



To Whom It May Concern:

**Re: The Lizard Centre’s position on the use of evidence-based intervention for treatment of autism spectrum disorder**

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental disorder characterised by deficits in social-communicative behaviours and the presence of restricted or repetitive interests or patterns of behaviour. Current data indicate that 1:50 children are affected by ASD worldwide (CDC, 2013). ASD can be diagnosed in children as young as 6-12 months of age, but more often a diagnosis is made later in life. Each individual with ASD presents with unique strengths and challenges, and treatment must be individually tailored to address the needs of the individual. A focused intervention may be appropriate for an individual with skill deficits in one or two developmental areas, whereas a comprehensive intervention would be appropriate for an individual with skill deficits or delays across multiple developmental areas. Individuals with ASD and co-occurring intellectual disability will likely need substantial support.

**What is the Problem with Autism Treatment in Australia?**

Given the prevalence of ASD and the demand for treatment, the intervention market is rapidly growing. As government investments into autism treatment are increasing, so too are fad treatments. Primary care, allied health, social care, and education professionals have a critical responsibility to protect families and individuals affected by ASD from fad and ineffective, controversial, or potentially dangerous interventions that are touted by self-proclaimed autism experts who are looking for financial gain (Dillenburger et al., 2014). Two key reports have recently highlighted the range of autism intervention that lack empirical support and thus should not be recommended or funded. These are the *National Autism Centre’s National Standards Report* and the recent Australian report commissioned by the NDIS titled *Autism Spectrum Disorder: Evidence-Based Evidence-Informed Good Practice for Supports Provided to Preschool Children, Their Families and Carers*. Unestablished interventions are those for which there is little or no evidence in the scientific literature that allows us to draw firm conclusions about their effectiveness with individuals with ASD. There is no reason to assume these interventions are effective. Further, there is no way to rule out the possibility these interventions are ineffective or harmful. Taken together, autism interventions that fall into the category of unestablished include:

Autism-assisted animal therapy	Miller Method	Social Behavioural Learning Strategy
Auditory Integration Therapy	Movement-based Intervention	Social Cognition Intervention
Concept Mapping	Music Therapy	Social Thinking Intervention
Cognitive Behaviour Therapy	Rapid Prompting Method	Son Rise
DIR/Floortime	SENSE Theatre Intervention	Shock Therapy
Facilitated Communication	Sensory Integration Therapy	Gluten-Free/Casein-Free Diet
Art Therapy	Sensory Diet	Homeopathy



According to the National Autism Centre's National Standards Report, there are likely many more interventions that fall into this category. Interventions that have not been investigated scientifically would fall into the category of unestablished. In some cases, if studies *have* been published, the accepted process for publishing scientific work was not followed. Interventions for which studies were published exclusively in non-peer-reviewed journals (such as magazines, blogs, or personal websites) would be classified as unestablished.

It should be noted that several unestablished interventions *continue to be widely recommended* by primary care, allied health, social care, and education professionals in Australia, often at a high cost. Unestablished interventions that may be recommended and practiced in Australia include auditory integration therapy, sensory integration therapy, and dietary interventions (other interventions on this list are likely practiced as well). Thus, we feel that primary care, allied health, social care, and education professionals are not doing enough to protect consumers from fad and ineffective, controversial, or potentially dangerous interventions.

### **What Works for Autism?**

Virtually all interventions for autism that are classified as *established* are based on the scientific discipline of applied behaviour analysis (ABA). ABA is the application of the principles of learning, derived from experimental psychology research, to systematically change socially significant behaviours. In addition, within the field of ABA, researchers and practitioners must demonstrate that the interventions used are responsible for the observable improvement in behaviour (and rule out that behaviour change occurred as a result of an uncontrolled variable). ABA methods are effective for increasing adaptive behaviours, reducing interfering maladaptive behaviours, teaching new skills, and generalizing behaviours to new environments or situations. The effectiveness of ABA-based interventions in ASDs has been well documented through more than 5 decades of research by using a variety of research methods, including single-subject designs, randomized controlled clinical trials, meta analyses, and cost benefit analyses. Children who receive early intensive behavioural treatment based on the principles of ABA have been shown to make substantial and sustained gains in IQ, language, academic performance, and adaptive behaviour, and their outcomes have been significantly better than those of children in control groups (including no treatment, low intensity treatment, or non-ABA treatment groups). Healthcare funders and managers, as well as primary care, allied health, social care, and education professionals, must be able to recognise the core characteristics of ABA ([http://bacb.com/wp-content/uploads/2015/07/ABA\\_Guidelines\\_for\\_ASD.pdf](http://bacb.com/wp-content/uploads/2015/07/ABA_Guidelines_for_ASD.pdf)), which include:

*An objective assessment and analysis of the client's condition by observing how the environment affects the client's behaviour, as evidenced through appropriate data collection*

*Importance given to understanding the context of the behaviour and the behaviour's value to the individual, the family, and the community*

*Utilization of the principles and procedures of behaviour analysis such that the client's health, independence, and quality of life are improved*



*Consistent, ongoing, objective assessment and data analysis to inform clinical decision-making*

Early intensive behavioural intervention (EIBI), an evidence-based, comprehensive intervention for ASD based on the principles of ABA, has been shown to be associated with the *most dramatic improvements* in prognosis for children with ASD (Eldevik, Hastings, Hughes, Jahr, Eikeseth, & Cross, 2009; Lovaas 1987; Peters- Scheffer, Didden, Korzilius, & Sturmey, 2011). The goal of EIBI is to change a child's learning trajectory so that the child's rate of learning approaches that of a typically developing peer. EIBI is characterized by the following:

*Early: Intervention begins as soon as a diagnosis is confirmed. EIBI may produce the greatest gains when intervention is started before age 2*

*Intensive: Intervention is provided for no less than 20 hours per week, with some studies recommending 30-40 hours per week*

*Behavioural: Intervention is focused on the objective identification of skill deficits and behavioural excesses, and the use of teaching tactics derived from ABA to build functional skills.*

Interventions for ASD based on the principles of ABA are now seen as medically and educationally necessary in the USA. In most states, healthcare providers are mandated to cover the cost of early intensive behaviour intervention, and public and private schools require and fund the provision of ABA in special education classrooms. In other words, ABA is considered "business as usual" in the education and treatment of children with ASD in many parts of the USA.

### **Why Does Intensity of Intervention Matter?**

Research has consistently shown that positive effects can be achieved when ABA therapy is delivered via a comprehensive, individualised and intensive intervention program. Comprehensive, individualized and intensive intervention programs such as EIBI are important for young children with ASD for several reasons:

1. The second year of life is a dynamic period of brain growth, during which increases in brain volume and atypical connectivity associated with ASD first emerge. However, this is also a time of substantial neural plasticity which may allow for rapid skill acquisition and alteration the child's developmental trajectory such that reaches age-appropriate developmental milestones
2. A proportion of children with ASD reportedly regress in the second year of life. However, intensive intervention during this period may counter the symptoms of regression and ultimately prevent ASD-related impairments before they fully manifest
3. Statistics show that between 25-50% of children who receive early intensive behavioural intervention will transition into mainstream school by Kindergarten. Many other children will need significant less support as they get older



4. Group design research and randomized controlled clinical trials suggest that behavioral programs that are implemented as early as possible and in an intensive manner can produce significant improvements in cognitive, adaptive, and social-communicative functioning in young children with ASD

Although the required number of hours of intervention may seem high, this is based on current research findings regarding the intensity required to produce good outcomes. Time spent away from therapy may have unwanted effects, such as the child falling further behind typical developmental trajectories. By delaying treatment and only doing a little bit of intervention, children with autism will likely be more dependent on intensive, costly services across their life span. **We contest that the cost of effective, intensive early intervention should be compared to the long-term cost of not intervening, which may carry a considerably more expensive burden over the longer term.**

### Who has Endorsed ABA?

Applied behaviour analysis is now widely endorsed. Dillenburger (2016) provides an overview of these endorsements:

As early as 1999, the Surgeon General endorsed ABA-based interventions:

*Thirty (now, 45+) years of research demonstrated the efficacy of applied behavioural methods in reducing inappropriate behaviour and in increasing communication, learning, and appropriate social behaviour (p.164)*

More recently, the New York State Department of Health (2011) recommended:

*That principles of applied behaviour analysis (ABA) and behaviour intervention strategies be included as important elements in any intervention program for young children with autism (p.33)*

The California Department of Education and Developmental Services (1997) recognised that:

*In areas such as social engagement, language, coping, and reduction of difficult behaviours... Applied behavioural analysis is usually needed to assist a child to gain skills and reduce negative or undesirable behaviours (p.10)*

The Federal U.S. Office of Personnel Management responsible for all federal government employees concluded that ABA-based interventions should be covered not only for educational but also for medical reasons:

*Based on ample scientific and empirical evidence, ABA therapy qualifies as a medical treatment, rather than purely educational (Bahsoun, 2012, p.1)*

In Canada, ABA-based interventions are supported, for example by the Ontario Department of Education Policy/Program Memorandum (PPM-140, 2007) that:

*Support(s) incorporation of ABA methods into school boards' practices ... The use of ABA instructional approaches may also be effective for students with other special education needs (p.1)*

The Maine Administrators of Services for Children with Disabilities confirmed their support in the Report of the Autism Task Force (Baldacci & Harvey, 2009):



*It is important to note that ABA is frequently perceived to be synonymous with discrete trial teaching. However, ABA is comprised of a broad scope of empirically derived behavioural principles used in interventions...(p.25)*

In Australia, ABA-based interventions have also been endorsed. In 2011, Prior, Roberts, Rodger, and Williams published their report titled *A Review of Research to Identify the Most Effective Models of Practice in Early Intervention for Children with Autism Spectrum Disorders*. This report was prepared funded by and prepared for the Australian Government of Families, Housing, Community Services and Indigenous affairs (FaHCSIA). ABA was the *only* intervention to be classified as eligible for funding based on established research evidence:

*The findings of the current literature review support the findings of previous reviews. Behaviourally based interventions, and specifically those that are intensive (often referred to as applied behavioural analysis (ABA) or early intensive behavioural intervention (EIBI), continue to indicate some positive outcomes for some children in a range of areas including cognitive skills, communication, and adaptive behaviour.*

Following in the footsteps of Roberts et al., The Helping Children with Autism (HCWA) package endorsed ABA as the *only* intervention that is eligible for funding based in established research evidence. In addition, the Raising Children Network ([http://raisingchildren.net.au/articles/applied\\_behaviour\\_analysis\\_th.html](http://raisingchildren.net.au/articles/applied_behaviour_analysis_th.html)) gives ABA a firm rating of *established*, noting that research consistently shows positive effects.

### **What's wrong with Speech Therapy and Occupational Therapy?**

Speech therapy and occupational therapy (OT) are wonderful accompaniments to ABA therapy, and should be included in early intensive behavioural intervention programs. Speech therapists address the mechanics of speech, including oral motor and articulation problems. Speech therapists may also address the child's ability to understand the language of others and to use language to communicate effectively. Occupational therapists address gross and fine motor development and skills related to self-help and personal independence (e.g., dressing, eating, hygiene, and toileting). All of these skills are extremely important components of any ABA program. What is problematic with speech therapy and OT is the **method** and **frequency** with which these therapies are delivered. Speech and OT may use teaching methods that are different to those used within an ABA program, and may not rely on data collection and analysis to make treatment decisions. Eikeseth et al. (2002, 2007) conducted an important group of studies comparing ABA therapy with speech and OT. Children with ASD were assigned to one of two groups, based on their availability for sessions. Children in the ABA group received 28 hours per week of ABA therapy, whereas children in the Eclectic group received 29 hours per week of speech and OT. At follow-up, the ABA group scored significantly higher than eclectic group on tests of IQ, language, adaptive functioning, and maladaptive functioning. The ABA group children gained an average of 25 IQ points, whereas the Eclectic group children gained an average of 7 IQ points. At follow-up, 7 of 13 children in the ABA group achieved normal IQ scores at follow-up, as opposed to 1 of 12 in Eclectic group.

These findings tell us that quality/type of intervention and the method in which therapy is delivered matters. In an ABA program, a baseline assessment is conducted to pinpoint skill



deficits prior to treatment. Once deficits are identified, larger skills are broken down into individual component parts, and component skills are taught to mastery before moving on to more complex or higher level skills. Data are collected on the child's performance and are reviewed frequently. Data allow the treatment team to determine when a skill is mastered, or to identify if the child is not progressing. If the child is not showing progress toward learning a specific skill, the problem is analysed and aspects of the program are modified to ensure continued progress. This data-driven approach is a hallmark of ABA and is often **not** incorporated into more traditional speech therapy or OT programs. Another problem with traditional speech and OT is the intensity of the intervention. A speech therapist or occupational therapist will see the child once per week or once per fortnight for a 30-min to 1-hour session. However, current research indicates that the *intensity of intervention* matters. Smith, Groen, and Wynn (2000) conducted a randomised controlled clinical trial of ABA therapy and parent-delivered therapy. Children were matched by age and IQ at intake and randomly assigned to one of two groups. The children in the ABA group received 25 hours per week of ABA therapy over a 2-year period, whereas the children in the Parent training group received 2 hours of in-home family training in ABA per week. At follow-up, the ABA group scored significantly higher than Parent group on tests of IQ, visual-spatial learning, language, and academics. The ABA group children gained an average of 16 IQ points, while the Parent group lost an average of 1 IQ point. Twenty seven percent of the children in the ABA group achieved average post-treatment scores and were integrated into regular education classrooms.

These findings have been replicated in several other group studies (e.g., Eldevik, Eikeseth, Jahr, & Smith, 2006). In their 2016 report prepared for the NDIS (*Autism spectrum disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers*), Roberts and Williams concluded that children who have received a diagnosis of autism should receive 20 hours per week of autism-specific early intervention. Intensity of intervention appears to be a critical factor, and has been shown to facilitate positive outcomes in young children with ASD. We believe that speech therapists and occupational therapists are important multidisciplinary team members that can (a) conduct relevant baseline assessments to pinpoint strengths and weaknesses prior to intervention, (b) provide recommendations regarding the skills that should be included as part of an individually-tailored ABA program, and (c) play an active role in progress monitoring and program modification during the course of ABA therapy. Speech and language, fine and gross motor skills, and self-care skills can be included and very effectively addressed as part of a child's comprehensive ABA program.

### **How does ABA Promote the Social Inclusion of People with Autism?**

ABA encourages socialisation and social inclusion by giving children with autism the skills they will need to be successful in inclusive environments. Within an ABA program, children learn to use language to express their wants and needs, learn to observe and imitate others, and learn to use many everyday items in functional ways. All of these skills are prerequisites to successful socialisation and social inclusion. These skills are initially taught during 1:1 therapy sessions in a structured environment to maximise the child's success. Once skills are learnt, the ABA therapist will assess the child's ability to perform the skill in different environments, with different people, and with different materials. If the child is unable to transfer learnt skills to new environments, the therapy team will conduct teaching and fading in other environments until the child is able to be independent. Simultaneously, the therapy



team will provide coaching and training to other people who frequently interact with the child (such as parents, siblings, and teachers) to ensure that they can respond appropriately to the new behaviours displayed by the child, and provide help to the child when needed to ensure continued success. When children with autism are placed into inclusive environments without the necessary pre-requisite skills and without support, they are significantly *more* likely to display behaviour problems and significantly *less* likely to participate in learning and social activities. This may lead to the child being removed from the inclusive environment and placed in a self-contained classroom. This may also drastically decrease opportunities for the child to make friends and learn from other children.

### **What do Cost-Benefit Analyses Tell Us About Autism Treatment?**

For individuals with ASD and a co-morbid intellectual disability, the lifetime cost society is thought to be in excess of \$1 million (Buescher, Cidav, Knapp, & Mandell, 2014). However, the quality of life cost to families is much greater (Dillenburger, 2016). For example, families of a child with autism frequently must pay higher than average childcare costs, and many times one parent is forced to give up work or reduce working hours due to provide care for the child with ASD. It is estimated that only 15% of adults with ASD are engaged in meaningful employment (Rosenblatt, 2008). In their review of cost benefit analyses of EIBI, Cross, Coyne, Broberg, and Lubbers (2013) determined that the cost savings substantially exceeds the early intensive treatment cost for a 3-year-old child with autism or ASD. Some reports have found a home-based program to be less expensive than alternative non-ABA based special school placements (Columbia Pacific Consulting, 1999).

Synergies Economic Consulting carried out a cost benefit analysis of providing EIBI to children with ASD ([www.synergies.com.au](http://www.synergies.com.au)). The authors designed three groups to capture the population of children with autism. The three groups were described as follows:

*Group 1 – children with severe intellectual impairment – likely to be nonverbal and suffer from significant behavioural issues and anxieties (estimated to account for approximately 20% of the children that would receive early intervention);*

*Group 2 – children with mild to moderate intellectual impairment – likely to experience difficulties with language and communication, particularly in social settings (estimated to account for approximately 60% of the children that would receive early intervention); and*

*Group 3 – children with High Functioning Autism – while not suffering from intellectual disabilities, individuals in this group can experience difficulties in other areas that can adversely impact long-term outcomes in key areas (estimated to account for approximately 20% of the children that would receive early intervention).*

The authors applied a cost-benefit analysis to each group, and determined that, with EIBI, the average total economic benefit per child exceeded \$1 million.



Key area outcomes	Group #1		Group #2		Group #3	
	Without EI	With EI	Without EI	With EI	Without EI	With EI
Unemployed	n/a	n/a	75%	30%	30%	5%
<b>Living Independence</b>						
FT care	80%	40%	30%	10%	0%	0%
Shared accom.	20%	60%	65%	65%	30%	10%
Independent/supervised living	n/a	n/a	5%	25%	30%	20%
Independent	n/a	n/a	0%	0%	40%	70%

Note: 'n/a' means the outcome is assumed to be not applicable to a child in this group.  
 Source: Proportions provided by the RAG.

#### Total economic benefit of early intervention for a cohort of children with autism

	Average benefit per child	No. Children	Total economic benefit
Group #1	\$1,297,000	237 (20%)	\$307,500,000
Group #2	\$1,202,000	711 (60%)	\$855,200,000
Group #3	\$747,000	237 (20%)	\$177,100,000
<b>Total</b>	-	<b>1,185</b>	<b>\$1,339,800,000</b>

Note: Totals may not add due to rounding.  
 Source: Synergies modelling.

Jacobson, Mulick, and Green (1998) also developed a cost-benefit analysis model of EIBI based on the range of outcomes reported by previous group studies. The authors applied representative costs from Pennsylvania, including costs for educational and adult developmental disability services, in a cost-benefit model, assuming average participation in EIBI for three years between the age of 2 years and school entry. Information on the proportion of individuals accounted for by each group, ABS data on the number of live births in Pennsylvania per annum, and autism prevalence data was applied to these estimates to determine the total economic benefit for a cohort of children with autism in (a) regular education without supports, (b) some in special education (partial effects), and (c) some in intensive special education (minimal effects). At varying rates of effectiveness, the model proposed by Jacobson et al. estimates that cost savings as a result of participating in EIBI range from \$187,000 USD to \$203,000 USD per child for ages 3-22 years, and from \$656,000 to \$1,082,000 per child for ages 3-55 years. In this study, the authors assumed that there would be differences in initial costs of \$33,000 and \$50,000 per year for EIBI, but found that these differences had a modest impact on cost-benefit balance. The cost of EIBI was greatly outweighed by estimated savings.

## Conclusions

Many people still believe that our current understanding of what works for autism is limited. This is wrong. Today, ABA is widely recognised as a safe and effective treatment for ASD. To ensure that all children with ASD in Australia have access to effective and safe intervention, we must do the following:

- We must ensure that access partners appointed by the NDIA are able to understand the core features of autism interventions that are classified as *established*. Access partners must also understand the core features of autism interventions that are *unestablished*,



and should protect families and individuals affected by ASD from fad and ineffective, controversial, or potentially dangerous interventions.

- We must also provide information to primary care, allied health, social care, and education professionals to help them distinguish between *established* and *unestablished* autism interventions. Again, these professionals have an ethical responsibility to ensure that families and individuals affected by ASD are protected from fad and ineffective, controversial, or potentially dangerous interventions.
- The Australian government should support the growth of applied behaviour analysis as a distinct field of professional practice in Australia. ABA is a specialized behavioural health treatment approach. Most graduate programs in psychology, education, or allied health do not provide training in this discipline. Therefore, it is important that the Australian government understands the process by which ABA professionals are trained and credentialed. The Behaviour Analyst Certification Board (BACB©) oversees the credentialing of behaviour analysts, and more information can be found at <http://bacb.com>. We must ensure that behaviourally based interventions, such as early intensive behavioural intervention, are supervised by credentialed behaviour analysts. Behaviour analysts should also be invited to work on interdisciplinary teams and/or sit on committees with other professionals who provide services to people with ASD and their families.
- Allied Health professionals, psychologists, and educators should also be aware of the practice guidelines for healthcare funders and managers published by the BACB©, which can be found here: [http://bacb.com/wp-content/uploads/2015/07/ABA\\_Guidelines\\_for\\_ASD.pdf](http://bacb.com/wp-content/uploads/2015/07/ABA_Guidelines_for_ASD.pdf)
- Finally, we must ensure that we spend smarter. Cost benefit analyses have allowed us to substantiate evidence of effective interventions. We know that best outcomes can be achieved when a diagnosis of autism is provided early (before age 3), when intervention begins as soon as a diagnosis is confirmed, when intervention is intensive (20+ hours per week), and when intervention is focused on teaching new adaptive life skills. We must provide the necessary funding to allow families from all socio-economic and cultural backgrounds to access early intensive behavioural intervention.

We at the Lizard Centre hope to work collaboratively with the NDIS and other government and community organisations to ensure that evidence-based intervention is available and accessible to people with ASD and their families, to protect families from fad, ineffective, or potentially harmful treatment, and to ensure that service providers are accountable for the treatments they recommend and provide.

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Dr Erin Leif, PhD  
Board Certified Behaviour Analyst – Doctoral  
Clinical Director  
Lizard Centre  
[erin@lizardcentre.com](mailto:erin@lizardcentre.com)  
[www.lizardcentre.com](http://www.lizardcentre.com)



## Key Supporting Documents

Autism spectrum disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers (2016). Retrieved from <https://www.ndis.gov.au/html/sites/default/files/Early%20Intervention%20for%20Autism%20research%20report.pdf>

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