



Science in Autism Treatment

Newsletter of the Association for Science in Autism Treatment

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On behalf of ASAT, I hope 2018 has brought you good things thus far. I also hope that this year will bring to all a deeper appreciation for the relevance of science in both grounding and guiding autism treatment, greater expectations of accountability from treatment providers regardless of their discipline, and greater accuracy within media portrayals of autism treatment. Collectively, I hope this would result in heightened awareness of the pitfalls, costs, and risks of pseudoscience; for there are, sadly, quite many.

The sad reality is that in contrast to many other disorders, parents of children with autism continue to have to work harder to identify and access effective interventions supported by scientific research. The Internet has an abundance of misinformation and marketing ploys, and media representations that are sometimes inaccurate and, at times, misleading. At ASAT, we truly believe that **parents deserve access to a community that values science over profit, expects accountability from treatment providers, and gravitates towards methods already proven to be effective.**

As you may recall, I shared many of our 2017 accomplishments in the Fall 2017 issue of *Science in Autism Treatment (SIAT)*. As we welcome in the new year, we are anticipating an even more productive 2018. Therefore, it is with great pride and optimism that I outline an array of goals and initiatives for 2018:

- Increase *SIAT* subscribers to 13,000 targeting underserved areas in the US and abroad.
- Increase our Facebook fans and Twitter followers.
- Expand ASAT's presence on quality autism community blogs.
- Identify and develop collaborative relationships with other organizations that share our values and commitment to science.
- Increase ASAT's presence at state, regional, national, and international conferences.

Table of Contents

Celebrating 20 years Together in Science	3
Clinical Corner: Problem Behavior Triggered by Specific Words	5
From the Archives: Discussing Medication Recommendations With the Doctor	9
Research Summaries: Atomoxetine and Parent Training Early Intervention and Normalized Brain Activity	13
Fundraising: Victoria Autism Expo	16
Media Watch ASAT Responds to The Inquirer's, "Falling Off the Cliff"	18
Is There Science Behind That?: Autism and Treatment with DIR/Floor Time	20
How ASAT Supports Column	24
Our Volunteers	25
Sponsorship Campaign	26
Professional Sponsors	27
Donor Wall 2017	28

(Continued on page 2)

(Continued from page 1)

- Continue to develop our website and newsletter content specific to medical providers, particularly pediatricians and family practice doctors.
- Continue to provide information regarding ASAT and autism to ABA faculty, special education, psychology, and speech pathology programs nationwide.
- Continue to publish synopses of research to keep up with the growing number of studies on interventions for autism.
- Continue to expand treatment summaries.
- Develop a resource booklet for parents of newly diagnosed children with autism available free online and in print and distribute a resource booklet to international journalists.
- Continue to expand our website pages for parents with a newly-diagnosed child, parents of older children and adults, and media professionals.
- Create Public Service Announcements in Spanish.
- Increase grant submissions to support our work.
- Tap more extensively into the wealth of experience and expertise of our Advisory Board members.
- Increase number of *Media Alert* posts in response to accurate/inaccurate portrayals of autism treatment, with heightened focus on international topics, biomedical advances and lifespan considerations.
- Prepare new monthly blogs with Different Roads to Learning (DRL).
- Implement 2018 strategic plan for our 20th anniversary.

Thank you for your support in the year ahead.

Yours in science,



David Celiberti, PhD, BCBA-D
Executive Director and
Co-Editor of *Science in Autism Treatment*

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CELEBRATING 20 YEARS TOGETHER IN SCIENCE

Zachary Houston, MS, BCBA



For two decades we have stood together in support of science. Since our first issue in 1999 we have **worked with you to adopt higher standards of accountability for the care, education, and treatment of individuals with autism.**

Since ASAT's inception, our all volunteer board has published [43 newsletters](#) with the latest information for individuals with autism, their families, and the practitioners who support them. Today, we continue this tradition with an issue that facilitates conversations between adolescents and providers, explores trigger words plaguing our community, and delves into the extent of the scientific support for Floortime.

Twenty years and dozens of newsletters later, the Science in Autism Treatment Newsletter remains an irreplaceable resource for learning more about the different treatments available for autism. More importantly, as new fad treatments are "discovered" every day, we are reminded that our vigilance cannot waver. **With 500 "treatments" marketed to people with autism and their families, we know that our shared efforts are of critical importance. To date, our impacts include:**

- ★ [178 Media Watch articles](#) published, holding the media accountable for responsible reporting of autism issues and applauding those that highlight science in their writing.
- ★ 100 countries represented in our subscriber base, ensuring safe, effective, science-based treatments are reaching the far corners of the world.
- ★ [Over 12,000 Facebook fans](#), advocating and engaging around the importance of science in autism.

This year, you will see exciting new initiatives from ASAT and continued progress with our ongoing projects, including a **Public Service Announcement on ASAT's work and resources, a resource booklet for parents of newly diagnosed individuals with autism, and a journalist's resource booklet.** We also continue to expand our reach through the newsletter, social media, and website.

None of this work would be possible without the support of our donors and subscribers. As one subscriber recently commented, **"This is the way to improve lives."** Or, as put by another commenter, **"A diagnosis of autism comes with so many worries and questions...it's nice to have a place to go for some science and data based answers."** Our success is your success, and together we will continue to promote safe, effective, science-based treatments for people with autism. Here's to another 20 years together!

Zachary Houston, MS, BCBA
President, ASAT



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CLINICAL CORNER

PROBLEM BEHAVIOR TRIGGERED BY SPECIFIC WORDS

Mary E. McDonald, PhD, BCBA-D, LBA

Many families and professionals encounter situations in which they must manage challenging behaviors in response to seemingly innocuous and idiosyncratic situations. Determining how best to address these challenges can be difficult without a resource for clinical direction. Here, Dr. Mary McDonald provides expert advice on the assessment and treatment of problem behaviors that occur in response to "trigger words" an individual hears in the environment.

Kate Fiske, PhD, BCBA-D
Clinical Corner Co-Coordinator



I have an adolescent with autism in my class who responds negatively when people say certain words. He seems to have a sensitivity to them and may respond with a behavioral outburst. Have you heard of this happening with other students with autism and do you have any thoughts on intervention?

Answered by:

Mary E. McDonald, PhD, BCBA-D, LBA
Hofstra University/Eden II Genesis Programs

This negative response to certain words, or "trigger words," that you describe can be a real problem for individuals with autism and their families. Individuals with autism may react to a particular word or set of words when they are said by familiar and unfamiliar people in their environment. The way in which they react may vary and can range from verbal protesting or body tensing to an extreme behavioral outburst including aggression, self-injury or destructive behavior. This response to trigger words can have a great impact on the person's ability to interact with

others, participate in social situations, and be involved in the community or at a job site.

Some examples are:

- *A student is with his class shopping at the supermarket and the cashier says, "Thank you." The student stomps his feet in reaction to hearing "thank you" and the staff quickly escorts him from the store before the behavior escalates.*
- *A family is at a restaurant and someone at another table says "Wow, that's beautiful" in conversation. The child starts to yell in response to the word "wow" and the parents attempt to distract the child from the conversation at the other table.*

Assessment

As with any behavior, it is important to assess the situation to be better able to provide an appropriate intervention. The function of the problem behavior can be assessed through a functional behavior assessment (FBA) (Alter, Conroy, Mancil, & Haydon,

(Continued on page 6)

(Continued from page 5)

2008). Function of behavior can be determined through interviews, structured observations and the collection and analysis of data to identify patterns in the behavior. Data can also be recorded on possible trigger words to determine the frequency, intensity and latency of behavior in response to various words (data collection considerations will be shared later).

If you have already conducted an FBA and determined that the trigger words have frequently been the antecedent to the behavior of concern, the question then becomes *why* do these words serve as an antecedent to this behavior? While it is true that there may be a reason, it is not always apparent what the reason is. For example, it may be that the student had a history with denial of a reinforcer paired with a specific word such as “later,” or demands were consistently paired with words such as “Let’s go.” In these cases, the words could have become aversive to the student through frequent pairings. However, you may not be able to determine what caused the word to become a “trigger word.” While knowing the history can be helpful for preventing future trigger words from developing, it is still possible to treat the behavior without knowing the initial reason the word became an antecedent for challenging behavior.

To further assess, you may want to observe how the student responds to the trigger word in various conditions. For example, you can analyze the occurrence of behavior based on who says the word (familiar or unfamiliar person), if it is spoken directly to the student or overheard, the setting in which the student reacts to a trigger word, and the ongoing activity (preferred or non-preferred). You can also assess the student’s reaction to various forms of the word (written word, spoken word, word in a sentence) to help plan for desensitization training. One can also assess whether a cumulative effect is observed (i.e., the first instance of the trigger word does not occasion the behavior; however, multiple instances of the trigger word cause the student to react). All of these factors can be reflected as columns on your ABC data sheet.

Comorbidity. The complexity of this behavior requires us to look at other factors that may affect its occurrence. Considerable evidence suggests that children and adolescents with autism spectrum disorders

(ASD) are at increased risk of anxiety and anxiety disorders (Ghaziuddin, 2002) and this may worsen during adolescence. Children with autism may display problematic emotional reactions and behaviors when faced with social situations (Lainhart, 1999). It is important to consider the possibility that the trigger words function as stimuli that increase the student’s anxiety. Behaviors associated with anxiety can appear on your ABC data sheet.

Researchers are attempting to study co-morbidity in individuals with autism. Leyfer et al. (2006) studied various disorders associated with autism. They found that specific phobia was the most common disorder (in 44% of participants) found in individuals with ASD, and even higher prevalence rates have been reported in other studies (Muris et al., 1998). There are a number of specific phobias that relate to words, including nomotophobia (fear of names) and verbotophobia (fear of words). Onomatophobia is an irrational or compulsive fear of hearing certain words. However, there is little research on this phobia and no research in relation to individuals with autism to date.

The second most frequent disorder found in the study was obsessive compulsive disorder (OCD), diagnosed in 37% of the children with autism (Leyfer et al., 2006). The most common type of compulsion was a ritual involving others. About 50% of the children diagnosed with OCD had compulsions that involved others having to do things a certain way. Examples included:

- Parents having to perform certain daily routines
- An adult having to act or respond in a certain way
- An adult having to respond to repeated questions

What was most interesting about the findings is that the two most frequent compulsions involved attempts to control the behavior of others. Given this, it is plausible that for some children with autism and OCD, the problem behavior that occurs in response to the trigger words may be attempts to control what is said by others. However, again, no research specifically addresses trigger words as an antecedent to behavior in children with OCD or autism.

(Continued on page 7)

(Continued from page 6)

Data Collection

When collecting data on behavior in reaction to trigger words, a frequency measure can be used but it may not provide you with the most accurate data. These data may be misleading as it can depend on how often the trigger word is heard by the student. Instead, it may be more accurate to record occurrence as a percent per opportunity, where an opportunity is when the trigger word is heard by the student. With this data, one can see the percentage of the time the student responds to the trigger word. It may also be helpful to note the time that the student hears each instance of the trigger word to determine if the student's reaction occurs after the first occurrence or after a number of occurrences indicating a more cumulative effect of the words on behavior.

Treatment Considerations

Prevention. Often the first reaction to increased problem behavior in response to trigger words is to prevent the behavior from occurring by avoiding the antecedent entirely. Therefore, adults may refrain from saying trigger words or reacting negatively to trigger words when they are spoken. However, the issue in this case is that it is not so easy to simply remove the antecedent from the environment. First, it is unlikely that someone can truly remove a word from their vocabulary consistently. Second, outside of the small circle of family and therapists, there are many people the individual will come in contact with whose behavior is not easily controlled.

Predictability and preparation. Predictability and preparation may be more viable options in reducing behavior. Predictability can be used by letting the individual know that the word is going to be used, similar to how you would warn a student with autism that the fire alarm is going to ring if preparing him for the aversive stimulus. This can be done verbally or with a non-verbal signal or visual cue. This warning may be one part of an intervention package. Preparation can also be used to prepare the student for when he/she is going to be in a community location where it may be likely that the student will hear a trigger word. For example, a student may choose to wear headphones while in the community.

Generalization. We know that newly acquired responses may be controlled not only by the original stimulus but also by others resembling those stimuli (Stokes & Baer, 1977). Therefore, it is possible that the problem behavior may generalize from the original trigger word to new but similar words. As a result, assessing responses to similar words could also be important so that generalized words can also be included in treatment from the onset. Generalization can also occur from one person to another and to novel settings, which could be considered during assessment.

Interventions

Systematic desensitization/exposure. The student may be able to learn to better tolerate the trigger words through systematic desensitization (Grös & Antony, 2006). In this behavioral intervention, the student is gradually exposed to the stimulus through a hierarchy of antecedents that increase in aversiveness based on the individual's behavioral response to the various steps. For example, desensitization may begin with the use of technology in the form of video or a virtual environment in cases where this presentation is more tolerable for the individual (Mager, Bullinger, Mueller-Spahn, Kuntze, & Stoermer, 2001). Providing reinforcement for successfully tolerating aversive stimuli is a key component of this procedure.

Sample desensitization steps for a student:

- Student hears audio recording of trigger word by unfamiliar person
- Student hears an app label the trigger word paired with a sight word presentation
- Student reads trigger word presented on a flashcard
- Student hears the trigger word stated aloud by a familiar staff person

Stimulus pairing and reconditioning. Another approach is to recondition the trigger words so that they do not evoke a negative behavioral response.

(Continued on page 8)

(Continued from page 7)

One can attempt to do this by pairing the trigger words with a preferred stimulus. For example, a slideshow in which videos of someone saying trigger words are interspersed with preferred videos (music, movie clips) could be used to pair the aversive stimulus with more preferred stimuli. Alternatively, the student could be engaged in a preferred activity when the trigger word is used (e.g., student is playing on the iPad) or the trigger word can be said while presenting a preferred item to the student (e.g., “Wow, I love chocolate, too”).

Functional communication training. Functional communication training (FCT) has been a highly successful approach for replacing challenging behavior with communication in students with ASD. As an example, Rispoli, Camargo, Machalicek, Lang, and Sigafoos (2014) demonstrated the effectiveness of FCT with students with ASD for behavior that was ritualistic in nature. It may be possible to teach the student some form of communication that may help him or her to communicate rather than engage in challenging behavior when a trigger word is heard. The individual may not be able to completely avoid hearing trigger words, but may be able to ask to leave a particular area, such as a crowded area with high probability of trigger words.

Summary

When working with a student with ASD engages in behavior related to trigger words, it will be important to acknowledge the complexity of this behavior. Consider conducting a thorough and ongoing assessment to determine the most appropriate interventions to best meet the needs of the individual, while always remembering the importance of data collection and data analysis to help guide decision making.

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FROM THE ARCHIVES

CLINICAL CORNER: DISCUSSING MEDICATION RECOMMENDATIONS FOR YOUR CHILD WITH YOUR HEALTHCARE PROVIDER

Megan Atthowe, MSN, RN, BCBA

What should you do when your child's doctor recommends trying medication? For a parent of a child with ASD, it can be extremely difficult to know the questions to ask and what information should be prepared in order to have these important discussions with your child's physician. In this installment of *From the Archives*, Megan Atthowe, a Registered Nurse and Board Certified Behavior Analyst, provides insight for parents and professionals on a variety of approaches that parents can take when medication is recommended for their child. Included, you will find a helpful list of key questions to ask and recommendations on how to best prepare.



Caroline Simard, MS, BCBA
From the Archives Coordinator

My son, who has been diagnosed with autism, has been struggling with self-injury. His doctor is considering whether medication could help. What can I do to prepare for this conversation?

Answered by Megan Atthowe, MSN, RN, BCBA

First, you should know that there is no medication that specifically treats autism. Medications approved by the United States Food and Drug Administration (FDA) for other conditions can be useful only to lessen certain symptoms. That said, off-label use of pharmaceuticals is by no means unique to autism and is common practice for many health conditions. While research on the use of medications with individuals with autism is growing, our body of knowledge is still limited. In addition, medications affect every individual differently. Children can respond differently to medications as they grow and develop, so it is likely to take time to find the best medication at the appropriate dose. In other words, medication management is a highly individualized,

complex, and continual process. It is a good idea to be prepared with the right information before your visit to your healthcare provider.

Second, you should know that if a child with autism shows a sudden onset of self-injurious behavior, it is urgent to rule out a medical explanation. The behavior may relate to pain from a medical issue (e.g., ear infection, reflux, constipation, dental pain). Please discuss this with your son's health care provider.

Third, do you know how often the self-injurious behavior occurs and what function(s) it may serve for your son? Frequency and/or intensity data, a specific definition of what the behavior looks like, and an understanding of the behavior's function will enable your child's team to treat the behavior more effectively, and it is helpful to share this information with

Medication management is a highly individualized, complex, and continual process.

(Continued on page 10)

(Continued from page 9)

your son's health care provider.

I encourage you to ask your son's teachers to share any information they have about the self-injurious behavior with your healthcare provider. For example, your son's teacher could provide the data gathered in the classroom for you to bring to your visit. Note that he or she would need your consent to talk to your healthcare provider or to share any confidential information such as behavior data. If your son's educational team is not already collecting data on this behavior, please ask them to start right away.

If you have not been keeping track of the self-injurious behavior at home, please start right away, even if there are only a few days until your visit. An easy way to do this would be to use a calendar or notebook. Record specifics about the incidents. You can do this by describing the behavior, listing specific triggers or antecedents that may have been present (i.e., what happened right before the behavior), recording how long each episode lasts, recording the time of day they occur, and indicating how you responded to it. Your son's teacher likely has a form that you can use and may have suggestions on how to carry out good record taking. Include any recent changes in the behavior you have noticed. It is difficult for anyone to recall these details accurately, especially if the behavior happens frequently, so writing them down right after the behavior occurs will help you share the most meaningful information you can with your healthcare provider.

In addition to writing down information about the current levels of the behavior, be prepared to describe how the school and your family are addressing the behavior and how long that plan has been in place. Some questions that would be helpful to consider include:

- Has your son's educational team considered a functional behavior assessment or used applied behavior analysis (ABA) to target the behavior?
- Does your child have an IEP (Individualized Education Program)? Does it include a formal be-

havior reduction plan?

- Is your son receiving other therapies (e.g., speech therapy, physical therapy, occupational therapy)? Are those providers collecting data and/or implementing coordinated behavior management strategies?

Research supports ABA as an effective intervention for decreasing problem behaviors, such as self-injury, as well as for teaching new skills to children with autism. It is important to ensure that a qualified behavior analyst is supervising all ABA interventions, as they must be implemented correctly to be effective and safe. Your healthcare provider may be able to refer you to a local ABA provider, or you can find a list of Board Certified Behavior Analysts (BCBAs) at the [Behavior Analyst Certification Board's website](#).

Before your visit to the healthcare provider, prepare a list of names and doses of any medications your

son takes, as well as any over-the-counter medications, vitamins, or other supplements. If your son receives any therapies such as ABA, speech therapy, etc., share that information too. The health care provider will want to ensure that any new medication is safe to

take and will not interact negatively with other medications or therapies.

If you and your healthcare provider decide to start your son on medication, decide beforehand what the goal is for the course of the medication. How will you know when the medication has been effective? How will you know if it is ineffective? Be specific and write the goal(s) down. Schedule a follow up appointment where you will check in with your healthcare provider on your son's progress. He or she may have specific suggestions about what type of data to keep.

There are some important questions you should have answered before you leave the medical office. Make sure you ask any questions you have and restate the doctor's recommendations; a responsible health care provider will want to know you understand how to

(Continued on page 11)

Research supports ABA as an effective intervention for decreasing problem behaviors, such as self-injury, as well as for teaching new skills to children with autism.

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use the new medication correctly.

Key Questions:

- Have medical factors that may cause or worsen self-injury been considered and ideally ruled out?
- What is the name of the medication?
- What is the medication used for?
- When and how should I give it to my son, and how much do I give?
- Should I give this medication with food?
- What desired effects should I expect to see?
- What are the common side effects?
- How long will it be until I notice the desired effects and side effects?
- What side effects are serious, and what should I do if I notice them?
- Will side effects lessen over time?
- Are there any food or drinks I should avoid giving my son while he is on this medication?
- If I decide that I would like to stop giving him

the medication, what should I do?

- What should I do if I miss a dose?

Although you did not mention if your son is on any other medication, again, it would be important to ask about any drug interactions that may occur. In addition, ask your health care provider to provide a note for your son's school describing any new medication or treatment. Teachers, therapists, and other members of the team should be informed to watch out for potential side effects. There may also be other aspects of the self-injurious behavior to assess and track through ongoing data collection.

Finally, if you think of questions later, do not hesitate to call and ask your physician, nurse, or pharmacist. Please note that there is information about research related to medications on the [ASAT website](#). Please visit our '[Treatment Summaries](#)' page on [medication](#) for more details. Again, I encourage your son's team to conduct a functional behavior assessment and develop a formal behavior plan as needed based on the assessment findings.

Megan Atthowe, MSN, RN, BCBA, LBA, is a registered nurse and behavior analyst who has worked with people with autism and other special needs in educational, home, and healthcare settings for over 15 years. She currently provides behavioral consultation and specialist services for students with autism served in a public school district.

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RESEARCH SUMMARIES

ATOMOXETINE, PARENT TRAINING AND THEIR COMBINATION IN CHILDREN WITH AUTISM SPECTRUM AND ADHD.

&

EARLY BEHAVIORAL INTERVENTION IS ASSOCIATED WITH NORMALIZED BRAIN ACTIVITY IN YOUNG CHILDREN WITH AUTISM

In this issue of SIAT, we summarize two studies. The first looks at the effects of a non-stimulant medication on treating ADHD symptoms in children with ADHD co-occurring with ASD. The second looks at the impact of the Early Start Denver Model (ESDM), a developmental behavioral intervention, on brain activity in toddlers with ASD. This ESDM study was already summarized in our Summer 2017 newsletter. Here, it is summarized by a second reviewer. We thought it might be interesting to see a second take on an important article. As always, we hope the information is useful to you.

Karen Fried, PsyD, BCBA-D
Research Synopses Co-Coordinator

Handen, B. L., Aman, M. G., Arnold, L. E., Hyman, S. L., Tumuluru, R., Lecavalier, L., . . . & Smith, T. (2015). Atomoxetine, parent training and their combination in children with autism spectrum and ADHD. *Journal of the American Academy of Child and Adolescent Psychiatry*, 54(11), 905-915.

Reviewed by:
Jennifer A. Scalera, Seton Hall University

Why research this topic?

Observed in about one-third of cases, attention deficit/hyperactivity disorder (ADHD) is one of the most common co-occurring conditions in children with autism spectrum disorder (ASD). Previous studies have demonstrated that children with ASD are being treated for ADHD symptoms, often accompanied by noncompliance, oppositional behavior and irritability, using stimulant medication. However, data show that the effectiveness rates of stimulants in children with ADHD and ASD are well below effectiveness rates in typically developing children with ADHD without ASD. In addition, side effects to stimulants are four times higher in the ASD population. The current study investigated the

effectiveness of atomoxetine, a non-stimulant medication for ADHD, in isolation and in combination with parent training for treating ADHD symptoms in children with ADHD co-occurring with ASD.

What did the researchers do?

The researchers examined the individual and combined effectiveness of atomoxetine and individualized, one-on-one parent training for ADHD symptoms and noncompliance in children also diagnosed with ASD. All participants in the study exhibited symptoms of overactivity and/or inattention, and met criteria for ASD. 128 children (ages 5-14), both male and female, were randomly assigned to one of four treatment groups: atomoxetine alone, atomoxetine + parent training, placebo + parent training, or placebo alone. The study was conducted for 10 weeks across three different sites. Families who were assigned to parent training met with a clinician for 60-90 minutes weekly, and sessions covered topics such as preventing problem behaviors, reinforcement, time out procedures, and planned ignoring. Medication dosages were monitored/adjusted accordingly by the study medical providers, and families kept a daily

(Continued on page 14)



(Continued from page 13)

medication log to assess medication compliance. Parents and teachers completed behavior rating scales prior to intervention to assess their child's pre-treatment symptoms and levels of noncompliance and again at the completion of the intervention phase.

What did the researchers find?

After concluding the study, researchers found that atomoxetine was an effective, non-stimulant treatment for ADHD symptoms in children with ASD, though it was associated with decreased appetite and abdominal pain in some children. In addition, parent training showed greater effectiveness than placebo alone. Contrary to the hypothesis of the researchers, the combination of parent training and atomoxetine was no more effective than atomoxetine alone. Since parent training alone was beneficial to the participants, is cost efficient, and can be used in an outpatient setting, it might be a viable treatment option for children with ASD and ADHD symptoms whose parents are not interested in pharmacological treatment.

What are the strengths and limitations of this study?

This study was the first to investigate the separate and combined effects of a non-stimulant medication and a psychosocial intervention on the treatment of ADHD symptoms and noncompliance in children with ADHD and ASD through a large sample, double-blind, group design. Limitations of the study included a lack of ethnic and cultural diversity of the participants, reliance on parent rating scales instead of data-based observations of behavior and the parent training intervention being limited to only a 10-week trial.

What do the results mean?

Overall, based on the results of the study, the researchers suggest that the use of the non-stimulant medication, atomoxetine, may be a viable alternative to stimulant medication in the treatment of ADHD symptoms in children with a diagnosis of ASD. In addition, because the results showed benefits from parent training alone, parents of children with ASD

who disagree with the use of pharmacological intervention should investigate the possibility of using a psychosocial intervention such as parent training for the treatment of co-occurring ADHD symptoms.

Dawson, G., Jones, E. J., Merkle, K., Venema, K., Lowy, R., Faja, S., . . . Webb, S. J. (2012). Early behavioral intervention is associated with normalized brain activity in young children with autism. *Journal of the American Academy of Child and Adolescent Psychiatry*, 51(11), 1150-1159.

Reviewed by:

Audrey Torricelli, Rutgers University

Why study this topic?

The Early Start Denver Model (ESDM) is a behavioral intervention for toddlers diagnosed with autism spectrum disorder (ASD). A previous randomized control trial demonstrated that children who received ESDM for two years improved in IQ, language, adaptive behavior, and ASD diagnosis compared to children who received a more commonly available community intervention. The researchers of the current study were interested in how early intervention with ESDM can alter the trajectory of brain development. They hypothesized that the lack of affective and social engagement in children with ASD may hinder behavioral and brain development, and that increasing such engagement through early intervention could lead to a more typical trajectory of brain development.

What did the researcher do?

The researchers recruited young children with a diagnosis of ASD or Pervasive Developmental Disorder (PDD) as well as age-matched typically developing peers. The children with ASD were randomly assigned into either the ESDM group or a community intervention (CI) group. ESDM is a treatment that combines developmental and applied behavior analysis strategies and that involves trained therapists – with experienced PhD-level supervisors – following a manual and curriculum providing 4 hours of intervention twice a day, five days a week, for two years, with additional parent training. The CI

(Continued on page 15)

(Continued from page 14)

group received comprehensive diagnostic evaluations with intervention recommendations, community referrals, and other resources. The researchers also used behavioral measures like the Autism Diagnostic Interview (ADI)-Revised, the Autism Diagnostic Observation Schedule (ADOS), the Mullen Scales of Early Learning (MSEL), the Vineland Scales of Adaptive Behavior, and the Pervasive Developmental Disorder Behavior Inventory (PDDBI) before and after the intervention to assess ASD symptoms and adaptive skills. All child participants in the study also underwent electroencephalography (EEG) observation, with 60% of the participants providing artifact-free (i.e., useable) data. Artifacts were caused primarily by excessive movement or inability to comply with the procedure. During the EEG procedure, children observed unique color photographs of toys and diverse female faces presented randomly on a screen. Researchers were interested in the neural activity in several brain areas while participants engaged in the task.

What did the researchers find?

The researchers found group differences in the central and anterior brain regions of participants when looking at people as compared to objects. The ESDM and typically developing groups showed greater cortical activation for and faster attention to faces, whereas the CI group showed greater activation for and faster attention to objects. These results did not differ by age. While ESDM and typical groups did not differ from one another, the ESDM and CI groups did differ. The researchers also

found that ESDM children who provided usable EEG data demonstrated improved autism symptoms, higher verbal and nonverbal IQ, better adaptive skills, and more social behavior with intervention. Greater attention to faces in the ASD groups (ESDM and CI) during the EEG task was correlated with better social communication abilities, and greater brain activation was correlated with fewer social pragmatic problems (like understanding social convention and initiating social interactions).

What were the strengths and limitations of the study? What do the results mean?

The authors suggest that children with ASD may have a delay in developing expertise for face acquisition, but that high rates of intervention can help these children acquire the face-processing abilities of their typically developing peers. This study supports the effectiveness of the ESDM model in developing social attention engagement, as evidenced on both the neural and behavioral levels. There are some limitations to this study: Only about 60% of children with ASD provided artifact-free EEG data, which limits the strength of the study's conclusions and its applicability to a wide range of children with ASD. Additionally, there was only one time point for EEG measurements; having a pre- and post-intervention design would enable researchers to examine to what degree changes may be attributable to the intervention. Finally, larger samples are needed, and the strength of these findings needs to be verified through replication. Even so, this study suggests that early interventions may have a positive effect on the social development of children with ASD.



FUNDRAISING

ASAT PARTICIPATES IN VICTORIA AUTISM EXPO

Franca Pastro, BA

The Victoria Autism Expo in British Columbia, Canada, was held on February 3rd, with a great turnout of parents, grandparents and professionals attending. It was an emotional experience for me to meet so many parents and family members who had their own individual stories to share. These stories showed not only their strong commitment to helping their children diagnosed with autism, but also their frustration and confusion in trying to navigate through the overwhelming myriad of information about therapies and services. This experience made me even more passionate about the work we do at ASAT. It further reinforced my belief in the value of ASAT's resources to these individuals.



Board Member and *Perspectives* Coordinator Franca Pastro at the Fair representing ASAT.



Newly Diagnosed?

Jane Asher discusses the challenges facing parents of newly diagnosed children with autism.

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MEDIA WATCH FEATURED LETTER

ASAT RESPONDS TO THE INQUIRER'S, "FALLING OFF THE CLIFF"

Mary Jane Weiss, PhD, BCBA-D

Maggie Haag, LSW

Rita M. Gardner, MPH, LABA, BCBA

Through our Media Watch initiative, we provide written feedback to journalists and other media professionals who write about autism and its treatment. We strive to acknowledge the efforts of those individuals responsible for educating the public with sound, accurate information. When an autism intervention is portrayed inaccurately, we provide feedback to encourage correction and suggest consideration when writing future articles. In this issue we feature a [letter to The Inquirer](#) about services for individuals with disabilities post school-age. You can check all past letters here: www.asatonline.org/for-media-professionals/media-watch/.

Renee Wozniak, PhD, BCBA-D, LBA
Media Watch Lead



Dear Ms. Polaneczky,

In response to your four-part series titled "Falling Off the Cliff," that was recently published in The Inquirer, we would like to share our feedback regarding several main points of your article. You highlighted important experiences of adults with disabilities and their families, including the long wait list for funding resources for adults in Pennsylvania, the barriers that occur when school-aged entitlements end and the Adult Services system begins, and the need for better trained and better paid direct support staff, to name a few.

While we emphatically agree with all of these points, and are equally concerned about the difficulties that are faced by adults with disabilities and their caregivers, we also feel it is important to point out that there is a body of literature that exists to inform the field of how to address many of these issues, including staff training, professional development, and transition services for students with disabilities, that should be adopted as industry standards. Additionally, there are federally funded programs of which all school districts need to be aware to support the transition process for their students as outlined below.

Your article rightfully points out the perils of adults with disabilities and their families when school-aged entitlements end. However, it is important to note that the ending of these entitlements can be planned for with appropriate attention to transitional needs. The Federal law, entitled Individuals with Disabilities Education Act (IDEA) [1], requires schools to provide transition planning for students with disabilities. IDEA "includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and, when appropriate, acquisition of daily living skills and functional vocational evaluation" (IDEA, 2004). Furthermore, research supports practices that aid in successful transition services for students, including use of scientifically-based strategies to promote independence (Schall, Wehman, & McDonough, 2012). Providing students with the skills necessary for adulthood can decrease the crisis families face as they wait for access to funding. Additionally, school

(Continued on page 19)

(Continued from page 18)

districts becoming educated on the funding options for adults with disabilities to help families prepare is critical, including not only an understanding of Medicaid Waiver options, but also Vocational Rehabilitation funding [2]. This requires that PA school districts provide educational services to students with disabilities that give each student the opportunity to make meaningful and “appropriately ambitious” progress as indicated in the recent Supreme Court decision *Endrew F. v. Douglas County School District* during their IEP years. The absolute best preparation for a meaningful life starts with providing an exceptional education for all children [3].

Your article also discusses the challenges of “finding good help,” and the low wages of the direct support staff. While we support the need for a better-paid work force, it is important to point out that it will take more than better pay to have a highly skilled workforce, in addition to the professional career path you wisely point out is missing in many organizations. Better education, credentials, training and supervision for direct support staff, and more training and support for front line managers, are critical to improve the quality of care for adults with disabilities. Fortunately, there is sound research supporting best practices in staff training and supervision. Ensuring employees have been trained to competency on their job responsibilities is a very important process in direct care staff training (Reid, Parsons & Green, 1989; Chok, Shlesinger, Studer, & Bird., 2013), however, traditional classroom-based training has been shown to be ineffective by itself (Fleming & Sulzer-Azaroff, 1989). Research indicates that classroom-based training, such as lectures and presentation of written material, is not effective in permanently changing or improving workplace behaviors (Alavosius & Sulzer-Azaroff, 1990), yet many organizations continue to use didactic, classroom training with little generalization to on-the-job work skills (Parsons, Rollyson, & Reid, 2012). While training using presentations and written materials can increase knowledge in certain areas, and can be important for certain knowledge requirements, it does not typically increase performance in targeted skills, which is the biggest need area for direct support staff (Parsons, Rollyson, & Reid, 2012). Skill-based competency training that includes modeling and performance feedback is necessary for effectively teaching skills (Roscoe, Fisher, Glover, & Volkert, 2006; Maguire, Weiss, & Bird, 2015). More support and funding for human services organizations to implement effective staff training, professional development, and management systems are critical for quality service delivery and prevention of serious incidents, and can decrease the amount of resources devoted to investigating these types of incidents after it has already happened. It is a more effective use of resources to develop high quality services to prevent poor, and in some cases tragic, outcomes, than money spent after these serious incidents occur.

In conclusion, your article highlighted important experiences of families and adults with disabilities that cannot be discounted. Further, you discussed important areas of need within the field of Human Services that are not currently being effectively addressed, but that certainly have the capacity to be addressed given the breadth of literature related to these issues. It cannot fall on one service system to address these enormous needs, and all service systems need to work together to ensure student and adult needs are adequately addressed, starting at the beginning of service delivery. Falling off of a services cliff is not an inevitable outcome for adults with disabilities and their families. Appropriate planning and preparation for adulthood can help to prevent these types of crises from occurring.

Sincerely,

Mary Jane Weiss, Ph.D. BCBA-D

Maggie Haag, LSW

Lifespan Content Co-Coordination, ASAT

& Rita M. Gardner, M.P.H., LABA, BCB

* Reference available on the website: www.asatonline.org/media-watch/asat-responds-inquirers-falling-off-cliff/

IS THERE SCIENCE BEHIND THAT?

AUTISM AND TREATMENT WITH DIR/FLOOR TIME

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Research has repeatedly demonstrated the benefits of early intensive behavioral intervention (EIBI) for children diagnosed with autism spectrum disorders (ASD; e.g., Lovaas 1993). Behavior therapists who provide EIBI often work in settings where a multi-disciplinary approach to treatment is used. It is not uncommon for behavior therapists to collaborate with colleagues from other disciplines (e.g., speech and language, physical therapy, occupational therapy). Although the multi-disciplinary approach can be beneficial, it may be detrimental if the proposed treatment in addition to EIBI is provided for multiple hours on a daily basis, as this can diminish available time for EIBI treatment. One increasingly popular approach to working with children with autism is the Developmental, Individual Difference, Relationship-based/Floortime (i.e., DIR/Floortime) model.

What is the conceptual link between ASD and DIR/Floortime?

The DIR/Floortime model was developed by Dr. Stanley Greenspan and Dr. Serena Weider (Greenspan & Wieder, 1999). It is based on a hypothesis that ASD is acquired as a result of a child's early environment not providing specific kinds of emotional nurturing. This leads to them missing one or more of the six hypothesized emotional developmental milestones. DIR is described by proponents as a child directed "process or concept, through which therapists, parents, and other caregivers make a special effort to tailor interactions to meet the child at his unique functional developmental level and within the context of his processing differences" (Hess, 2009). It considers the "Development of functional emotional capacities, Individual processing differences, and the parent or caregiver-child Relationship" to create new learning opportunities and centers around circles of communication. A circle of communication involves two participants who respond to each other verbally or nonverbally

(Dionne & Martini, 2011). DIR proposes six developmental milestones that create the foundation for a child's learning and development. Specifically, the milestones are 1) self-regulation or interest in the world, 2) engagement and relating, 3) two-way intentional communication, 4) purposeful complex problem solving communication, 5) creating and elaborating ideas, and 6) building bridges between ideas (Wieder & Greenspan 2003).



Each milestone increases the length and complexity of the circle of communication. Floortime is the intervention technique used to facilitate mastery of the DIR developmental milestones. Specifically, Floortime involves guiding the child through the developmental milestones by following the child's lead through play. That is, the therapist or caregiver will build on the child's current skills to create more complex circles of communication. Proponents of Floortime suggest it facilitates generalization because each interactive circle of communication is created in a natural environment. Additionally, family involvement is a large component of Floortime, again to facilitate generalization (Dionne & Martini, 2011). Proponents recommend that DIR/Floortime be implemented in 20-minute blocks of time for six to ten sessions per day.

Is there any research to support Floortime?

Currently, research is limited on the use of Floortime

(Continued on page 21)

(Continued from page 20)

to treat ASD (National Research Council, 2001). Additionally, the available research findings lack empirical validity (i.e., the experimental rigor of the available research is weak). In general, Floortime studies focus on training parents and therapist to implement Floortime interventions and evaluating the fidelity of the training on the interventions (e.g., Solomon, Van Egeren, Mahoney, Quon Huber, & Zimmerman, 2014). Although many of the studies look at changes in the hypothesized milestones developed by Greenspan and colleagues, to date none of the studies have evaluated the effects of Floortime on standardized measures of development or language. The studies have additional concerns. For example, one of the first studies to evaluate Floortime as an intervention for children with ASD was completed by Greenspan & Wieder in 1997. These authors retrospectively evaluated the charts of 200 children ages 22 to 48 months, who were diagnosed with ASD or pervasive developmental disorder not otherwise specified (PDD-NOS). All children were provided the Floortime intervention for two to five hours per day for two or more years by family or professionals. Outcomes of the intervention were determined using parental and therapist report to complete the Functional Emotional Assessment Scale (FEAS), a nonstandardized observation tool created by Greenspan and Wieder to assess the emotional functioning of a child based on the six developmental milestones that guide treatment in DIR. Greenspan and Wieder suggested 58% of the children had “good to outstanding” outcomes. That is, 58% of the children demonstrated 50 spontaneous circles of communication, mastered all six milestones, and created or participated in pretend play (Greenspan & Wieder, 1997). These results may at first glance seem promising; however, the lack of experimental control, experimenter bias, and use of non-standard measures greatly limits these findings. First, all outcomes were based on information found in a child’s chart (i.e., therapist and parental report) as opposed to direct observation. Second, a subjective observational tool was used to determine treatment outcomes. Both the reliance on anecdotal report and the use of a subjective observational tool allow for results to be greatly affected by biases. Third, the authors do not clearly describe the comparison group that was meant to serve as a control. Therefore, it is unclear if any treatment gains on standardized measures of development and language actually occurred due to the Floortime treatment.

In 2007, Solomon, Necheles, Ferch, and Bruckman evaluated the effects of parents using the DIR/Floortime model with 68 children over an 8-12 month period. Floortime was delivered 15 hours per week.

Treatment outcomes were determined using blind raters who scored videos of each child before and after treatment using the FEAS (again no standardized measures of development were assessed). Results suggested 45% of the children made good to very good functional developmental progress on the FEAS. However, much like Greenspan and Wieder (1997), Solomon and colleagues (2007) were lacking a control group and used a subjective measuring tool. Additionally, many of the participants in this study were simultaneously enrolled in other early educational programs. Therefore, it is unclear whether the increase in functional development should be attributed to Floortime or other outside educational programs.

In 2011, Dionne and Martini attempted to control for several of the limitations present in previous research by evaluating Floortime using a single-subject AB design with one boy age 3 years and 6 months with a diagnosis of autism. During Phase A (observation), the parent simply interacted with the child naturally and did not implement Floortime. During Phase B (intervention), Floortime was implemented by the parent. Phase A and Phase B were completed back-to-back a total of 28 times. Two blind observers watched 20 minutes of each phase for all 28 sessions and coded the number of circles of communication during each phase. Results were evaluated using visual analysis as well as statistical analysis. The authors concluded that the results of the visual analysis demonstrated great variability in the number of circles of communication observed during Phase A and Phase B, making a trend difficult to determine. However, there was a slight increase in the number of circles of communication observed during Phase B as compared to Phase A. Additionally, a statistical analysis of the number of circles of communication in Phase A as compared to Phase B showed a significant increase during Phase B as compared with Phase A. Although the use of the AB design increases experimental control as compared to previous research, it is still extremely limited because the results were never replicated either with the current participant or across other participants. Therefore, additional research that evaluates the effects of Floortime on standardized

(Continued on page 22)

(Continued from page 21)

measures of development and language is still needed to determine if the Floortime treatment model has any significant impacts on the core diagnostic features of ASD, particularly when compared to treatments that have already been shown to have such effects. Pajareya and Nopmaneejumrulers (2011) conducted what they described as a pilot study to assess the extent (if any) to which DIR/Floortime would enhance client outcomes of children with autism who were already involved in other clinical interventions. The researchers trained parents to conduct the treatment. Two groups of participants were involved – both groups were already receiving one-to-one behavioral treatment (discrete trial teaching); the experimental group supplemented that treatment with DIR/Floortime hours. The experimental design was pre/post test (or AB), with global assessments being made at the start and end of the experiment. The results showed a significant improvement in scores in the children who were treated by both DIR/Floortime and behavioral interventions. However, there were several methodological flaws that suggest skepticism in any causal relationship between DIR/Floortime and a reduction in autistic symptomology. First, there is the obvious influence of behavioral treatment in the group of children receiving DIR/Floortime. Second, the authors admitted that some of the parents of these children had to be taught how to play with their children, irrespective of the DIR/Floortime procedures. Third, there was no direct observation check on the fidelity of the parents implementing the DIR/Floortime procedures. That is, there is no proof that parents actually implemented the Floortime procedures as required. In a related study, Solomon and colleagues (2014) recently investigated the impact of DIR-type procedures when training parents to implement with their young children diagnosed with autism. Mixed results were obtained, with the strongest data showing superiority of DIR coming from changes in scores on the Autism Diagnostic Observation Schedule-Generic (ADOS-G). However, there were several limitations with this research, including the use of statistical analyses as opposed to direct observation of behavior, use of self-report survey data of questionable reliability and validity, and a lack of verification that parents actually implemented the required protocols.

Future Research

The current research on DIR/Floortime is lacking in

experimental control and empirical validity and objective measurement of treatment effects. Therefore, future research is needed to evaluate the efficacy of DIR/Floortime as a treatment for children with ASD. One major barrier to evaluating DIR/Floortime as a treatment is the subjectivity of the treatment itself. Currently, operational definitions/descriptions of both the procedures and the outcome measures are lacking and are inherently subjective, making replicating of identical procedures almost impossible. However, if more objective procedures could be identified, more research like Dionne and Martini (2011) may lend information on the effects of DIR/Floortime as a treatment for ASD. Specifically, future research should continue to utilize the within-subject research design to control for individual differences across participants and continue to measure results by collecting data on the effects of observable behaviors such as circles of communication or standardized measures of learner development. Additionally, future research should replicate results both within and across participants. Finally, future research may consider replicating results using different populations such as different age groups or different severities of delay as well as replicating results when treatment is delivered by trained therapists or caregivers.

Concerns with the DIR/Floortime model

Floortime may seem like an attractive treatment on the surface. For example, following a child's lead rather than directing or controlling them as some perceive to be the case in applied-behavior-analytic based treatment may appear more progressive. However, inherent in the model are several concerns. First, Greenspan explicitly warns against rigidity and repetitive routines, instead encouraging variability of teacher behavior. For learners whose strengths are in creating and learning from routine, DIR/Floortime may be frustrating or confusing. Procedures such as those modeled by Dr. Greenspan in a video training series (Floortime DVD Training Guide) can also potentially cause greater levels of problem behavior or shape progressively lower levels of response effort in communication and in skills due to how those behaviors access reinforcement over time. Second, proponents of the DIR/Floortime model often cite the fact that they "follow the child's lead" rather than require "compliance" to adult directions (Greenspan & Wieder, 2009). This is described as preferable because it allows for more creativity and flexibility on the part

(Continued on page 23)

(Continued from page 22)

of the child and teacher. This lack of formal structure is reputed to be “good” for children, and in particular for children with ASD as it addresses their reported tendencies toward rigidity of routine. However, in a school, one of the most critical skills needed in a child’s repertoire is the ability to follow the direction (lead) of the teacher. Children who do not respond to the teacher’s directions and remain on their own agenda are unlikely to be successful in a classroom environment. To date no studies have shown a correlation between correct implementation of Floortime and success in a regular education setting. Third, the DIR/Floortime interaction style of following the child’s lead can result in the child practicing play skills that are non-functional and inappropriate. Dr. Greenspan in *Engaging Autism* repeats the mantra that “Floortime is not about doing the right or wrong thing,” “There is no right or wrong answer,” and “Vary what you do” (p 181-185). This approach is likely to interfere with any program that attempts to establish specific functional play skills.

What is the bottom line?

Currently, DIR/Floortime simply does not meet the basic standards of care for use as a treatment intervention. Specifically, there is little to no objective evidence of effectiveness. No one has demonstrated that results can be replicated across a range of children with ASD. And, no one has demonstrated reliable implementation of treatment procedures because treatment procedures are individualized based on the child’s behavior during treatment. Finally measurement of treatment effects has been limited to evaluations of DIR/Floortime procedures and effects on the DIR/Floortime created measures (Functional Emotional levels) rather than standardized assessments of development and language.

On the contrary, there is objective evidence of the effectiveness of EIBI (e.g., Lovaas 1993) that has been replicated across a wide range of children with ASD and can be reliably implemented while still individualized to the child’s specific needs. Because DIR/Floortime is a time consuming treatment (i.e., it is recommended that Floortime be implemented at least 20 hours a week), it may be detrimental to implement DIR/Floortime as a treatment for ASD as it greatly decreases the amount of time the child can be exposed to EIBI, a treatment that is empirically sup-

ported for ASD.

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(Continued on page 24)

(Continued from page 23)

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ASAT SUPPORTS

AN UPDATE ON OUR “HOW ASAT SUPPORTS _____” COLUMN

David Celiberti, PhD, BCBA-D, Executive Director

As our readers know, we launched a series of articles early last year that showcases the myriad ways that ASAT supports key groups within the autism community.

To date, we have published three such articles:

- *How ASAT supports behavior analysts
- *How ASAT supports teaching [faculty members](#) (Summer 2017 issue)
- *How ASAT supports [parents of older children and adults with ASD](#) (Fall 2017 issue)

In 2018, we plan to publish the following:

- *How ASAT supports members of the journalism community (Spring 2018)
- *How ASAT supports center-based programs (Summer 2018)
- *How ASAT supports special education and general education teacher (Fall 2018)
- *How ASAT supports speech pathologists (Fall 2018)

Thereafter, this series will include:

- *How ASAT supports pediatricians and medical providers
- *How ASAT supports parents of newly diagnosed children with autism
- *How ASAT supports occupational therapists

ASAT

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Uma Patil (High school student)
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Brizida Vinjau, MS, BCBA

For more information about our Externship, please see:

www.asatonline.org/description-application-process/#externship

Thank You!

OUR REAL SCIENCE, REAL HOPE

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Does Your Agency Share ASAT's Values?

ASAT believes that individuals with autism have the right to effective treatments that are scientifically-demonstrated to make meaningful, positive change in their lives.

We believe that it should not be so challenging for families to find accurate information about the efficacy of various autism interventions. ASAT works toward a time when:

- ★ All families will be empowered with skills in identifying and choosing the most effective, scientifically-validated interventions for their child.
- ★ The media will educate and not confuse parents by providing accurate information and asking the right questions.
- ★ All providers will be guided by science when selecting and implementing interventions and use data to demonstrate effectiveness.

What It Means to Be a Sponsor:

ASAT's Sponsors indicate their support of the following tenets:

1. All treatments for individuals with autism should be guided by the best available scientific information.
2. Service providers have a responsibility to rely on science-based treatments.
3. Service providers should take steps necessary to help consumers differentiate between scientifically validated treatments and treatments that lack scientific validation.
4. Consumers should be informed that any treatment lacking scientific support should be pursued with great caution.
5. Objective data should be used when making clinical decisions.

Become a Sponsor Now!

These sponsorships not only provide financial support used specifically for our dissemination efforts, but also send a clear message that ASAT's vision is shared by others within the professional community.

The tasks of educating the public about scientifically-validated intervention and countering pseudoscience are daunting ones, and ASAT appreciates the support of all of our sponsors.

Please visit our website to learn about the [Sponsorship Benefits](#) for Sustaining, Partner, Champion, Benefactor, Alliance and Patron levels: www.asatonline.org/direct-financial-support/

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