From: DLOPrentice s47E(d) - certain operations of agencies
Sent: Tuesday, 5 December 2017 11:37 AM
To: parliamentary
Cc: DLOPrentice
Subject: FW: the NDIS and early intervention for autistic children [SEC=UNCLASSIFIED]

Categories: - Joanne -, - IN PROGRESS -

The AMO would like an AM reply Ministerial Correspondence for the below writer.

Many thanks

DLO Prentice

From: Prentice, Jane (MP) [mailto:Jane.Prentice.MP@aph.gov.au]
Sent: Tuesday, 5 December 2017 9:53 AM
To: 'Bob Buckley (A4 Convenor)' <convenor@a4.org.au>
Subject: RE: the NDIS and early intervention for autistic children

Thank you for taking the time to contact my office, please accept this as confirmation that your email has been received.

Due to the large number of emails received each day, it is not possible to reply immediately.

However your email has been forwarded to the Department to provide a response as soon as possible.

Response times will vary depending on the complexity of the issues raised.

Yours sincerely

OFFICE OF THE HON. JANE PRENTICE MP | Federal Member for Ryan | Assistant Minister for Social Services and Disability Services
Suite R1-93, Parliament House, Canberra, ACT, 2600. Telephone: (02) 6277 4426
http://janeprentice.dss.gov.au/

From: Bob Buckley (A4 Convenor) [mailto:convenor@a4.org.au]
Sent: Tuesday, 5 December 2017 8:49 AM
To: The Hon C Porter MP
Cc: Prentice, Jane (MP); Macklin, Jennifer (MP); Brown, Carol (Senator)
Subject: Fwd: the NDIS and early intervention for autistic children

Dear The Hon. Mr Porter MP

Autism Aspergers Advocacy Australia (known as A4) has growing concerns over the operation of the NDIS in regard to early intervention for autistic children[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. [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] A4 advocates for families being able to make *informed choices* about their child's early intervention. [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 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] 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 [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] See https://ndis.gov.au/medias/documents/h91/hbc/8805559468062/Report-to-the-COAG-Disability-Reform-Council-for-Q1-of-Y5.pdf [4]. The NDIA's ECEI Approach is a clear and deliberate barrier meant to divert

autistic children into “mainstream services” that in many instances simply does not meet their needs. The NDIA’s strategy excludes many 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

--

Bob Buckley
Convenor, Autism Aspergers Advocacy Australia (A4)
website: http://a4.org.au/

A4 is the national grassroots organisation advocating for autistic people, their families, carers and associates. A4 is internet based so that Australians anywhere can participate.

“The first step in solving any problem is recognising there is one.” *Jeff Daniels as Will McEvoy in The Newsroom.*

Unclassified

Ministerial Correspondence

Office:	Assistant Minister for Social Services and Disability Services
Subject:	Complaint - early intervention for autistic children
Correspondent:	Mr Bob Buckley (o.b.o. Bob Buckley) Convenor, Autism Aspergers Advocacy Australia
PDR:	MC17-001397
Correspondence date:	05 December 2017
Due in AMO:	27 December 2017
Overdue Reason:	Nil
History:	Nil
Contact officer:	Sheree McGuffin Director National Complaints Team M: s22(1)(a)(ii) -
Comments:	Nil

Ministerial and Parliamentary Section | s22(1)(a)(ii) - | parliamentary@ndis.gov.au

Unclassified

The Hon Jane Prentice MP
Assistant Minister for Social Services
and Disability Services
Federal Member for Ryan

MC17-001397

Mr Bob Buckley
Convenor, Autism Aspergers Advocacy Australia

Dear Mr Buckley

Thank you for your personal representation of 5 December 2017 on behalf of Mr Bob Buckley to the Minister for Social Services, the Hon Christian Porter MP regarding early intervention for children with autism spectrum disorder. Your email has been referred to me as the Assistant Minister for Social Services and Disability Services as the matter raised is within my portfolio responsibilities.

I appreciate the time you have taken to provide feedback about early intervention for children with autism spectrum disorder

s47E(d) - certain operations of agencies Members of the community are encouraged to contact the NDIA by calling 1800 800 110 or by visiting the NDIS website at: www.ndis.gov.au.

Yours sincerely

JANE PRENTICE
Assistant Minister for Social Services and Disability Services

s47E(d) - certain operations of agencies

MC17-001434

GPO Box 700
Canberra ACT 2601
1800 800 110

ndis.gov.au

Mr Bob Buckley
Convenor
Autism Aspergers Advocacy Australia (A4)
convenor@a4.org.au

Dear Mr Buckley

Thank you for your emails of 5 and 11 December 2017 to the Assistant Minister for Social Services and Disability Services, the Hon Jane Prentice MP, about National Disability Insurance Scheme (NDIS) support for children with autism. The Assistant Minister has asked me to reply to you on her behalf.

The National Disability Insurance Agency (NDIA) is committed to ensuring participants receiving supports prior to the introduction of the NDIS are able to achieve the same outcomes under the NDIS. This does not mean the same level of funding or supports will be provided in the same way. The NDIA will seek to identify alternative support options, or make referrals to other systems, with a view to ensuring the same outcomes can be achieved.

No two NDIS plans are ever the same because no two people's goals or aspirations and individual circumstances are the same. Planners aim to be consistent in their application of what is reasonable and necessary for the NDIS to provide. However, plans are always tailored to the needs of the individual.

The Early Childhood Early Intervention (ECEI) approach supports children aged 0-6 years who have a developmental delay or disability and their families/carers. The ECEI approach supports families to help children develop the skills they need to achieve the best possible outcomes throughout their life.

There are supports that are unable to be provided under the NDIS, as they are the responsibility of other service systems. These systems and their responsibilities are outlined in the Council of Australian Governments (COAG) Principles to Determine the Responsibility of the NDIS and other Service Systems. These principles were agreed to by respective jurisdictions and the Commonwealth. More information about the COAG principles that govern the NDIS can be found at: www.coag.gov.au.

The NDIS will continue to provide community linking and individualised support for people with permanent and significant disability, their families and carers. The NDIA will continue to build relationships with mainstream service providers and the local community. This will improve their understanding about how they can assist people with disability.

Thank you for bringing your concerns to the Assistant Minister's attention.

Yours sincerely

Christine Faulkner
General Manager
Operations Division

20 December 2017

MC17-001434

GPO Box 700
Canberra ACT 2601
1800 800 110

ndis.gov.au

Mr Bob Buckley
Convenor
Autism Aspergers Advocacy Australia (A4)
convenor@a4.org.au

Dear Mr Buckley

Thank you for your emails of 5 and 11 December 2017 to the Assistant Minister for Social Services and Disability Services, the Hon Jane Prentice MP, about National Disability Insurance Scheme (NDIS) support for children with autism. The Assistant Minister has asked me to reply to you on her behalf.

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Thank you for bringing your concerns to the Assistant Minister's attention.

Yours sincerely

Christine Faulkner
General Manager
Operations Division

20 December 2017

From: DLOPrentice s22(1)(a)(ii) - irrelevant material
Sent: Monday, 11 December 2017 12:44 PM
To: parliamentary
Subject: FW: letter from Assistant Minister - MC17-001051 [SEC=UNCLASSIFIED]
Attachments: 13979.pdf

Follow Up Flag: Follow up
Flag Status: Completed

Categories: - IN PROGRESS -, - Joanne -

Hello
For this email, the AMOs view is - Agency response please.
DLO Prentice

From: Prentice, Jane (MP) [mailto:Jane.Prentice.MP@aph.gov.au]
Sent: Monday, 11 December 2017 12:31 PM
To: 'Bob Buckley (A4 Convenor)' <convenor@a4.org.au>
Subject: RE: letter from Assistant Minister - MC17-001051

Thank you for taking the time to contact my office, please accept this as confirmation that your email has been received.

Due to the large number of emails received each day, it is not possible to reply immediately.

However your email has been forwarded to the Department to provide a response as soon as possible.

Response times will vary depending on the complexity of the issues raised.

Yours sincerely

OFFICE OF THE HON. JANE PRENTICE MP | Federal Member for Ryan | Assistant Minister for Social Services and Disability Services
Suite R1-93, Parliament House, Canberra, ACT, 2600. Telephone: (02) 6277 4426
http://janeprentice.dss.gov.au/

From: Bob Buckley (A4 Convenor) [mailto:convenor@a4.org.au]
Sent: Monday, 11 December 2017 11:27 AM
To: Prentice, Jane (MP)
Cc: The Hon C Porter MP; Ms Prue Car MP; Macklin, Jennifer (MP); Brown, Carol (Senator)
Subject: letter from Assistant Minister - MC17-001051

The Hon Jane Prentice MP,
Assistant Minister for Social Services and Disability

Dear The Hon Jane Prentice MP

Autism Aspergers Advocacy Australia, known as A4, recently received a copy of a letter (MC17-001051, 16/11/2017) that you sent to Ms Prue Car MP. The Hon Ms Car MP passed the letter on to her constituents. Eventually, A4 received a copy.

Your letter said ...

> With regard to the level of support the NDIS can provide for early intervention, the NDIA will review the level of support required on a case-by case-basis, including requests for intensive support such as Applied Behavioural Analysis (ABA) therapy. In order for the NDIA to make a decision, evidence is required on how intensive supports like ABA will result in outcomes for the individual participant. The evidence must detail how the support will deliver outcomes above those that are ordinarily achieved through less intensive support. If a participant has already received a period of intensive support, the NDIA requires evidence of the support's efficacy, including detail of how the support was delivered and what outcomes have been achieved.

Your policy, described above, is concerning because ...

1. it denies most autistic children access to necessary supports that relevant experts consistently and repeatedly describe as evidence-based and good practice early intervention; instead, your policy prefers "less intensive supports" that are largely ineffective, not evidence-based and are considered less-than-good practice;
2. cost modelling shows that the approach you have taken for autistic children is *the most expensive* in the long-run and has particularly poor outcomes for autistic adults, their families and the community generally.
3. in practice the NDIS does not operate as you describe (see here and here); an autistic child's NDIS plan is unlikely to include good practice early intervention even when the family provides the evidence you say is required.
4. your policy is contrary to expert advice that the Government obtained in recent years about best practice and good practice early intervention for autistic children. Government sought and received reports in 2006, 2011 (MS Word version and Early Intervention Table) and then in 2016. The Government published these reports on various government websites. Experts in ASD advised consistently that each autistic child needs a comprehensive program of individualised intensive ASD-specific early intervention. The ASD community agrees as was evidenced by the 1000 hours campaign. Alarmingly, the Australian Government chooses to reject/ignore most of the expert advice it obtained on early intervention for autistic children.
5. the NDIA says "three key research pieces form the basis of the ECEI approach" (see here) and selected bits from the latest advice on good practice for autistic children merely "informed the ECEI approach". The NDIA's ECEI Approach promotes/emphasises parent-delivered intervention/therapy (support?) in "natural settings". Only one of the "three key research pieces", the KPMG 2011 document, mentions autistic children. It reports on Aspect's *Building Blocks program*, a family-centred "less intensive support" for autistic children, observing that "Children in the centre-based program has the largest improved [Vineland score] followed by the wait list, the home-based group had the smallest increase" (the wait-list group were untreated, the NDIA's ECEI Approach most resembles the home-based group). Outcomes for all groups were well short of those achieve through good practice (requiring sufficient program intensity) for autistic children. The basis for the NDIA's preferred ECEI approach reports that the NDIA's approach has the least benefit for autistic children. Also, a Cochrane review concluded "important outcomes such as other aspects of children's language, children's adaptive skills and parent stress did not show change" from parent-delivered supports. All this means that the ECEI Approach is not evidence-based for autistic children.
6. A4 cannot find your policy documented anywhere other than in this letter. We would like more detail, such as what outcomes "are ordinarily achieved through less intensive support".
7. A4 is not aware that the Government applies this or a similar policy to therapies for non-autistic children, such as a cochlea implant for deaf children.
8. Government should not require a family to furnish proof that good practice is effective for their child since there is already a large body of evidence relevant to autistic children, a major participant group in the NDIS (note: over 25% of NDIS participants are autistic, mostly children).

The NDIA's view of early intervention for autistic children is far too simplistic. The NDIA claims "research and evidence shows children learn and develop best in their natural, everyday settings, hence the importance

of family-centred practice ..." so it refuses (or is extremely unwilling) to fund early intervention for an autistic child when the early intervention isn't primarily delivered by parents in a "natural setting". The "research and evidence" that the NDIA refers to is generic; it does not relate to autistic children. This approach is akin refusing to fund a wheelchair for any child, no matter what their need, because children need to run around for their gross motor development.

The NDIA rejects repeated and consistent advice about early intervention for autistic children, advice that good or best practice is a comprehensive program of individualised intensive ASD-specific early intervention for at least 20 hours per week for at least two years.

The NDIA prefers advice it got from Early Childhood Intervention Australia (ECIA) rather than advice from specialists in early intervention for ASD. ECIA has no discernible expertise in early intervention for ASD. ECIA provides generic advice that does not recognise the distinct needs of autistic children. Advice from ECIA must not override specific advice about early intervention for autistic children.

Your approach:

a. denies autistic children access to good practice early intervention unless their family pays for a trial of intensive early intervention for their child out of their own pocket. This is contrary to the United Nations Convention on the Rights of the Child which says the state is responsible for ensuring a child has access to treatment - with the flow-on of access to effective education for autistic children. The failure/refusal to provide necessary early intervention for autistic children is unfair; it is precisely the type of inequity that the Productivity Commission wanted the NDIS to reduce.
b. put the risk of an expensive initial trial on the family. This is contrary to the "insurance principles" that Government claims the NDIS is based on.

The advice the Government commissioned and received in 2011 said that ABA (sometimes called Early Intensive Behavioural Intervention - EIBI) is the *only* early intervention approach for autistic children that is rated as having "established research evidence", the highest rating. The best other early intervention approaches for autistic children are rated (optimistically?) as having "emerging or best practice evidence" (the raters were mostly proponents of second level approaches). An attached report by Paul Terdal from 2013 shows that numerous reviews from overseas (mostly USA) came to similar conclusions (see https://olis.leg.state.or.us/liz/2013R1/Downloads/CommitteeMeetingDocument/13979).

The NDIA relies on a *selected* bit of the latest local advice about early intervention for ASD. The NDIA says "the report highlights the need to match early childhood programs and services to the child's natural setting". But effective early intervention for ASD has always involved generalising a child's learned skills, that is practicing the skills they learn across a range of natural settings. Generalisation is only part of effective early intervention for ASD. Effective early intervention for ASD requires that skills are learned before they are generalised ... and NDIA planners and delegates (with little or no knowledge of EI for ASD) mostly reject funding requests for early intervention that develops and generalises maximally a child's skills. Skill development is usually best done in a clinical setting then generalisation is done necessarily conducted in natural settings.

A4 understands that the NDIA, a Government agency, did not receive the advice it hoped for in the 2016 report on good practice for ASD. The NDIA wanted information about how and when to individualise early intervention funding for each child. Some relevant information, at least in relation to ABA, can now be found here.

Research publications indicate that

a. only ABA achieves "optimal outcomes" for a significant number of autistic children - an "optimal outcome" is when a child "loses" her/his ASD diagnosis (when a child learned sufficient skills, is as independent as peers and no long needs support for ASD-related characteristics); and

b. typically ABA results in around 85% of autistic children learning lasting life skills that significantly reduce their support needs and cost of support in later life.

By the way, ABA is not always "intensive" nor is it only for early intervention; ABA is usually relevant in addressing unwanted or challenging behaviour in all age groups.

A4 notes that few if any allied health graduates in Australia are trained to provide good practice early intervention for autistic children. Mostly, allied health graduates are taught a few techniques but they are not taught how to sustain intensive early intervention for 20+ hours per week, how to train and supervise a team of therapy technician to deliver good practice for ASD, or how to achieve "optimal outcomes" for autistic children.

Government should be concerned that most autistic people are diagnosed too late to access early intervention.

Government should restore the Autism Advisor service, previously part of the Government's *Helping Children with Autism* package that the NDIA annihilated, so families can make informed choices about early intervention for ASD. Rather than funding "less intensive support" initially, the NDIS should start out fund good practice and monitor each child's progress. If necessary, the NDIS can review each child's progress as early as is appropriate and revise their early intervention plan according to ASD-specific clinical advice.

Apparently A4 is not alone in its disappointment in the NDIS. Since you wrote your letter, the Joint Standing Committee on the National Disability Insurance Scheme published its report on the Provision of services under the NDIS Early Childhood Early Intervention Approach. The Committee is critical of the NDIA's whole approach to assessment of autistic children. The Committee is concerned that the current approach "runs the risk of introducing inequity by benefiting families of children with a diagnosed condition over those without a diagnosis. Moreover, families may attempt to obtain a costly diagnosis to expedite entry to the Scheme". A4 expects that your expectation that families fund and bear all the risk of an expensive trial of intensive early intervention for their child would alarm the Committee.

In relation to NDIS plans involving early intervention for autistic children, the ***Committee's view*** in the report says

> *Underfunded plans for children with autism*
>
> 4.63 The committee received concerning evidence in relation to recurring funding shortfalls in Plans for children with autism. It appears that the level of funding granted in many Plans does not meet Participants' needs and does not align with recommended evidence-based practice guidelines. This is resulting in those children not accessing the right level of support and therapies to achieve optimal outcomes.
>
> 4.64 Alarmingly, the committee heard that NDIS funding levels are often lower than previous national funding models such as Helping Children with Autism. It is concerning that some Participants and their families are potentially worse off than under previous funding models.
>
> 4.65 With almost 40 per cent of NDIS Participants age 0–6 years having autism as their primary disability, it is of paramount importance that the NDIA urgently addresses the issues of scope and level of funding in Plans for children with autism.
>
> ***Recommendation 11***
> ***4.66 The committee recommends the NDIA urgently address the issues of scope and level***

of funding in Plans for children with autism with a view to ensuring that recommended evidence-based supports and therapies are fully funded.

The Committee's report makes numerous other constructive criticisms most of which would improve outcomes for autistic children and deliver long-term financial benefits for the community.

In conclusion:

- the NDIA's existing policy and practice denies many autistic children access to good practice and evidence-based early intervention.
- A4 urges you to review the Government's response to the advice it received on good practice for autistic children and reconsider your position on the NDIA's approach to early intervention for autistic children.

--
Bob Buckley
Convenor, Autism Aspergers Advocacy Australia (A4)
website: http://a4.org.au/

A4 is the national grassroots organisation advocating for autistic people, their families, carers and associates. A4 is internet based so that Australians anywhere can participate.

"The first step in solving any problem is recognising there is one." *Jeff Daniels as Will McEvoy in The Newsroom.*

Evidence for Effectiveness of ABA as a Treatment for Autism

Introduction

This document summarizes medical and scientific evidence for effectiveness of applied behavior analysis (ABA) as a treatment for autism spectrum disorder. It includes:

- Peer-reviewed literature
- Findings, studies or research conducted by or under the auspices of a federal government agency or a nationally recognized federal research institute
- Clinical practice guidelines that meet Institute of Medicine criteria
- Reports by other professional and governmental associations
- Expert analysis by autism researchers
- Legal rulings by courts of law
- Decisions by Regulatory Agencies

Documents listed in the first three categories (peer-reviewed literature, findings from federal government agencies or research institutes, and clinical practice guidelines meeting Institute of Medicine criteria) meet the requirements from Oregon Administrative Rules (OAR) 836-053-1325 for medical, scientific, and cost effectiveness evidence for use by Independent Review Organizations in External Review decisions to determine whether a treatment is medically necessary, or is an experimental / investigational treatment.

Peer-reviewed literature

Article:	Content / Findings:
Dawson G., "Behavioral interventions in children and adolescents with autism spectrum disorder: a review of recent findings." *Current Opinion in Pediatrics*, 2011; Vol 23: pp 616–620	• Reviews and summarizes 27 studies published in peer-reviewed literature since January, 2010 on behavioral interventions for children and adolescents with autism spectrum disorder (ASD) • Key findings: behavioral interventions are effective for improving language, cognitive abilities, adaptive behavior, and social skills, and reducing anxiety and aggression.
McEachin J, et al. "Long-Term Outcome for Children With Autism Who Receive Early Intensive Behavioral Treatment." *American Journal on Mental Retardation*, 1993; Vol. 97, No. 4: pp 359-372	• Follow-up to 1987 Lovaas study (below), assessing long-term progress of the same 38 children at a mean age of 11.5 years • Results showed that the experimental group (who received intensive behavioral intervention) preserved its' gains over the control group

Article:	Content / Findings:
Lovaas O. "Behavioral Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children." *Journal of Consulting and Clinical Psychology*, 1987; Vol. 55, No. 1: pp3-9	• Examines the impact of intensive behavioral intervention (Applied Behavior Analysis, or ABA) • Compared an experimental group of 19 children who received 40 hours of ABA per week for two years to comparison groups • 9 out of 19 children in the ABA group attained average cognitive functioning, and were able to perform in school with minimal supports, compared to only 1 of 40 children in the control group
Cohen, H., Amerine-Dickens, M. and Smith, T. "Early Intensive Behavioral Treatment: Replication of the UCLA Model in a Community Setting." *Journal of Developmental Pediatrics*, 2006; Vol. 27, No. 2: pp145-155	• Replicated 1987 Lovaas study (above). Compared 21 children who received 35 to 40 hours of ABA per week to a control group of 21 age- and IQ-matched children in public school special education classes • ABA group obtained significantly higher IQ and adaptive behavior scores than control group • 6 of 21 ABA children were fully included in regular education without assistance at year 3, and 11 others were included with support (for 17 out of 21 placed in regular education), compared to only 1 of 21 comparison children in regular education
Dawson, G. et al, "Randomized, Controlled Trial of an Intervention for Toddlers With Autism: The Early Start Denver Model." *Pediatrics*, 2010; Vol. 125, No. 1: pp17-23 http://pediatrics.aappublications.org/content/125/1/e17.full.pdf+html	• Randomized controlled trial of Early Start Denver Model (ESDM), a developmental behavioral intervention based on developmental and ABA principles • 48 children with autism between 18 and 30 months of age were assigned to either intensive ESDM by trained therapists, or referred to community providers • Compared with children who received community intervention, children who received ESDM showed significant improvements in IQ, adaptive behavior, and autism diagnosis
Maglione, M.A. et al, "Nonmedical Interventions for Children With ASD: Recommended Guidelines and Further Research Needs," *Pediatrics*, 2012;Vol. 130;S169 http://pediatrics.aappublications.org/content/130/Supplement_2/S169.full.html	• Developed consensus guidelines on nonmedical interventions that address cognitive function and core deficits in children with autism • Guidelines were developed by a Technical Expert Panel (TEP) based on a systematic overview of research findings • "The TEP agreed that children with ASD should have access to at least 25 hours per week of comprehensive intervention to address social communication, language, play skills, and maladaptive behavior. They agreed that applied behavioral analysis … have shown efficacy."

Article:	Content / Findings:
Landa. R. J., and Kalb, L.G., "Long-term Outcomes of Toddlers With Autism Spectrum Disorder Exposes to Short-term Intervention," *Pediatrics* 2012;Vol. 130;S186 http://pediatrics.aappublications.org/content/130/Supplement_2/S186.full.html	• Forty-eight patients with autism received a 6-month applied behavior analysis -based intervention beginning at age 2 • Cognitive (IQ) and communication ability, as well as severity of autism symptoms, were assessed by using standardized measures • Significant gains in IQ and Vineland Communication domain standard scores as well as a reduction in ASD severity were achieved
Fein, D., et al, "Optimal outcome in individuals with a history of autism," Journal of Child Psychology and Psychiatry 54:2 (2013), pp 195–205 http://onlinelibrary.wiley.com/doi/10.1111/jcpp.12037/pdf	• Analyzes the cases of 34 individuals who had a clear documented history of autism, yet no longer met criteria for autism as per the ADOS and clinical judgment • The results substantiate the possibility of "optimal outcome" from autism spectrum disorders and demonstrate an overall level of functioning within normal limits for this group • The authors noted that parents who "advocate vigorously for the best interventions" "may maximize the chance" for an "optimal outcome"

Findings, studies or research conducted by or under the auspices of a federal government agency or a nationally recognized federal research institute

Agency:	Report:	Finding:
Federal Agency for Healthcare Research and Quality	Comparative Effectiveness Review # 26: Therapies for Children With Autism Spectrum Disorders, Agency for Healthcare Research and Quality, AHRQ Publication No. 11-EHC029-EF, April 2011 http://www.effectivehealthcare.ahrq.gov/ehc/products/106/656/CER26_Autism_Report_04-14-2011.pdf	• "Evidence supports early intensive behavioral and developmental intervention, including the University of California, Los Angeles (UCLA)/Lovaas model and Early Start Denver Model (ESDM) for improving cognitive performance, language skills, and adaptive behavior in some groups of children." (p. vi) • "Within this category, studies of UCLA/Lovaas-based interventions report greater improvements in cognitive performance, language skills, and adaptive behavior skills than broadly defined eclectic treatments available in the community. However, strength of evidence is currently low." (page ES-7)
National Institute of Mental Health	Autism Spectrum Disorders Pervasive Developmental Disorders, NIH Publication No. 08-5511, 2008 http://www.nimh.nih.gov/health/publications/autism/nimhautismspectrum.pdf	• "Among the many methods available for treatment and education of people with autism, applied behavior analysis (ABA) has become widely accepted as an effective treatment." (p. 19)
National Academy of Sciences	Educating Children with Autism, Committee on Educational Interventions for Children with Autism, National Research Council, ISBN: 0-309-51278-6, 2001 http://www.nap.edu/catalog/10017.html	• "Forty years of single-subject-design research testifies to the efficacy of time-limited, focused applied behavior analysis methods in reducing or eliminating specific problem behaviors and in teaching new skills to children and adults with autism or other developmental disorders." (p.120)
Center for Medicaid and Medicare Services	IMPAQ International, LLC, Final Report on Environmental Scan, Autism Spectrum Disorders (ASDs) Services Project, March 9, 2010 http://www.impaqint.com/files/4-content/1-6-publications/1-6-2-project-reports/finalasdreport.pdf	• Identified 15 ABA, Developmental, and other behavioral interventions as "Established"

Clinical practice guidelines that meet Institute of Medicine criteria

Organization:	Clinical Practice Guideline:	Finding:
American Academy of Pediatrics	Scott M. Myers, MD, Management of Children With Autism Spectrum Disorders, Pediatrics, 2007 http://pediatrics.aappublications.org/cgi/reprint/120/5/1162	• "The effectiveness of ABA-based intervention in ASDs has been well documented through 5 decades of research by using single-subject methodology and in controlled studies of comprehensive early intensive behavioral intervention programs in university and community settings. Children who receive early intensive behavioral treatment have been shown to make substantial, sustained gains in IQ, language, academic performance, and adaptive behavior as well as some measures of social behavior, and their outcomes have been significantly better than those of children in control groups." [Emphasis added]
American Psychological Association	Autism Treatment Options, American Psychological Association website http://www.apa.org/topics/autism/treatment.aspx	• "Medication and behavioral interventions can help children cope with autism. Since medications on their own rarely improve behavior, behavioral interventions are crucial." [Emphasis added]
New York State Department of Health	Clinical Practice Guideline Report of the Guideline Recommendations Autism / Pervasive Developmental Disorders Assessment and Intervention for Young Children (Age 0-3 Years), New York State Department of Health Early Intervention Program, 1999 http://www.nyhealth.gov/community/infants_children/early_intervention/disorders/autism/ http://www.nyhealth.gov/publications/4216.pdf	• "It is recommended that principles of applied behavior analysis (ABA) and behavior intervention strategies be included as an important element of any intervention program for young children with autism. [A]" • "It is recommended that intensive behavioral programs include as a minimum approximately 20 hours per week of individualized behavioral intervention using applied behavioral analysis techniques (not including time spent by parents). [A]"

Organization:	Clinical Practice Guideline:	Finding:
American Society of Child and Adolescent Psychiatry	American Academy of Child and Adolescent Psychiatry, "Practice Parameters For The Assessment And Treatment Of Children, Adolescents, And Adults With Autism And Other Pervasive Developmental Disorders," 1999. P. 37. http://www.aacap.org/galleries/PracticeParameters/Autism.pdf	• "Early and sustained intervention appears to be particularly important, regardless of the particular philosophy of the program, so long as a high degree of structure is provided. Such programs have typically incorporated behavior modification procedures and applied behavior analysis. These methods build on a large body of research on the application of learning principles to the education of children with autism and related conditions. Procedures that strengthen desired behaviors and/or decrease undesired maladaptive behaviors are utilized in the context of a careful and individualized plan of intervention based on observation of the individual. It is clear that behavioral interventions can significantly facilitate acquisition of language, social, and other skills and that behavioral improvement is helpful in reducing levels of parental stress." [Emphasis added]
United States Surgeon General, U.S. Department of Health and Human Services	Department of Health and Human Services. Mental Health: A Report of the Surgeon General. Rockville, MD: Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institute of Mental Health, 1999. http://www.surgeongeneral.gov/library/mentalhealth/chapter3/sec6.html#autism	• "Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior."

Reports by other professional and governmental associations

Organization:	Report:	Finding:
National Autism Center The National Autism Center is May Institute's center for the promotion of evidence-based practice http://www.nationalautismcenter.org/	National Standards Report, National Autism Center, 2009 http://www.nationalautismcenter.org/pdf/NAC%20NSP%20Report_FIN.pdf	• Developed by an expert panel, "based on a thorough review of the educational and behavioral treatment literature that targets the core characteristics and associated symptoms of ASD that was published between 1957 and the fall of 2007" • Identified "11 'Established' Treatments: treatments that produce beneficial outcomes and are known to be effective for individuals on the autism spectrum. The overwhelming majority of these interventions were developed in the behavioral literature (e.g., applied behavior analysis, behavioral psychology, and positive behavior support)."
Maine Departments of Health and Human Services and Department of Education, Children's Services Evidence-Based Practice Advisory Committee http://www.maine.gov/dhhs/ocfs/cbhs/ebpac/index.shtml	Interventions for Autism Spectrum Disorders: STATE OF THE EVIDENCE, October 2009 http://www.maine.gov/dhhs/ocfs/cbhs/ebpac/asd-report2009.pdf	• Reviewed more than 150 studies of 43 different treatments for children with ASD, using a validated rubric, the *Evaluative Method for Determining Evidence-Based Practice in Autism* (Reichow, Volkmar, & Cicchetti, 2008), and assigned each intervention a level of evidence rating. • Found that applied behavior analysis for challenging behavior, communication, and social skills and earlier intensive behavioral intervention met criteria for "Established Evidence"
The Missouri Autism Guidelines Initiative Missouri Department of Mental Health http://www.autismguidelines.dmh.mo.gov/default.htm	Autism Spectrum Disorders: Guide to Evidence-based Interventions: A 2012 Consensus Publication, 2012 http://www.autismguidelines.dmh.missouri.gov/documents/Interventions.pdf	• Describes evidence based interventions for individuals with autism spectrum disorders (ASDs) based on six recent nationally recognized systematic research reviews. • Concluded that many forms of Applied Behavior Analysis (ABA), such as Comprehensive Behavioral Treatment for Young Children, Early Intensive Behavioral and Developmental Approaches, and Focused Behavioral Interventions have been shown to be effective treatments for autism

Organization:	Report:	Finding:
New Zealand Guidelines Group New Zealand Ministry of Health http://www.health.govt.nz/	Guideline Supplementary Paper -- New Zealand Autism Spectrum Disorder Guideline Supplementary Evidence on Applied Behaviour Analysis, May 2010 http://www.health.govt.nz/system/files/documents/publications/asd-guideline-supplementary-paper.pdf	• "Interventions and strategies based on applied behaviour analysis (ABA) principles should be considered for all children with ASD." (Grade A) [The recommendation is supported by GOOD evidence (where there is a number of studies that are valid, applicable and clinically relevant)] • "Early intensive behavioural intervention (EIBI) should be considered as a treatment of value for young children with ASD to improve outcomes such as cognitive ability, language skills, and adaptive behaviour." (Grade B) [The recommendation is supported by FAIR evidence (based on studies that are mostly valid, but there are some concerns about the volume, consistency, applicability and/or clinical relevance of the evidence that may cause some uncertainty, but are not likely to be overturned by other evidence).]

Expert analysis by autism researchers

Article:	Content / Findings:
Larsson, E.V., "Is Applied Behavior Analysis (ABA) and Early Intensive Behavioral Intervention (EIBI) an Effective Treatment for Autism? A Cumulative Review of Impartial Reports", The Lovaas Institute for Early Intervention, 2013	• Reviews research findings related to the effectiveness of EIBI and ABA therapy as a treatment for autism, against standard definitions of experimental or investigational treatments • Concludes that applied behavior analysis, behavior therapy, and early intensive behavioral intervention are all well-established interventions that can't be considered experimental or investigational
Larsson, E.V., "Applied Behavior Analysis (ABA) for Autism: What is the Effective Age Range for Treatment?", The Lovaas Institute for Early Intervention, 2012	• Provides a list of 237 references documenting the clinically important impact of Applied Behavior Analysis (ABA) with children and adolescents who are between the ages of 5 and 21

Legal rulings by courts of law

Case:	Content / Findings:
McHenry v PacificSource Case CV-08-562-ST, United Sates District Court for the District of Oregon, 1/5/2010 and 9/28/2010	• "ABA therapy is firmly supported by decades of research and application and is a well-established treatment modality of autism and other PDDs. It is not an experimental or investigational procedure" (document 59, 1/5/10, page 19) • "ABA therapy is not primarily academic or social skills training, but is behavioral training. Accordingly, it is not subject to the exclusions under the Plan for academic or social skills training." (document 59, 1/5/10, page 27) • "McHenry is entitled to reimbursement for ABA therapy provided by Hoyt, effective February 5, 2010, and defendants are directed to process McHenry's claims for ABA therapy provided by Hoyt on and after that date." (document 118, 9/28/10, page 24)
D.F.et al v Washington State Health Care Authority; PEBB Case No. 10-2-29400-7 SEA, Superior Court of Washington for King County, June 8, 2011	• "From the evidence presented to the court, it is apparent that ABA therapy may provide benefit to some individuals." • "The court concludes that, as a matter of law, plaintiffs are entitled to a declaration that specific exclusions contained in health benefit plans administered by the defendants that exclude coverage of Applied Behavior Analysis therapy, even when medically necessary and performed by licensed health providers, do not comply with Washington's Mental Health Parity Act…. The Court further declares that under the Mental Health Parity Act defendants are required to cover medically necessary Applied Behavior Analysis therapy, as determined on an individualized basis, when provided by licensed therapists." • "The Court reserves ruling, at this time, whether defendants are required to cover Applied Behavior Analysis therapy when provided by certified or registered – as opposed to licensed – health providers."
K.G. et al v. Florida Agency for Health Care Administration CASE NO. 11-20684-CIV-LENARD / O'SULLIVAN, United States District Court for the Southern District of Florida, March 26, 2012.	• "I find that applied behavior analysis is medically necessary and not experimental …. I find that … the determination by AHCA that ABA is experimental was unreasonable in its process, was arbitrary and capricious and unreasonable in its conclusion." • "it is imperative that autistic children in Florida receive ABA immediately to prevent irreversible harm to these children's health and development." • "the State of Florida is hereby ordered to provide, fund, and authorize Applied Behavioral Analysis treatment … to all Medicaid-eligible persons under the age of 21 in Florida who have been diagnosed with autism or Autism Spectrum Disorder, as prescribed by a physician or other licensed practitioner."

Case:	Content / Findings:
Berge v United States of America (Tricare) Civil Action No. 10-0373 (RBW), United States District Court for the District of Columbia, July 26, 2012	• "… the assessments cited by the Agency suggest that behavioral modification therapy is the closest intervention medical professionals have identified as the standard means for treating autism. … (ABA is "the dominant and preferred treatment modality" for autism). Therefore, this Court is left to wonder what forms of autism treatment would satisfy the Agency's regulatory requirement of being proven when the very sources the Agency relies upon to declare ABA therapy unproven cannot identify one form of treatment that is more effective than ABA therapy. Since the Agency has failed to articulate a reasoned explanation for its determination that ABA therapy is unproven, particularly in light of evidence before it suggesting the contrary, the Court must conclude that the Agency's determination is arbitrary and capricious." • "Agency's denial of ABA therapy coverage under the Basic Program is arbitrary and capricious" • "the Court will remand this case back to the Agency with instructions that ABA therapy coverage be provided to Basic Program beneficiaries"

Decisions by Regulatory Agencies

Government Agency / Report:	Content / Findings:
State of California Department of Insurance, "Senate Select Committee on Autism & Related Disorders Informational Hearing on Health Insurance Coverage for Autism Spectrum Disorders (ASD): Current Regulatory Oversight of Behavioral Intervention Therapy", July 13, 2011 http://www.insurance.ca.gov/0100-consumers/0070-health-issues/upload/PartISenateSelect-CommitteeSubmissionV2.pdf	• "Based on the numerous decisions of CDI's independent medical reviewers concerning the medical necessity of behavioral health treatment, which includes Behavioral Intervention Therapies (BIT), such as Applied Behavioral Analysis therapy (ABA), CDI has concluded that ABA therapy is medically necessary treatment for individuals with autism." • "CDI's clinician reviewers consistently find that ABA therapy is neither experimental nor investigational; and leads to significant improvements in IQ, communication and language skills, and adaptive behaviors; as well as to reduction in self injurious behaviors." • "CDI regulated health insurers may not legally continue to deny ABA claims unless there is a clear basis for determining that for that specific patient at that point in time, ABA therapy is not medically necessary."

From: DLOPrentice s47E(d) - certain operations of agencies
Sent: Tuesday, 5 December 2017 11:37 AM
To: parliamentary
Cc: DLOPrentice
Subject: FW: the NDIS and early intervention for autistic children [SEC=UNCLASSIFIED]

Categories: - Joanne -, - IN PROGRESS -

The AMO would like an AM reply Ministerial Correspondence for the below writer.

Many thanks

DLO Prentice

From: Prentice, Jane (MP) [mailto:Jane.Prentice.MP@aph.gov.au]
Sent: Tuesday, 5 December 2017 9:53 AM
To: 'Bob Buckley (A4 Convenor)' <convenor@a4.org.au>
Subject: RE: the NDIS and early intervention for autistic children

Thank you for taking the time to contact my office, please accept this as confirmation that your email has been received.

Due to the large number of emails received each day, it is not possible to reply immediately.

However your email has been forwarded to the Department to provide a response as soon as possible.

Response times will vary depending on the complexity of the issues raised.

Yours sincerely

OFFICE OF THE HON. JANE PRENTICE MP | Federal Member for Ryan | Assistant Minister for Social Services and Disability Services
Suite R1-93, Parliament House, Canberra, ACT, 2600. Telephone: (02) 6277 4426
http://janeprentice.dss.gov.au/

From: Bob Buckley (A4 Convenor) [mailto:convenor@a4.org.au]
Sent: Tuesday, 5 December 2017 8:49 AM
To: The Hon C Porter MP
Cc: Prentice, Jane (MP); Macklin, Jennifer (MP); Brown, Carol (Senator)
Subject: Fwd: the NDIS and early intervention for autistic children

Dear The Hon. Mr Porter MP

Autism Aspergers Advocacy Australia (known as A4) has growing concerns over the operation of the NDIS in regard to early intervention for autistic children[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. [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] A4 advocates for families being able to make *informed choices* about their child's early intervention. [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 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] 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 [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] See https://ndis.gov.au/medias/documents/h91/hbc/8805559468062/Report-to-the-COAG-Disability-Reform-Council-for-Q1-of-Y5.pdf [4]. The NDIA's ECEI Approach is a clear and deliberate barrier meant to divert

autistic children into “mainstream services” that in many instances simply does not meet their needs. The NDIA’s strategy excludes many 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

--

Bob Buckley
Convenor, Autism Aspergers Advocacy Australia (A4)
website: http://a4.org.au/

A4 is the national grassroots organisation advocating for autistic people, their families, carers and associates. A4 is internet based so that Australians anywhere can participate.

“The first step in solving any problem is recognising there is one.” *Jeff Daniels as Will McEvoy in The Newsroom.*