

ABA4ALL

FOR PROFESSIONALS:

ON TREATING AUTISTIC SPECTRUM DISORDERS AND OTHER DEVELOPMENTAL DELAYS

Autism affects 1 in 100 children in the UK - around 100,000 children in total.

We are parents who are using evidence-based therapy based on ABA (applied behaviour analysis) for our children with autism, with good results. We therefore want all health and education professionals with an interest in autism to know more about it.

So we have written and produced this booklet ourselves; there are no vested interests or big corporates behind us, it is just us parents. We have however checked our words for accuracy with some experts.

ABA-based interventions, particularly in the pre-school years, have a better research backing than any other interventions for autism. We include some links and excerpts from the research at the end.

The reason NICE does not explicitly recommend ABA is it says there are not enough randomised controlled trials.

But you will note that neither does NICE recommend Speech and Language Therapy (SALT) or Occupational Therapy (OT), which for some odd reason the NHS and education systems are happy to dole out daily to children with autism.

Yet there is so much less evidence for SALT and OT with autism; you will see the wealth of meta-analysis and systematic reviews for ABA at the end.

We think there is a bit of prejudice built into the system against ABA.

It is not cruel, as you may have heard, nor is it 'too intense', but rather it is often play-based and all about harnessing the autistic child's own interests to motivate them to learn. That is especially important given that children with autism often lack the 'social desire to please' and so what motivates them will be different from their typically-developing peers.

ABA is very good for communication skills and challenging behaviours, but is about so much more than that. Using behavioural techniques, a good ABA team can teach pretty much any skill.

There is a proper set of professional qualifications for ABA practitioners: the Masters-level BCBA, graduate-level BCaBA and the new RBT qualification for tutors.

It can be expensive, but this is mainly due to the fact that it is not offered within the state system. We believe that the early years 15 hours a week free education funding should be available to spend on ABA. We also think the NHS should help our children with autism, by offering ABA rather than SALT and OT. LSAs in school with ABA training can also be highly effective. The benefits that our children will get from ABA-based interventions will save the state a lot in the long run.

ABA works for children at both the higher and the lower ends of the spectrum, of all ages, and there is ample research showing that it can help a good proportion of children with mainstream inclusion.

Please open your minds and look at the scientific evidence for ABA for our children; it is their best chance.

WHAT PARENTS SAY

"Our son has autism and has been having ABA/Verbal Behaviour therapy for 2 years with amazing results. Before ABA our son couldn't speak, couldn't play, wasn't toilet trained, had limited understanding and couldn't communicate, couldn't tolerate his teeth brushed or having his hair cut. Now he can do all of those things and much more!!! In our experience very little has been offered to our son by the NHS or education system and what has been offered has been too little or hasn't helped him."

Joanne Cockayne - Rugely, Staffordshire

"ABA for our little girl has been 100% play based. And incredibly effective - I'll never forget the ear-to-ear grin on my daughter's face as she made her first real communication at our first ABA team meeting. From a non verbal beginning, she had functional language after only 2 weeks and rapidly developing play skills."

Gwyneth Duque, London

"Without ABA, my beautiful boy would be headed for 6ft 5, still aggressive, still punching himself in the head, and still non-verbal. Without ABA, we would eventually have had no choice but to send him to an institution, which would destroy our family and which the state can ill afford. Please reconsider outdated attitudes to ABA".

Jane McCready, Surrey

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"Our world collapsed when we got her diagnosis and life has never been the same. She is a beautiful child who we love immensely but with her disorder came sleepless nights, uncontrolled behaviour (like biting, slapping, pinching, never-ending crying and tantrums), self stimulating behaviour (which could keep her busy all day with no awareness of her surroundings), no language and communication, no social interaction, no sense of danger and many more such heart-breaking facts. We as parents wanted to help her the most and found the answers in the ABA/VB approach. Since the time we started her programme, we could notice her improving in each area. She can now not only say words but even phrases (with 4-5 words combined) to communicate, she is much more confident in social gatherings and while meeting new people, she is toilet trained, she can self feed with little support from an adult (as her fine motor skills are still limited), her play skills have come a long way, she is getting more interested in arts and craft (like drawing, painting etc) and many more improvements. She still has a long way to go but we are so happy to see her progress each single day, all thanks to her ABA/VB programme."

Shilpi Saxena and Rahul Rattan, Croydon, Greater London

"We are the parents of a beautiful five year old boy called Caden. Up until we started using the ABA therapists and their desensitising programs we struggled severely on a daily basis with all aspects of Caden's personal and health care. This included any appointments with doctors, dentists, opticians and ENT specialists, due to the problems he has been having with glue ear, perforation of the ear and constant ear infections. Caden's ENT appointments were always extremely difficult and in the past he would not allow the Consultant to examine his ears at all which caused us great concern. We have now seen a huge improvement as Caden will now allow the Consultant to examine his ears with no fuss at all.

Caden would not brush his teeth, let me wash or cut his hair, cut his nails and the list could go on, but after the therapists putting desensitising programs in place Caden managed to overcome these problems within a matter of weeks. The introduction of signing saw a significant increase in his manding, which has also led to him starting to make sounds. This has led to a significant decrease in his levels of frustration as he is now able to communicate in a meaningful and functional way. It is absolutely ridiculous that the NHS will

not offer this to our son and that is what is cruel, not the ABA. "

Nicola Davies and Chris Evans - Swansea, Wales

Both my boys are on ABA and it has been the best thing I've ever done for them! ABA approach has helped not only my boys but my husband and I as parents too!"

Valeria Mazzaro and Ali Talbi, Croydon, London

"I have found that an ABA-trained 1-to-1 for my boy Yogi at mainstream school has made all the difference. They know how to manage and motivate him in a busy classroom. Without that ABA training for the LSA, things went wrong pretty quickly, so ultimately it is the child who suffers if school won't accept the ABA candidates".

Kasthuri Subramanian, Stevenage, Herts

"My son was diagnosed with Autism at 2.5 years old and I was lucky enough to meet a mother who had been using ABA therapy for her autistic child. I started ABA immediately and my son is now 4 and will be attending a mainstream school in September."

Meena Bahia-Taylor, Twickenham, London

"I have twin boys, aged 6, who have severe autism and are non-verbal. We self-fund ABA (using a mix of savings, benefits and extensive fund-raising) which has delivered remarkable results. We are dismayed that the extensive academic evidence that supports ABA is given no recognition"

Mike Stevens, Dunfermline, Scotland

"Ryan has autism, he is now 4yrs old and has been in an ABA programme for over 1.5 years. Ryan is now verbal and is in mainstream school thanks to ABA. ABA has been life changing for us: Ryan's behaviours nearly destroyed us as a family. Now thanks to ABA we are able to experience family days out and social situations."

Louise O'Neill, Belfast, N Ireland

"My son has been receiving 15 hrs ABA per week for a year & is doing amazingly well. Without ABA he would probably still be wandering the house banging cupboards to this day, instead he has learnt his alphabet & numbers, can spell, do puzzles, is starting to speak amongst other things! ABA really shouldn't be called a 'controversial' therapy for autism, I truly believe it's controversial that it's not offered for ALL children with autism."

Natalie McClay - Pontefract, West Yorkshire

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WHAT IS ABA FOR AUTISM?

ABA is the application of the science of behaviour analysis. This science has its roots in the work of pioneering psychologist Dr BF Skinner in the last century.

One of the earliest applications of ABA with children with autism was the work of Ivar Lovaas. Of course, like any science, ABA has developed since Lovaas's early interventions, but the principles remain the same: reward or "reinforce" the behaviours we want to see; ignore, or give a dull consequence to behaviour we do not want to see. And the words "reward" and "behaviour" are both misleading. Many think that reward is synonymous with a "treat" – rather, for a behaviour analyst, reinforcement is a consequence that is likely to lead to an increase in a behaviour occurring again, and is therefore meaningful for the individual child. And the word "behaviour" colloquially has come to mean "bad behaviour". This is why some think, mistakenly, that ABA is just about "managing out" an autistic child's bad or anti-social "behaviours". But to a behaviour analyst the word behaviour covers everything a person "does" - from all our actions, through to talking, reading and writing and even thoughts and feelings.

The principles of learning are universal and are applied systematically by behaviour analysts in many areas aside from just autism: from helping workers in a high-risk environment to carry out a procedure safely, through to adults with problems of addiction. At the societal level, behaviour analysts have designed effective interventions for increasing recycling, reducing drink driving, and increasing seatbelt use.

In the context of autism, ABA will encourage a child to learn important "behaviours" eg talking, and may discourage behaviours which the family and ABA team together decide are unhelpful or even harmful - for instance aggression or self-harm.

The intervention will not start until all around the child have discussed desired outcomes. What is it that the child needs to learn? Often these aims will be really obvious, as the child may have zero speech and may spend their entire time spinning like a top, or self-harming, or screeching loudly. There may be aggression if thwarted from pursuing their own agenda all day long.

For a more severely affected child, possibly with co-occurring learning difficulties, the ABA intervention will often start by rectifying one of the core deficits of autism: the inability to imitate. Without the ability to imitate what another person is doing, little learning is possible. This is one of the key steps missed out by non-ABA approaches for children with autism.

The other issue for the child with autism is motivation: the ABA tutor teaches the child by using "reinforcers" such as the activities or items that will particularly motivate a given child. The point here is that children with autism often lack the "social desire to please" and therefore what is motivating for them is often different from typically-functioning children (this is another aspect of autism missed in much of our state autism therapy and education).

So, for instance, a child might say his first ever word - perhaps "push" - when tutors teach him that this particular sound will produce his desired outcome on a swing. Teaching a child to say his or her first words in order to get particular reinforcers (or desired items) is called "mand" training - mand is the ABA word for demand. Many children with autism will copy or echo what an adult says, but will not develop functional language. So, for instance, mum will ask "do you want an apple?" and the child will reply "do you want an apple?" - which may mean "yes". The ABA professionals will have the skills to turn echoic speech into functional speech: without this (fairly simple) technique, many UK children with autism never grow out of their echoed speech. This is clearly unacceptable.

ABA programmes can be devised for all manner of learning targets - from toilet-training or eating with cutlery, right through to reading or riding a bike..

The other key ingredient of ABA is that skills are broken down into their smallest elements, and each element learned and rewarded until it is mastered. So, for instance, a child learning to brush his teeth will be guided hand-over-hand to get the toothbrush, put toothpaste on, turn tap on and then brush each part of the mouth. Later, the prompts will be faded until the child can brush teeth all by themselves.

The brain is at its most "plastic" before six, and real change can be effected on how the child develops.

Critics of ABA are most vociferous when tutors work on minimising "stims" or self-stimulatory behaviours (like hand-flapping). They will argue that these behaviours help the autistic person manage anxiety. This may sometimes be true, and when a "stim" serves a purpose for a child, is not harmful and is not a barrier to learning or to functional living, ABA will not attempt to change that behaviour. However there are some stims that take over the child's life, allowing no room

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for learning, and are habits that can be unlearned perfectly safely. Some stims can also involve self-harm, eg biting own hands or head-banging on concrete - this is clearly no good for child or family.

THE ABA PROFESSION

ABA programmes, whether home- or school-based, should be overseen by a consultant who holds a BCBA masters-level qualification, or equivalent masters qualification. The BCBA is awarded by the BACB, the Behavior Analyst Certification Board, which is US-based; however, the BCBA is an internationally-recognised qualification.

The requirements to become a Board Certified Behavior Analyst (BCBA) are stringent and include a relevant master's degree, 270 hours of postgraduate level coursework in behaviour analysis, and 1500 hours of supervised practice. The second level credential for ABA supervisors, Board Certified Assistant Behavior Analyst (BCaBA), necessitates a bachelor's degree, 180 hours of undergraduate level coursework, and 1000 hours of supervised practice.

And below the supervisor sits a team of hands-on tutors, for whom a formal qualification has recently been introduced: the Registered Behavior Technician (RBT).

There are currently five universities in the UK offering Behavior Analyst Certification Board (BACB) accredited courses: Bangor University; University of Glamorgan; University of Kent; University of Ulster at Coleraine; Queen's University Belfast. A masters at one of the above universities can lead to a BCBA qualification, after a conversion exam.

Today, in the UK, there are 134 BCBA/BCaBA certificants, an estimated 1000 ABA home programmes (Peach figures, 2013) and 14 ABA schools - including Treetops, Treehouse School, Jigsaw, Rainbow and others (Griffith et al, 2012). These 14 schools at the time of surveying were supporting 258 state-funded pupils with autism and employed 382 members of staff.

The area of residential care for adults with Learning Disabilities and/or challenging behaviours is also a crucial growth "market" for behaviour analysis, often under the term Positive Behaviour Support (PBS). After Winterbourne View and similar scandals, this kind of professionalism in the area of ethical behaviour management is much sought after.

In short, Behaviour Analysis is a mature and well-regarded and regulated profession, with clear career paths, qualifications and codes of ethics and practice. All certificants are registered on the BACB site, and professional conduct is monitored rigorously (see register at www.bacb.com).

Founded last year, the UK-SBA, the UK Society for Behaviour Analysis, is the industry body for the profession in the UK (www.uk-sba.org).

WHOSE ISSUE IS THIS - EDUCATION OR HEALTH?

Both. Far from being just an educational intervention, ABA deals with many life and health skills which go way beyond just academics.

The evidence all points to the fact that the earlier you intervene on autism, the better the outcome.

Starting ABA before school age is best. This is often called EIBI, or early intensive behavioural intervention. In the recent Fein "Optimal outcomes" research* the children who did the best in terms of improved IQ, communication and adaptive behaviours were those who had been given the most early intensive behavioural intervention.

But there is no age at which it stops being effective. ABA can help many children with autism negotiate the busy classroom environment and carry on learning.

We would ask professionals in both health and education to think of ABA before referring children with autism down the usual OT or SALT routes, or into the TEACCH system. We understand that there is no new money around, but there really is a more robust evidence base for ABA, and we in the UK lag badly behind the US, Canada, Scandinavia etc on intervention for autism. You will note that ABA programmes fulfil many of the NICE criteria for "psychosocial" interventions - the choice of which they leave to the discretion of CCGs.

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EVIDENCE BASE FOR ABA

There are four decades of research backing for ABA, with several robust meta-analyses, systematic reviews and some RCT evidence.

We give here references and abstracts drawn from a selection of important studies:

**** Intervention for Optimal Outcome in Children and Adolescents with a History of Autism, (J Dev Behav Pediatr 0:1-10, 2014) Alyssa J. Orinstein, MA, Molly Helt, MA, Eva Troyb, MA, Katherine E. Tyson, MA, Marianne L. Barton, PhD, Inge-Marie Eigsti, PhD, Letitia Naigles, PhD, Deborah A. Fein, PhD***

OBJECTIVE: Autism spectrum disorders (ASDs) were once considered lifelong disorders, but recent findings indicate that some children with ASDs no longer meet diagnostic criteria for any ASD and reach normal cognitive function. These children are considered to have achieved “optimal outcomes” (OO). The present study aimed to retrospectively examine group differences in the intervention history of children and adolescents with OO and those with high-functioning autism (HFA).

METHOD: The current study examined intervention histories in 25 individuals with OO and 34 individuals with HFA (current age, 8–21 years), who did not differ on age, sex, nonverbal intelligence, or family income. Intervention history was collected through detailed parent questionnaires.

RESULTS: Children in the OO group had earlier parental concern, received earlier referrals to specialists, and had earlier and more intensive intervention than those in the HFA group. Substantially, more children with OO than HFA received applied behavior analysis (ABA) therapy, although for children who received ABA, the intensity did not differ between the groups. Children in the HFA group were more likely to have received medication, especially antipsychotics and antidepressants. There were no group differences in the percent of children receiving special diets or supplements.

CONCLUSION: These data suggest that OO individuals generally receive earlier, more intense interventions, and more ABA, whereas HFA individuals receive more pharmacologic treatments. Although the

use of retrospective data is a clear limitation to the current study, the substantial differences in the reported provision of early intervention, and ABA in particular, is highly suggestive and should be replicated in prospective studies.

Vismara, L. A. & Rogers, S. J. 2010. Behavioral Treatments in Autism Spectrum Disorder: What Do We Know? Annual Review of Clinical Psychology, 6, 447-468.

Although there are a large and growing number of scientifically questionable treatments available for children with autism spectrum disorder (ASD), intervention programs applying the scientific teaching principles of applied behavior analysis (ABA) have been identified as the treatment of choice. The following article provides a selective review of ABA intervention approaches, some of which are designed as comprehensive programs that aim to address all developmental areas of need, whereas others are skills based or directed toward a more circumscribed, specific set of goals. However, both types of approaches have been shown to be effective in improving communication, social skills, and management of problem behavior for children with ASD. Implications of these findings are discussed in relation to critical areas of research that have yet to be fully explored.

Eldevik, S., Hastings, R. P., Hughes, J. C., Jahr, E., Eikeseth, S. & Cross, S. 2010. Using Participant Data to Extend the Evidence Base for Intensive Behavioral Intervention for Children With Autism. American Journal on Intellectual and Developmental Disabilities, 115, 381-405.

We gathered individual participant data from 16 group design studies on behavioral intervention for children with autism. In these studies, 309 children received behavioral intervention, 39 received comparison interventions, and 105 were in a control group. More children who underwent behavioral intervention achieved reliable change in IQ (29.8%) compared with 2.6% and 8.7% for comparison and control groups, respectively, and reliable change in adaptive behavior was achieved for 20.6% versus 5.7% and 5.1%, respectively. These results equated to a number needed to treat of 5 for IQ and 7 for adaptive behavior and absolute risk reduction of 23% and 16%, respectively. Within the behavioral intervention sample, IQ and adaptive behavior at intake predicted gains in adaptive behavior. Intensity of intervention predicted gains in both IQ and adaptive behavior.

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Reichow, B., Barton, E. E., Boyd, B. A. & Hume, K. 2012. Early intensive behavioral intervention (EIBI) for young children with autism spectrum disorders (ASD). *Cochrane Database of Systematic Reviews*.

BACKGROUND: The rising prevalence of autism spectrum disorders (ASD) increases the need for evidence-based behavioral treatments to lessen the impact of symptoms on children's functioning. At present, there are no curative or psychopharmacological therapies to effectively treat all symptoms of the disorder. Early intensive behavioral intervention (EIBI), a treatment based on the principles of applied behavior analysis delivered for multiple years at an intensity of 20 to 40 hours per week, is one of the more well-established treatments for ASD.

OBJECTIVES: To systematically review the evidence for the effectiveness of EIBI in increasing the functional behaviors and skills of young children with ASD.

SEARCH METHODS: We searched the following databases on 22 November 2011: CENTRAL (2011 Issue 4), MEDLINE (1948 to November Week 2, 2011), EMBASE (1980 to Week 46, 2011), PsycINFO (1806 to November Week 3, 2011), CINAHL (1937 to current), ERIC (1966 to current), Sociological Abstracts (1952 to current), Social Science Citation Index (1970 to current), WorldCat, metaRegister of Controlled Trials, and Networked Digital Library of Theses and Dissertations. We also searched the reference lists of published papers. Selection criteria: Randomized control trials (RCTs), quasi-randomized control trials, or clinical control trials (CCTs) in which EIBI was compared to a no-treatment or treatment-as-usual control condition. Participants must have been less than six years of age at treatment onset and assigned to their study condition prior to commencing treatment.

DATA COLLECTION AND ANALYSIS: Two authors independently selected and appraised studies for inclusion and assessed the risk of bias in each included study. All outcome data were continuous, from which standardized mean difference effect sizes with small sample correction were calculated. We conducted random-effects meta-analysis where possible, which means we assumed individual studies would provide different estimates of treatment effects.

MAIN RESULTS: One RCT and four CCTs with a total of 203 participants were included. Reliance on synthesis from four CCTs limits the evidential base and this should be borne in mind when interpreting the results. All studies used a treatment-as-usual comparison group. We synthesized the results of the four CCTs using a random-effects model of meta-analysis of the standardized mean differences. Positive effects in favor of the EIBI treatment group were found for all outcomes. The mean effect size for adaptive behavior was $g = 0.69$ (95% CI 0.38 to 1.01; $P < 0.0001$). The mean effect size for IQ was $g = 0.76$ (95% CI 0.40 to 1.11; $P < 0.0001$). Three measures of communication and language skills all showed results in favor of EIBI: expressive language $g = 0.50$ (95% CI 0.05 to 0.95; $P = 0.03$), receptive language $g = 0.57$ (95% CI 0.20 to 0.94; $P = .03$), and daily communication skills $g = 0.74$ (95% CI 0.30 to 1.18; $P = 0.0009$). The mean effect size for socialization was $g = 0.42$ (95% CI 0.11 to 0.73; $P = 0.0008$), and for daily living skills was $g = 0.55$ (95% CI 0.24 to 0.87; $P = 0.0005$). Additional descriptive analyses of other aspects related to quality of life and psychopathology are presented. However, due to the inclusion of non-randomized studies, there is a high risk of bias and the overall quality of evidence was rated as 'low' using the GRADE system, which rates the quality of evidence from meta-analyses to determine recommendations for practice.

AUTHORS' CONCLUSIONS: There is some evidence that EIBI is an effective behavioral treatment for some children with ASD. However, the current state of the evidence is limited because of the reliance on data from non-randomized studies (CCTs) due to the lack of RCTs. Additional studies using RCT research designs are needed to make stronger conclusions about the effects of EIBI for children with ASD.

Keenan, M. & Dillenburger, K. 2011. When all you have is a hammer RCTs and hegemony in science. *Research in Autism Spectrum Disorders*, 5, 1-13.

People diagnosed with autism spectrum disorder (ASD) deserve the same respect as any other person and should be free to benefit from scientific research that can help them achieve skills which enable them to reach their full potential. Over the past 40 years Applied Behaviour Analysis (ABA) has utilised inductive, natural science methods to investigate techniques for the analysis and augmentation of socially significant behaviours. Unfortunately, many individuals with ASD in the UK cannot avail of these techniques because of an obdurate reliance on randomised controlled trials (RCTs) as the single most respectable measure of effectiveness of interventions. In this paper we focus on how the debate about RCTs is played out in the 'autism wars'.

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Remington, B., Hastings, R. P., Kovshoff, H., Degli Espinosa, F., Jahr, E., Brown, T., Alford, P., Lemaic, M., Ward, N. & Maclean, J. W. E. 2007. Early Intensive Behavioral Intervention: Outcomes for Children With Autism and Their Parents After Two Years. American Journal on Mental Retardation, 112, 418-438.

An intervention group (n = 23) of preschool children with autism was identified on the basis of parent preference for early intensive behavioral intervention and a comparison group (n = 21) identified as receiving treatment as usual. Prospective assessment was undertaken before treatment, after 1 year of treatment, and again after 2 years. Groups did not differ on assessments at baseline but after 2 years, robust differences favoring intensive behavioral intervention were observed on measures of intelligence, language, daily living skills, positive social behavior, and a statistical measure of best outcome for individual children. Measures of parental well-being, obtained at the same three time points, produced no evidence that behavioral intervention created increased problems for either mothers or fathers of children receiving it.

Dawson, G., Rogers, S., Munson, J., Smith, M., Winter, J., Greenson, J., Donaldson, A. & Varley, J. 2010. Randomized, Controlled Trial of an Intervention for Toddlers With Autism: The Early Start Denver Model. Pediatrics, 125, e17-e23.

OBJECTIVE: To conduct a randomized, controlled trial to evaluate the efficacy of the Early Start Denver Model (ESDM), a comprehensive developmental behavioral intervention, for improving outcomes of toddlers diagnosed with autism spectrum disorder (ASD). **METHODS:** Forty-eight children diagnosed with ASD between 18 and 30 months of age were randomly assigned to 1 of 2 groups: (1) ESDM intervention, which is based on developmental and applied behavioral analytic principles and delivered by trained therapists and parents for 2 years; or (2) referral to community providers for intervention commonly available in the community. **RESULTS:** Compared with children who received community-intervention, children who received ESDM showed significant improvements in IQ, adaptive behavior, and autism diagnosis. Two years after entering intervention, the ESDM group on average improved 17.6 standard score points (1 SD: 15 points) compared with 7.0 points in the comparison group relative to baseline scores. The ESDM group maintained its rate of growth in adaptive behavior compared with a norma-

tive sample of typically developing children. In contrast, over the 2-year span, the comparison group showed greater delays in adaptive behavior. Children who received ESDM also were more likely to experience a change in diagnosis from autism to pervasive developmental disorder, not otherwise specified, than the comparison group. **CONCLUSIONS:** This is the first randomized, controlled trial to demonstrate the efficacy of a comprehensive developmental behavioral intervention for toddlers with ASD for improving cognitive and adaptive behavior and reducing severity of ASD diagnosis. Results of this study underscore the importance of early detection of and intervention in autism.

The parent who gave you this leaflet is happy to be a contact for other families seeking advice about ABA - see name and phone number below:
