

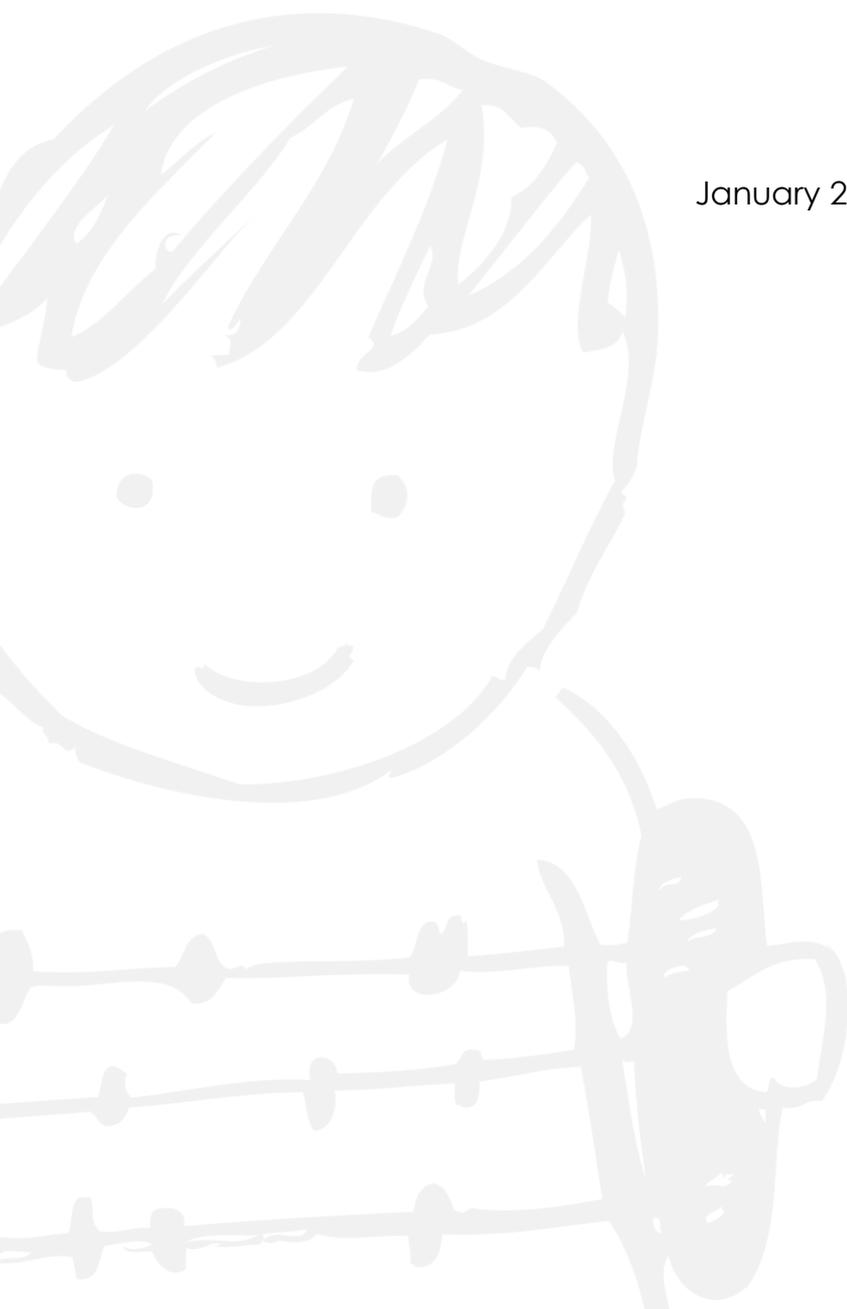
Consultation paper: supporting young children and their families early to reach their full potential

Proposed improvements to the NDIS Early Childhood approach

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 about the way the NDIA supports children and their families.

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 twelve 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 2 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.

Evidence provided in the Autism CRC umbrella research paper Intervention for children on the autism spectrum: A synthesis of research evidence (Whitehouse, A. 2020) concludes positive outcomes across all categories of intervention provided by ALC.

4. Consultation questions

4.1 General questions

- **Do you have any specific feedback in relation to:**
 - The increased focus on STEI outside of access to the scheme

There is little clarity around what services would be considered for STEI. The proposal seems to indicate that the ECEI partners in the community would be the provider or "key worker" for the service.

One of our key concerns that affect us and our clients, is the knowledge the ECEI planners may or may not have of EIBI and specifically, ABA as a best practice, evidence informed therapy. With our clients and student's transition into the NDIS, we have had feedback from families that they are told by the ECEI planner that the NDIS does not fund ABA, or that the NDIS does not fund intensive therapy for children. ABA has been referred to by planners as "alternative" and "not recommended". Further, families have reported that planners have compared their child to other children the planner has "observed" and been told they should "consider themselves lucky".

The EIBI industry is fast moving and ever evolving. It would be essential for all ECEI planners to have up to date knowledge on best practice to provide accurate and useful advice to families.

While the concept of STEI is supported, it is imperative that choice and control is not taken from families around the services they would choose. Short term intervention must also not dilute the role of best practice, evidence informed therapies.

Short term early intensive behavior intervention may be effectively delivered if an initial assessment indicates the functional impact of Autism on the individual would respond to STEI. In our experience, we

have run programs for three to six months, intensively, then provided transition support to mainstream services and education with success. There is nothing in the documentation that defines a timeline for short term intervention.

The other consideration for our co-hort of participants is the experience of regression. The child may present with some language and as meeting some milestones while delayed in others, then experience regression resulting in the loss of all language and engagement with learning and development. It would be important to have a protocol available for participants that if the STEI did not meet the goals, within a defined timeline, that there was immediate access available to the full scheme.

Ultimately, research still supports the cost benefit of effective early intervention when considering long term financial impact of Autism on the individual, family and society, as discussed in a report written by Synergies Economic Consulting, Cost-Benefit Analysis of Providing Early Intervention to Children with Autism Estimation of the net economic benefit of early intervention for a cohort of children with autism, 2013. It is therefore essential that early intervention for the participant is individualised, best practice and able to provide evidence of progress to ensure the best chance of long term-success.

- o The proposed increase in age range for the EC approach from under 7 to under 9 years of age

ALC provides transition support to participants who are moving from early intervention into the mainstream education system. This allows the best chance of success for the participant, supports the family, and provides strategies and knowledge to the school team.

Currently there are varied responses from school administration to the families request for therapy staff to attend school to provide short term support to the participant and information and education to the school team.

There are also responses from school that NDIS funds can not be used at the school premise.

To ensure the success of provisions of supports to participants in school for the foundation years, there would need to be consistent and active support from the Department of Education for the State Education system, the Catholic Education Commission, and Christian Schools Australia. There would also need to be education of the ECEI planners to understand how NDIS funds can be used for the participant in the school setting.

With a consistent approach and appropriate oversights of the providers capability to provide effective transition supports, ALC views the increase in age range for the EC approach as a positive change. It

would also provide further opportunities for participants who are diagnosed later in life as having a disability, still prevalent for girls with autism who are more likely to be “missed”.¹

- o The desire to see more successful transitions from the scheme to the next stage of life

ALC fully supports the aim of moving from high support provision, into other funded environments, such as health and education, so participants can practice learned skills in natural settings and continue to successfully participate with appropriate supports.

Participants have only been accessing NDIS funding for ALC services for around two years. In this time, we have evidence of participants who have moved out of EI, into mainstream schooling with minimal supports.

In our experience, families with young children who have behaviours that interfere with learning, particularly children who have high support needs, experience high levels of stress and anxiety when moving away from capacity building therapy if their goals have not been met to the extent they “want” them to be. This would be of particular note for parents whose child is non-verbal, who demonstrates challenging behaviours and does not engage in social relationships.

ALC considers it critical that families receive ongoing affordable support. Currently families who access ongoing supports in the community, even with a Mental Health Care Plan (MHCP) or Helping Children with Autism (HCWA) plan, still pay a significant gap to the provider after any Medicare rebate. For families with a child with Autism, or other disabilities, the ongoing access required of these services is significantly greater, and more long term than their typically developing peers. This puts additional financial strain on the families and carers.

- o How can we help families and carers better understand some of the terms in the NDIA, and Early Childhood partners

The terms used by the sector should be consistent, non-jargonistic and have operational definitions that are short and referred to at the beginning or end of any documentation provided. The use of abbreviations should also be minimised and only used if it can reasonably be expected that they are widely known, such as NDIS.

The terms of reference should include the proposed outcomes for the participant and caregiver.

¹ Ratto, AB. Et al. (May 2018) What About the Girls? Sex-Based Differences in Autistic Traits and Adaptive Skills
doi: [10.1007/s10803-017-3413-9](https://doi.org/10.1007/s10803-017-3413-9)

Best practice and evidence could be defined as requiring a systematic evaluation process. To ensure clarity, the practical elements of the evaluation process should be included. Discussion around how the provider involves the family in the therapy, how the provider records outcomes of intervention, how the provider reports progress to the family, should be understood by the families and carers when seeking the best service provider for their child. This would provide useable information for caregivers when seeking information about therapy options for their child.

4.2 Support with achieving goals

- **What is the best way for us to check in with families and carers on how their child is tracking to meet the goals for their child?**

ALC would support increased focus on industry measures that can be introduced to practically monitor individual participant progress towards their goals.

ALC would advocate for a scheme that may include ECEI visitors who would attend the EI provider to view therapy, check data and speak with family, to measure participant progress. It would be expected that the visitor had knowledge of evidence informed practice so would be able to interpret raw data that is recorded for the participant. They would also need to have established measurable goals with the family, so the progress is defined and achievable. This would create further opportunities for collaboration as well as holding providers accountable for the services provided. This process could be included as part of the "check-in" process outlined in the consultation paper around planning and personalised budgets.

- **Would a mandatory early childhood provider report developed between families and their provider be useful for tracking against their goal**

ALC currently provides annual progress reports to the NDIA for each participant at scheduled plan review. These reports include summaries of the hours of therapy according to the six domains identified in the NDIS Act around functional capacity, and graph progress and barriers using criteria-based assessment tools. As one of the main determiners of evidence-based practice is data, it is crucial for services to provide mandatory reports regularly. It would be efficient and timely if reports could be submitted directly onto an application programming interface (API) that is shared with the participants families, planners, providers and the NDIA delegates.

A CMS such as the DHHS Client Relationship Information System for Service Providers (CRISSP) could be developed for use by Participants, Registered Service Providers, the NDIA and funded and mainstream supports. By having a database that allows referral and update from service to service with the participant having access to service types

and options, information can be shared with security, consistency and transparency.

- **How can we better support families to connect with services that are either funded or available to everyone in the community?**

ALC advocates for appropriate transition support to community services and providers. By working as a trans-disciplinary team, information can be shared to ensure a smooth transition with best chance of success for the participant.

Caregivers should be given the opportunity to attend information sessions and expos that showcase the available services. These sessions could be held in collaboration with registered disability service providers who can assist in informing families about how the participant will benefit from the community service and how the participant may be initially supported if and as required. This would allow the families an experience of graduation from a disability provider to a mainstream provider with knowledge and support.

4.4 Tailored Independent Assessment Approach

ALC has immediate concerns around using Independent Assessments when making access and planning decisions for children under 7 years of age.

Children demonstrate constant changes in development and function. The functional impairment of a disability may be less evident in a child at the age of 2 years, but by the age of, for example, 2.4 years, the child may be experiencing significant impact to their development due to their disability as their deficits become more impactful on their daily lives.

For early childhood, any assessment process should include a collaborative, family centred approach. A standardised assessment, such as Vineland Adaptive Behaviour Scales, can form part of the holistic assessment process, but paediatricians, child-care workers, Kindergarten educators, are all a part of the knowledge base of how the disability impairs the child's ability to learn and participate. Any standardised assessment needs to be taken in context of the child's experience and environment.

It is understood that the aim of the Independent Assessments is to provide equity of access and planning outcomes for applicants and participants. The risk remains that families who are better able to articulate the functional impact of the disability for their child, may again receive higher levels of funding. This again may create inequity for families who are culturally and linguistically diverse, or from a lower socio-economic background with less educational opportunities.

Children constantly progress and regress. This would raise the possibility of multiple and regular assessments which has a high cost associated and causes stress and anxiety to the family.

There would also be concern about the potential to remove choice and control for the family by providing budgets that will not fund intensive programs based on an individual assessment outcome.

4.5 Greater transparency on providers of best practice

- **What mechanisms do you think could help achieve this?**

ALC supports introducing mechanisms that ensure service providers are delivering safe, quality, evidence based, best practice therapy. While registration would be the obvious mechanism, transparency could be assured in other ways.

ALC would encourage NDIA to consider the use of visitors to services to observe and interact with therapists, managers and families of the participant. These visits could be unscheduled and act as an audit of compliance around best practice. These visits could target one or two quality indicators in the practice standards and conclude with a report with a rating, that is made available to existing service users as well as widely available on the NDIA provider register listing EI providers, including unregistered providers.

- **Who would be best placed to lead the development of, and manage, any additional complementary measures?**

The NDIS Quality and Safeguarding Commission could establish an Early Childhood Department that would complement their Behaviour Support Department and would be able to develop and manage this program.

- **What do you think of the following ideas for potential mechanisms? What are the benefits or concerns with these potential mechanisms?**

- Provide greater information to families about the benefits of using providers registered by the NDIS Commission.

Providers of early intervention should be held to a high standard and able to prove compliance with Child Safe regulations as well as NDIS Quality and Safeguarding Practice Standards. The differences of registered and unregistered service providers are often not apparent to families whose main goal is to find the best therapy for their child. Information provided to families at planning could include what being registered means beyond the enforcement of pricing according to the price guide. Information could include the screening requirements for staff, how a child's safety is assured and assessed with incident

management systems and Zero Tolerance policies and what provisions are made to ensure continuity of support for the child.

ALC has completed and passed the NDIS Quality and Safeguarding audit for Certification but would welcome the opportunity to demonstrate the outcomes of individual participants to the NDIS delegate or ECEI planners. This could be done with on-site visits to observe the student, talk to the family, read data and talk to the therapy team.

- Establish a 'quality feedback/rating system'

ALC strongly supports the ideology of service user feedback. Peer experience for parents with children with disabilities is invaluable. There could be a State or National quality/rating system that services make public, or that is conducted by an independent provider such as Care Navigator or Clickability.

- Make registration with the NDIS Commission mandatory for all providers operating in the EC space

Regulating Early Childhood to be a stated support, would further impact the already thin market of EIBI providers. The expectation of all providers registering, particularly sole traders, may be prohibitive due to the cost to the service provider. This would mean waiting times for participants to access early intervention would increase from already unreasonable timelines.

A possible mechanism to enhance provider compliance may be a tiered system that requires more frequent "check-ins" or mandatory report scheduling for unregistered providers than is required for registered providers.

Summary

ALC supports greater accountability and transparency for providers of high-risk service including early intervention. Best practice and evidence informed therapies should be available and provided to children with a disability and these services should be family centred and collaborative. It is essential that reports are provided which show progress of participants towards their stated goals with the use of data collected across the provision of service.

There would be concerns about children accessing supports using the outcomes of a single standardised assessment and how many times such an assessment must be administered in the first years of life to ensure the child receives reasonable and necessary supports. These assessments are designed to compare the function of a child with a disability to the function of a typically developing child. Caregivers express extreme stress and grief when having to undertake these assessments due to the clinical nature of the results that emphasis the deficits of the child assessed.

Abacus Learning Centre would also support greater education and partnership between the Early Childhood disability service providers and the ECEI partners in the community, specifically ECEI planners. A cohesive approach to intervention for the child and family has the best opportunity for success. Planners should have specific knowledge of not just the types of interventions available but should be funded to visit local disability service providers to view facilities and understand the model used so they have knowledge of best practice both theoretically and practically.

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