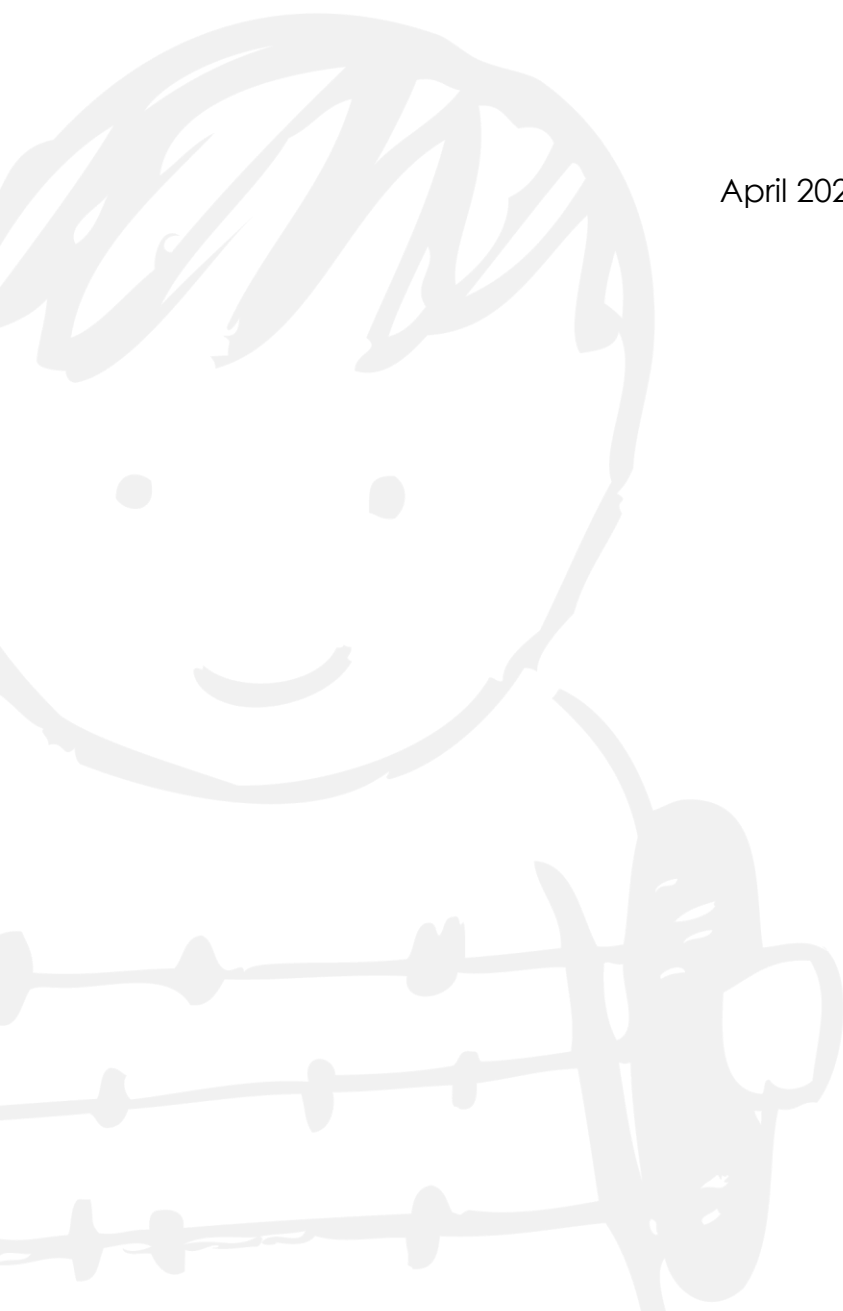


National Disability Insurance Scheme  
**Consultation paper: Interventions for children on the  
autism spectrum**

A Submission from **Abacus Learning Centre Ltd**

**A registered service provider**

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## Introduction

Abacus Learning Centre welcomes the opportunity provided to make a submission to the National Disability Insurance Agency as part of the consultation process on interventions for children on the autism spectrum.

Abacus Learning Centre (ALC), established in 2008, is a not-for-profit centre-based early intensive behavior intervention service provider for children with Autism Spectrum Disorder, based on the Mornington Peninsula in Victoria.

ALC is governed by a volunteer Board of Directors.

Over the last thirteen years, ALC has provided individualised, intensive Applied Behaviour Analysis (ABA) programs to hundreds of children with autism and their families as well practical strategies and training for educators and other disability service providers working with children who experience any behaviours that interfere with their ability to learn.

ALC provides:

- Individualised centre based intensive early intervention programs for children with autism, syndromes and/or developmental delays, aged 3 to 7.
- ABA in natural settings including education institutions and community.
- Discrete Trial Training (DTT)
- Augmented and alternative communication training
- School readiness program
- Counselling services
- Secret Agent Society Social Skills Group Program
- Positive Learning Solutions consultation services. A service that involves an ALC Program Supervisor who is embedded in mainstream schools for the school year, including schools Balcombe Grammar School and Cornish College
- In-school therapy with the provision of professional development to a school's team of Learning Assistants or Aides, then program development for children whose learning is interrupted by their disability to be delivered in school by the school aide and supervised by an ALC Program Supervisor.
- Online learning support for students who benefit from additional individualised program support in social emotional regulation, self-care and language development and are in school full time.

In 2019 ALC received \$1.2 million in federal government funds to develop a purpose-built centre to expand our EIBI services to children with autism and their families on the Mornington Peninsula.

## Applied Behaviour Analysis in the NDIS

As discussed in the NDIA funded report, *Autism Spectrum Disorder: Evidence-based/evidence informed good practice for supports provided to preschool children, their families and carers*; evidence shows programs for children with

autism to be effective with hours between 15 and 25 per week with a midpoint of 20 hours for at least one year (JM Roberts & K. Williams 2016).

Before the staged roll out of the National Disability Insurance Scheme in Victoria in 2016, families were required to self-fund the majority of their children's programs with the fees subsidised by donations and fund raising.

The opportunity for families to realise choice and control over the services they choose for their child has seen the demand for our service significantly increase with families being able to access best practice therapy for their child and fund the program with the participant's NDIS plan.

#### **4. Consultation questions**

Abacus Learning Centre emailed all current Participant Representatives who access our service, providing the Autism CRC Research paper with a written summary, the NDIS Consultation paper and an invitation to attend a Zoom meeting to provide any feedback they wanted to contribute to this submission.

The meeting was attended by eight different families who have children with Autism ranging in age from three to nine years of age. All families use funding from their NDIS plans to fund therapy.

During the meeting, Jack Massey Centre Manager scribed all comments then emailed the statements made to the families asking if they were accurate and for permission to use in this submission. Permission was received from all families. All comments are de-identified.

#### **Reasonable and necessary**

#### **4. Building from the Autism CRC research the consultation paper outlines specific principles that the NDIS considers as early intervention best practice for young children on the autism spectrum (Section 6.1) Is there anything you would like to add?**

This question was posed to families and the overwhelming response was their experience is when accessing interventions like Speech Therapy and Occupational Therapy, they are working with professionals who do not understand how to teach a student with Autism, particularly a student with no expressive language and significantly impaired receptive language.

A parent of a student who has been attending ALC for ABA therapy for three months reported; "The NDIS provided funding however they never mentioned ABA therapy, just speech and OT. We were completely new, so we went and found speech and OT. Our expectation was seeing a speech therapist should mean our child will be talking. We realised nothing was being improved and our therapist was only seeing our child 45 minutes at a time. We changed multiple [speech] therapists and found everyone almost the same as their methodologies are the same. 45-minute session, 10 minutes of this for report writing, 35 minutes are then left, and

they'll talk to the parents for 25 minutes, maybe be with the child for 10 minutes maximum. And that's once in a week- it doesn't help us much basically."

Another parent whose child started at ALC when he was three years old stated: "At the time the Speech Therapist who was seeing (child) was completely lost. She'd never come across a child like (child) who never made a noise. The Speech Therapist was way out of her depth."

Another parent talked of her experience of being given video footage to watch as training material, only to discover the child in the video was verbal and the strategies demonstrated were completely irrelevant for her as her child was non-verbal.

*A growing evidence base suggests that some children receiving early intensive behavioural and developmental interventions (e.g., many hours of intervention a week over the course of 1–2 years) show substantial improvements in cognitive and language skills over time compared with children receiving low-intensity interventions, community controls, and eclectic non-ABA based intervention approaches.<sup>1</sup>*

**5. Building from the Autism CRC research the consultation paper outlines specific standards that the NDIS considers as early intervention best practice for children on the autism spectrum (Section 6.2). Is there anything you would like to add?**

Many of the families spoke of the apparent contradictions between the standards expressed and the subsequent tables of indicative levels of funding. Specifically delivering the intervention following established guidelines and that there are significant and lasting benefits without the necessary level of funding available to support this.

One parent of a current student at ALC reported "(child) was only at Speech and OT before Abacus for almost 18 months. It was hardly ever evident that he had been. He'd go once a week and he hadn't even retained what he'd learned the week before. It was a waste of time and money."

Another parent reported "(child) would sit in a speech therapy session and stare off into space."

All parents spoke of the often unrealistic, expectation to be able to apply strategies described by Allied Health professionals to teach their own children complex skills such as how to make a request or label an item or toilet, while the parent was managing complex behaviours and attempting to work or care for other children or care for elderly parents and so-on.

One parent spoke of asking an OT to engage more with his child rather than expect him to be a therapist, and he was then asked by the OT "have you tried ABA?". After research this parent chose to commence ABA therapy as an intervention for his son.

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<sup>1</sup> Weitlauf AS, et al. Therapies for Children With Autism Spectrum Disorder: Behavioral Interventions Update Abstract Conclusion

Some families are also disadvantaged by never having any experience themselves with a child with a disability before their own or of working with Allied Health Professionals in any capacity.

A Participant Representative who has a child with a rare syndrome that includes Autism, blindness, hearing loss and intellectual disability shared her journey accessing services that were developed for children with vision loss or for children with Autism. She said that the professionals she worked with “didn’t get it”. The OT and Orientation and Mobility (O&M) Specialist did not know how to teach a child with Autism and the Allied Health Professionals did not know how to work with an Autistic child who could not see.

ABA therapy was the most successful intervention for her child, and he is now mobilizing independently, greeting people, learning to read and continuing to master new self-care skills including dressing and teeth brushing. She talked of how Abacus was able to “bring everything together” and work with the O&M and the Braille Instructor to teach them how to present information to a child with Autism who could not see.

**8. Table 2 (0-6 years) and Table 3 (7-12 years) are an example of how we might explain indicative levels of funded support for children on the autism spectrum (Section 7.5) Do these table/s clearly explain the indicative levels of funded supports?**

The functional impact of each level described in Table 2 and Table 3 does not describe the presentation of most students who commence ABA therapy at Abacus Learning Centre. The description of Level 4 defines a high area of need with language and communication development including being able to request basic needs and following one step instructions. Most students who commence ABA therapy at ALC can not follow any instruction and are unable to request even the most preferred item. Students who start early intervention often are unable to sit to attend a therapist, may engage in self-harm or other challenging behaviours and be significantly delayed in all daily living activities including, sometimes, keeping clothes and shoes on.

In response to reading the functional impact of the levels in the Table/s, one parent commented; “If [my child] was at level 4, we would be happy. He’s not even there yet.” Another parent said, “it’s scary how low it [the funding] was. I can’t do ABA therapy if we get that funding. It’s disappointing.”

*The most favourable outcomes are suggested to occur when ABA programs are started early in life (before age 5 years) and implemented intensively (20 hours or more per week for two or more years). Early intensive ABA intervention programs are intended to be comprehensive, targeting all areas of development, and may result in accelerated gains including increased scores in IQ and other standardised tests;*

*enhanced communication, cognition, and socioemotional functioning; and mainstream school places.* <sup>2</sup>

Another parent spoke of not being able to recognize her son in any of the levels described reporting; "when I consider (child) in that scenario, he has more than three areas of high need; sensory, behavioural, safety awareness, communication, that's just four off the top of my head. Whoever has written this has not considered the whole child."

It is understood that the indicative levels of funding are proposed for children with Autism and the consultation paper concedes that there may be further considerations in determining funding for children who have an additional disability or significant behaviours of concern. (p. 26)

Many students who attend Abacus to access ABA therapy start from the age of three and have a diagnosis of Autism. It is only as the student is able to engage in standardized assessments that they may be assessed for an intellectual disability that further inhibits the student's learning.

The Australian Bureau of Statistics reports in 2009 almost two thirds of children aged 5-14 years with a disability had an intellectual disability. This was more than twice the proportion of children aged 0-4 years with an intellectual disability. It is hypothesized that this proportional discrepancy may be due to the lack of formal testing in younger children with disabilities as they are unable to participate in the assessment process.

The concern around the proposed levels of funding is that there is no additional level available when a student presents with more significant functional impact on communication, social skills, emotional regulation and self-care, either as a result of their Autism or as they may have an as yet undiagnosed additional disability or syndrome.

## Summary

The standards and principles detailed in the consultation paper continue to focus on the best outcomes for the Participant and the Participants family by recommending evidence based, individualized, holistic interventions that should be regularly reviewed to ensure progression towards the stated goals and be provided by a qualified and experienced professional. These principles and standards align with best practice delivery of ABA therapy.

It is evident from the feedback from families that the proposal to remove the funding option for an intensive behaviour intervention program causes anxiety and fear and goes against the fundamental principles of the NDIA in allowing choice and control. Additionally, the highlighted principle of the insurance scheme is to invest now to save in the future. Intensive early intervention provides the best prospect of reduced economic and social support for children with Autism who then become adults with Autism.

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<sup>2</sup> Vismara LA & Rogers SJ, Behavioural Treatments in Autism Spectrum Disorder: What do we know? Annual Review of Clinical Psychology, (Jan 2010) p 460

## Bibliography:

1. Australian Bureau of Statistics, Australian Social Trends, Jun 2012  
ARCHIVED ISSUE Released at 11:30 AM (CANBERRA TIME) 26/06/2012
2. Roberts, J. M. A., & Williams, K. (2016). *Autism spectrum disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers*. Retrieved from <http://www.ndis.gov.au/sites/default/files/documents/Research/AutismResearchReport.pdf>.
3. Vismara LA and Rogers SJ, Behavioural Treatments in Autism Spectrum Disorder: What do we know? *Annu. Rev. Clin. Psychol.* 2010.6:447-468. Downloaded from [www.annualreview.org](http://www.annualreview.org) by Georgetown University Medical Centre – First published online as a Review in Advance on January 4, 2010
4. Weitlauf AS, McPheeters ML, Peters B, et al. Therapies for Children With Autism Spectrum Disorder: Behavioral Interventions Update [Internet]. Rockville (MD): Agency for Healthcare Research and Quality (US); 2014 Aug. (Comparative Effectiveness Review, No. 137.) Discussion. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK241447/>