypothesis of autism. What parents of autistic children need most is reassurance and self-confidence. They do not need to not be around people who undermine them and doubt their parenting capacity.

The IAC does not have sufficient knowledge or experience of autism to be providing advice like this. Few people in the ASD community would offer or provide advice about services and supports for disabilities where they do not have expertise. It is disappointing that IAC members would do so.

The information in the IAC's Advice about the nature of best practice early intervention for ASD is selective.

#### **Factors related to the intervention**

Of the jurisdictions reviewed, the Scottish evidence (SIGN) specifically sought to identify the impact of different models of service deliver on outcomes in children with ASD. Specifically, the review sought to explore issues related to:

- ASD-specific service versus general service
- Multi-disciplinary service/ agency versus single agency
- Clinically integrated pathway compared to single service
- Single day assessment clinics.

The UK evidence (NICE) sought to identify the impact of key components of service delivery on outcomes, namely:

- Intensity of the intervention
- Duration of the intervention
- Length of follow up
- Program components

No evidence was found addressing any of these issues.

This is selective misuse of the source material. [The SIGN report](#) says:

## 6.1 PARENT-MEDIATED INTERVENTIONS

Parent-mediated intervention programmes are used to both advance the development and communication of an affected child and to offer practical advice and support to parents.<sup>125,126,127,128</sup>

A well-conducted Cochrane review of parent-mediated early intervention for young children (aged 1–6 years) with ASD identified 17 studies, all of which had a risk of bias and used a variety of interventions, intensity and treatment duration.<sup>129</sup> Results were inconsistent and inconclusive. There was a statistically significant benefit from parent-child interaction for joint attention. Small improvements were also seen in language comprehension and expression and reduction in parental stress, although these results need to be substantiated by further, larger randomised controlled trials (RCTs).

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- ✓ Parent-mediated intervention programmes should be considered for children and young people of all ages who are affected by ASD, as they may help families interact with their child, promote development and increase parental satisfaction, empowerment and mental health.

and

- R Access to support from staff trained in applied behaviour analysis-based technologies (eg Picture Exchange Communication System, discrete trial training, task analysis, prompting, fading or shaping) to build independence in adaptive, communication and social skills should be considered for children with ASD.

Apparently, the SIGN report recommends “parent-mediated intervention programs” despite their relatively low level of evidence: “results were inconsistent and inconclusive” and had “statistically significant” (barely discernible) and “small improvements” which is well short of substantial improvements and optimal outcomes reported for real best practice for autistic children. It says “ASD symptoms can constitute a significant barrier and psychoeducational interventions for ASD are employed in this context”. It identifies the need for techniques from the ABA/EIBI repertoire of therapies in autistic children’s programs.

The SIGN report also warns against getting parents to deliver services that were developed and research using trained and supervised therapists or moving techniques into “naturalistic settings”. It says:

Where evidence-based interventions are available, they should be delivered by personnel with the appropriate skills and training, according to the protocols used in the original research.

The IAC’s Advice that this document does not advise that autistic children need ASD-specific services is a complete misrepresentation. It is dishonest.

Previously, we have shown that “optimal outcomes” have been reported in the research literature in the USA. Some research observes “best outcomes” in Scandinavian studies and elsewhere. Research reviews of EI for ASD from Australian and USA have reported repeatedly the evidence for intensive individualised ASD-specific EI for autistic children is best practice: The IAC’s Advice is inaccurate in saying “no evidence” was found; it is more accurate to say that the IAC’s Advice is based on the one anomalous review that avoided relevant evidence relating to best outcomes for autistic children.

The IAC's Advice reference [The National Autism Centre's \(NAC\) report](#). The NAC's report reaffirms advice<sup>7</sup> from the National Research Council (2001):

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. What constitutes these hours, however, will vary according to a child's chronological age, developmental level, specific strengths and weaknesses, and family needs. Each child must receive sufficient individualized attention on a daily basis so that adequate implementation of objectives can be carried out effectively. The priorities of focus include functional spontaneous communication, social instruction delivered throughout the day in various settings, cognitive development and play skills, and proactive approaches to behavior problems. To the extent that it leads to the acquisition of children's educational goals, young children with an autistic spectrum disorder should receive specialized instruction in a setting in which ongoing interactions occur with typically developing children.

Regrettably, the Government's reviews of early intervention for autistic children<sup>8</sup> chose to ignore the NRC's comprehensive review of education, including early intervention, for autistic children and to ignore its findings.

The IAC's Advice does not have explicit authorship. Apparently, a social worker, an occupation with little relevance<sup>9</sup> to autism, prepared this document for the IAC. [Her CV](#) does not mention autism.

9/10/2020

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<sup>7</sup> National Research Council (2001). Educating children with autism. Committee on Educational Interventions for Children With Autism, Division of Behavioral and Social Sciences and Education. Washington, DC: National Academy Press.

<sup>8</sup> The three government reviews mentioned previously.

<sup>9</sup> The limited data available suggests autism diagnosis rates are higher in higher socio-economic groups because poorer people are less likely to afford the relatively expensive diagnosis process. There is little or no evidence showing social workers have improved access to ASD diagnosis or ASD-specific disability supports that improve outcomes for their autistic clients.