

# Science in Autism Treatment

## Newsletter of the Association for Science in Autism Treatment

Vol. 12, No. 2

Spring 2015

pring is always a special issue of SIAT. April 2<sup>nd</sup> is World Autism Awareness Day and Autism Awareness is celebrated the entire month. Although for ASAT every day is for autism awareness and dissemination of evidence-based treatments, we enthusiastically join the community in making April blue for Autism.

## This Spring issue is dedicated to our Partner Level Sponsor



We are thankful for their generous support and delighted to feature their program description (<u>page 3</u>) and an interview with three members of BACA's multidisciplinary team, Dr. Carl Sundberg, PhD, BCBA-D, Hayleigh Kanzler, MA, CCC-SLP, and Angela Seal, MOT, OTR, conducted by our Executive Director, Dr. David Celiberti, and newsletter contributor, Patrick O'Leary. BACA has also contributed a Clinical Corner, jointly written by Drs. Carl Sundberg and David Celiberti, answering a question

about Applied Behavior Analysis and sensory issues (<u>page</u> <u>11</u>). See the <u>next page</u> for career opportunities at BACA. We are proud to feature our **2015 Professional Sponsors** (<u>page 16</u>). These are organizations committed to evidence in autism treatment and to ASAT's mission. With their support and that of our **2014 Donors** (<u>page 32</u>) we are making reality the many goals we established for this year (please see the letter from our Executive Director in the <u>Winter issue</u>).

Thank you for your continued support through direct financial donations and dissemination of ASAT and our newsletter *SIAT*. We enjoy preparing each issue and love to receive your feedback by email to <u>newsletter@asatonline.org</u>.

Have a wonderful Spring! Warm wishes,

Daniela F. Fazzio, PhD, BCBA-D SIAT Co-editor

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#### ASAT



BEHAVIOR ANALYSIS CENTER FOR AUTISM

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## **BCBA CAREER OPPORTUNITIES**

#### **JOB RESPONSIBILITIES:**

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FOR QUESTIONS CONTACT AMY WILLIAMSON AWILLIAMSON@THEBACA.COM 317-288-5232

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BEHAVIOR ANALYSIS CENTER FOR AUTISM





### ABOUT BACA

The Behavior Analysis Center for Autism (BACA) uses the principles and procedures of Applied Behavior Analysis (ABA) to teach language, social, self-help, academic, daily living, and life skills to individuals with autism and related disorders. BACA was established in 2009 by Carl T. Sundberg, Ph.D., BCBA-D, and a group of highly trained Board Certified Behavior Analysts (BCBAs) who have been working with Dr. Sundberg for several years. BACA has four centers in Indiana: BACA 1 and BACA Prep in Fishers, BACA Z in Zionsville, and BACA Hart in Elkhart. Staff provide intervention to individuals ages 2-22 who have been diagnosed with autism or a developmental disability. BACA continuously educates and trains its staff through regular seminars and consultation by its esteemed clinical team.

### **OUR PROGRAMS**

BACA offers unique programs for families in the area, nationwide, and internationally.

BACA 1, Prep, Hart, and Z provide center-based programs with one-on-one and small group therapy overseen by Ph.D. level behavior analysts. The centers are open year round. BACA has BCBA and BCBA-D level consultants, as well as occupational and speech therapists, who are always available. These facilities include areas designed for specific clientele to facilitate transition to the next appropriate living or learning environment. These areas include a typical-peer preschool for ages three-to-five, called the Sprouts program. For older clients, the Geof Mohs Achievement Center is designed to prepare adolescents for adult life by focusing on hygiene, employment, and independent living skills.

BACA Atlas is an intensive therapy clinic that provides families with access to renowned behavior analysts and therapy services. Families that are seeking direction for their child have the opportunity to engage in a clinic that creates programs to be implemented in the home setting. The staff assesses client skills, provides behavioral therapy and trains the family, caregivers, and therapy team to implement the treatment program. The clinic sessions are based on the child's needs and the family's schedule and budget. In addition, staff receive ongoing supervision.

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BACA also offers Extended Services which are part-time services for students needing social, behavioral, and academic assistance. Clients receive up to 20 hours of ABA therapy per week under the direction of the program's director, who is a BCBA, and a team of trained behavior technicians. Additionally, BACA offers flexible scheduling and services that are available in the evenings and on weekends.

#### **ABOUT OUR CLINICAL TEAM**

Dr. Carl Sundberg received his doctorate degree in ABA from Western Michigan University under the direction of Dr. Jack Michael. While a graduate student, he taught behavior analysis at WMU for seven years. Dr. Sundberg has publications in *The Analysis of Verbal Behavior* and *A Collection of Re -prints on Verbal Behavior*. Dr. Sundberg has over thirty years of experience using behavioral interventions to teach individuals with autism and other developmental disabilities. He oversees the training of BACA staff and consistently spends time with the clients. Eighty percent of his time is spent contributing to the training of staff and addressing specific client programs.

BACA's extensive clinical team also consists of Dr. Mark Sundberg, Dr. Barbara Esch, Dr. John Esch, Dr. Peter Gerhardt, Dr. Patrick McGreevy, Bob Ryan, Troy Fry and Dr. Genae Hall. Each possess expertise in the field of ABA and all are viewed as leaders in the field. Dr. Mark Sundberg is the author of the *Verbal Behavior Milestones Assessment and Placement Program* (VB-MAPP) which is a tool utilized widely including at BACA. Dr. Barb Esch is a behavior analyst and speech pathologist with over 30 years of experience in behavioral interventions for individuals with developmental disabilities. Dr. John Esch has over 30 years of experience as a psychologist, teacher, and consultant. He has worked with individuals of all ages whose diagnoses include autism spectrum disorder, emotional impairment, mental impairment, brain injury, hearing loss, learning disability, and ADHD/ADD.

Dr. Peter Gerhardt is the president of Peter Gerhardt Associates, LLC, in New York City. He has more than 30 years of experience utilizing the principles of ABA in support of adolescents and adults with autism spectrum disorder in educational, employment, residential, and community-based settings. Dr. Patrick McGreevy has over 30 years of experience with individuals of all ages with developmental disabilities. He is the first author of *Essential for Living*, a new assessment, curriculum, and teaching manual for children and adults with moderate-to-severe disabilities. Bob Ryan acts as a consultant to schools and families, co-instructs for the Florida Institute of Technology's ABA online program and works with Dr. Carl Sundberg at BACA. Troy Fry has worked with children and adults with developmental disabilities for the past 25 years. He is also a co-author of *Essential for Living*. Dr. Genae Hall works with BACA's research department and clinic staff, to support the building of a research center within the facility.

For more information about BACA or to schedule a tour, contact Colin Clayton at: 317-436-8961 or at: <u>cclayton@thebaca.com</u>. You can also visit the website at: <u>www.thebaca.com</u>.

## Related Services in an ABA Setting: Epiphanies, Opportunities, and Reflections from the Field

An Interview with Carl Sundberg, PhD, BCBA-D, Hayleigh Kanzler, MA, CCC-SLP, & Angela Seal, MOT, OTR, Behavior Analysis Center for Autism

By David Celiberti, PhD, BCBA-D & Patrick O'Leary, MA, BCBA

e want to thank you all for participating in this group interview. Meaningful and effective multi-disciplinary collaboration is something that may not come easily for many teams, particularly when there are different views about the relevance of science in the treatment of autism. We are very grateful for the opportunity to showcase the model used at the Behavior Analysis Center for Autism.

## Dr. Sundberg, please describe how BACA came to include OTs and SLPs.

Carl Sundberg: In the years before BACA was established, I consulted for families who were doing in-home ABA programs. In most cases, the child was also receiving speech and/or OT services through the school or another provider. It was often difficult to coordinate services between the various providers. In many cases where the child was receiving speech services, the speechlanguage pathologist (SLP) involved would also target general language acquisition. Sometimes these recommendations/programs would differ from the recommendations/programs made and established by the ABA provider. About 10 years ago, when I was working for an ABA center, I had suggested that we begin contracting with an SLP so that we would all clearly be on the same page. We would create the language programs based on the principles of applied behavior analysis (ABA) and the SLP would focus on issues related to vocalization, articulation, feeding, swallowing, etc. We then started contracting with an

occupational therapist (OT) and eventually hired an SLP and OT full time. BACA now employs three SLPs and two OTs.

Our experiences have been similar with providers working on similar targets but in different ways, and, in many cases, those divergent methods were not necessarily compatible or complementary. In many cases, there may actually be an absence of communication and coordination altogether. We can see how having providers onsite has the potential to promote consistency and synergy. Was the hiring process challenging?

**Carl Sundberg**: The hiring was a bit tricky. We needed to find people who would fully embrace ABA and especially Skinner's analysis of verbal behavior, commit to data-based decision making, as well as agree to focus on more narrow objectives relating to the mechanics of speech, articulation, and feeding. For the OT, we needed to find someone who could help us with our OT

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Sounds like the

expectations are

ers a bit more

needs yet not be a major supporter of sensory integration. Once hired our SLPs and OTs participate in the same trainings as our other clinical staff, beginning with the training required to become a Registered Behavior Technician. They attend all in house training and are sent to behavioral conferences and workshops as well. One of our SLPs has finished her BCBA coursework, sat for and passed the exam while working at BACA.

#### When you use an SLP in a program, what does he or she typically address that a BCBA cannot?

Carl Sundberg: Before we worked closely with SLPs, we already had an understanding of how to use the methods of ABA such as stimulusstimulus pairing, differential reinforcement, and shaping to attempt to produce new sounds, to establish echoic responding, and to improve articulation. However, we were lacking a true me-

chanical and devel-

opmental under-



#### Carl Sundberg: Not

sues?

every child is in need of OT services. Those who do receive services vary in need. Our OTs will assess our clients' gross and fine motor skills, and design, oversee, and train staff on programs (exercises) to improve any weaknesses. Our OTs also assess the need and make recommendations for adaptive equipment (such as special scissors, shoes or wrist guard to help with writing, etc.) and program equipment (such as swings, balance beams, large balls, etc.).

variable when deciding on a response form for a student, if continuing with vocalizations is feasible, when to fade out sign language, other forms of augmentative communication, etc. The input provided by our SLPs related to these areas has been invaluable to us.

Thank you for sharing these experiences as I know that many programs for individuals with autism have grappled with how to create synergy through effective multi-disciplinary

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collaboration and coordination. We have the good fortune to have Hayleigh Kanzler available to answer some questions. Hayleigh, how do you incorporate ABA into your therapy sessions when focusing on communication skills?

Hayleigh Kanzler: My work is heavily guided by ABA principles and, in fact, I use reinforcement strategies all the time in therapy! I have found that the students I work with respond well and will work harder if there is a tangible reward at the end. I also use transfer trials for teaching generalization. More specifically, we use ECTER: error (child makes an error), correction (correct error with prompt), transfer (take away that prompt for a correct response), expansion (have the child do something else), and return (come back to the target). That system of teaching really allows the child to be successful, but also take that skill beyond just knowing how to answer in a specific situation. It allows learners to transfer the skill beyond that one moment in time when they know the answer- they have to do other things that distract them from the correct answer and come back to it. Obviously, it would start with one, small expansion, but the expansion time and number of expansion activities increases! I think the greatest asset we have as SLPs at an ABA center is having a behavior technician with us during therapy. I am constantly asking questions to promote consistency and also teaching how to implement my speech goals within their daily practice. The great thing is that the behavior technicians follow through with practice, so I see faster progress than I typically would if this carryover was not part of the culture.

Do you work in a consultative capacity or are you typically working one-on-one with children? In other words, do you provide exer-

#### cises for line therapists to use, or do you do all the work directly with the children?

Hayleigh Kanzler: To answer that question, yes and yes! I do see children for direct therapy (one-to-one), but also have the flexibility to do some consultations with children who are not on my caseload. Sometimes a consultation will include helping to create vocal goals for children who are just starting at BACA and sometimes it can be with a child on my caseload to help brainstorm with that child's team. I see around 25 children per week for direct services and then I leave exercises to be practiced until I see them the next week. It's a great model for daily practice and since I am often in the same building, I am there to train and answer any questions the behavior technicians may have.

#### What are some underpinnings of ABA that can guide the practice of SLPs involved with individuals with autism?

Hayleigh Kanzler: Coming from a research background, I appreciate the data-driven nature of ABA programming. I do think SLPs can implement many ABA techniques to increase success in working with kids with autism. Many SLPs already use reinforcement naturally but not necessarily as intentionally or systematically as they could! Other behavior analytic teaching techniques- such as errorless learning, transfer trialsare also great tools to have as an SLP when working with students with autism.

# What advice do you have for BCBAs on school based teams who are trying to make inroads with OTs and SLPs?

**Hayleigh Kanzler**: The biggest thing with collaboration is to realize that we are all working for the same thing- for the good of the child. SLPs, OTs, and BCBAs may disagree with some things,

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but these can often be worked through in a professional and open manner. Every member of the team benefits when each person has an open mind to the others' specialties. Each professional has knowledge and instead of getting frustrated, ask "why" something is being done a certain way and, then, actually listen. These discussions are enhanced when research is incorporated and data are used to back up assertions being made.

discuss activities that will support the child's program. When a client is not on my caseload, one of our BCBAs can request a consult with an OT. Usually during these consults, I give recommendations related to specific questions related to fine or gross motor skills, daily living skills or feeding.

What are some underpinnings of ABA that can guide the practice of OTs involved with individuals with autism?

Last, but not least, we wanted to bring Angela Seal into the conversation in her role as an OT at BACA. How do you incorporate ABA into your therapy sessions when focusing on skills?

Angela Seal: Primarily, I use reinforcement procedures to strengthen the skills that I am teaching our clients. I also rely on shaping and fading procedures to teach skills. I utilized these procedures before I



Angela Seal: In my opinion, the basic underpinning is the careful analysis of antecedent and consequences through the collection of ABC data. OTs should be analyzing what is happening before and after a client's behaviors, specifically what a therapist's response is to the behavior. The OT must understand how various modes of attention, such as eye contact, proximity to client, physical touch, etc., can reinforce a

joined the Behavior Analysis Center for Autism; however, with guidance from our clinical staff, I have been able to refine my skill level in implementing these procedures.

#### Do you work in a consultative capacity or are you typically working one-on-one with children?

**Angela Seal:** The majority of my time is spent one-on-one with clients with brief consultations following with behavior therapists to teach and behavior (adaptive or maladaptive).

As you know, your skill building approach to OT is not universally shared. For many students with autism, OT services are defined by the delivery of sensory experiences. What are your views on sensory integration therapy?

**Angela Seal:** I would not consider myself an expert in sensory integration theory as I don't use

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it personally. I would be more inclined to utilize sensory integration if there was a strong base of research to support it. I have also observed fellow OTs who are misapplying this theory. In many cases, utilizing sensory integration techniques during behaviors has the potential to reinforce that behavior. For example, placing a child on a swing to calm the child during a maladaptive behavior only teaches him or her that initiation of the maladaptive behavior is one way in which he or she can access the swing. Therefore, instead of utilizing a mand for the swing, a child will learn to exhibit a maladaptive behavior to access the swing.

#### What advice do you have for BCBAs on school based teams who are trying to make inroads with OTs and SLPs?

Angela Seal: As professionals, we all want respect for the profession to which we chose to devote our lives. So, my number one piece of advice: respect the OT and SLP you work with in the school system. Listen to them and let them describe what frames of references they are working from when they are treating their clients - whether it be SIT, neuromuscular, cognitive, etc. Discuss deficits and strengths of mutual clients. Ask how the OT and/or SLP focus on strengthening the deficits, and then offer insight on how principles of applied behavior analysis may impact or enhance that plan. Share information about ABA, how it can be utilized to strengthen skills, and how data collection can be used to objectively measure progress. I would like to think that most professionals in the school system are there for the good of the clients. The strength of a client's program often lies in the strength of the relationships of those who are creating the program. Those relationships are built on a mutual understanding and respect, as well as collaboration.

# What can behavior analysts learn from OTs? What can OTs learn from behavior analysts?

Angela Seal: OTs are able to teach behavior analysts how to identify basic deficits for common tasks and then common activities or exercises to address those deficits. For example, clients who have difficulty maintaining a grasp on a toothbrush most likely have strength deficits within the hand. There are common activities and exercises that would strengthen the hand, such as animal walks or playing with resistive materials. It would still be advantageous to request a consult from an OT because there could be underlying issues but these activities could be utilized until that consult could take place.

Another example would include feeding in which I would assess muscle tone; strength; oral motor skills; feeding skills (can the child use a fork or



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spoon); tolerance to certain textures, temperatures, tastes, feeding equipment; and/or positioning (does the child require special support, is the child in a chair where he or she is stabilized with feet on the ground). I would also consider whether the child or family have certain foods that should be avoided (for example, certain faiths do not allow pork to be eaten). Once areas of concern have been identified, I can offer recommendations to the behavior analyst that may include positioning; types of utensils to utilize; methods in which to focus on desensitization to textures, temperatures and tastes; and oral motor strengthening exercises (often times this is in collaboration with Speech Therapy). Together, the behavior analyst and I can create a feeding protocol reflecting our respective areas of expertise. In sum, a behavior analyst can learn about underlying deficits preventing skill acquisition and basic ways in which to address the deficits.

Behavior analysts are obviously skilled in the analysis of behavior, more specifically the function of the behavior. I have learned valuable lessons from behavioral analysts when observing them complete a functional analysis of the behavior. After we have discussed the results and they have given recommendations on behavior protocols, I have been more successful in my treatment of the child.

Thank you all for a wonderful interview. We are very grateful that you were able to share your experiences and hope that the elements of your model can be considered by others. It takes a village to help a person with autism realize their fullest potential and a strong multi-disciplinary team that relies on science and is grounded and guided by data is essential.

## **ASAT Advisory Board**

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## **Clinical Corner**

## Sensory Issues: Is a BCBA the Right Person?

By Carl Sundberg, PhD, BCBA-D & David Celiberti PhD, BCBA-D

In this Clinical Corner, Dr. Carl Sundberg and Dr. David Celiberti tackle a common question among parents of children with autism regarding sensory issues and BCBAs. By discussing motivation and its many faces, these authors explain how, from a behavior analytic point of view, identifying sensory issues as the cause of problem behavior, may not lead to an effective intervention. Instead, a comprehensive assessment of problem behaviors can identify all the underlying motivation and lead to a more individualized treatment.

Amanda Fisher, PhD, BCBA-D Clinical Corner Coordinator

I am the mother of a young boy who was just recently diagnosed with autism. I was referred to a board certified behavior analyst (BCBA) by my pediatrician for a behavioral assessment to help with some problem behaviors my son is having at home, such as biting. I have heard from others that BCBAs don't "believe in sensory issues," and these problems are central to autism. Is a BCBA the right professional to help me since he or she won't even believe my son has a problem?

Answered by:

Carl Sundberg, PhD, BCBA-D Behavior Analysis Center for Autism David Celiberti, PhD, BCBA-D Association for Science in Autism Treatment e are really glad this question was asked, as it comes up often. Some people believe behavior analysts are "antisensory" — opposed to offering sensory diets, massages, deep pressure, jumping on a trampoline, etc., for individuals with autism spectrum disorders. However, this is not necessarily true, and we would like to take this opportunity to clarify how behavior analysts tend to approach sensory issues. In fact, the term "issues," in and of itself, can be problematic and ambiguous because it does not specify whether an individual is showing sensory preferences or sensory aversion, nor whether the sensory experience is a "like" or a "need." These distinctions are significant in devel-

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oping a treatment plan, as we will highlight below.

First and foremost, it would be beneficial to discuss the many faces of motivation. Each of us, and children in particular, may be highly motivated by sensory experiences that vary in modality, variation, movement and pressure. Ever catch yourself tapping your pencil, twiddling your thumbs, biting your nails, or popping bubble wrap (a personal favorite of the first author)? If so, would you say you have "sensory needs" or "sensory issues?"

It is important to keep in mind that we are *all* highly motivated by *other* experiences as well. Sometimes we are motivated by attention such as a smile, a knowing look, or laughter. Other times, it is something tangible and specific which motivates us, such as a new pair of sneakers or a piece of artwork. We all engage in a wide array of behaviors to access these experiences. On the flip side, sometimes we are motivated to avoid or get away from certain forms of attention (e.g., closing our office door or ignoring the incoming call of a telemarketer) or other specific things (e.g., a traffic ticket or non-preferred vegetables).

Why is this important? First, assessment of challenging behavior must carefully investigate the motivation of that behavior (i.e., the "function" of the behavior) in order to have the greatest likelihood of leading to effective intervention. It is through recognition of the function of the challenging behavior that effective behavioral intervention is developed. A "knee-jerk" or "cookie cutter" approach would do a disservice to your son or to anyone else who may be attempting to negotiate their environment in less than desirable ways. Let's explore a few scenarios using some fictitious children. We intentionally referenced the same behavior (biting) in each example.

- Tommy bites his teacher when she attempts to help him put on boots.
- Gunner bites his teacher as soon as she put his sight word cards on his tabletop.
- Lisa bites her father as soon as he stops playing with her and attempts to leave the room to take a call.
- Sudhir may bite his older brother when the older brother is accessing the iPad.
- Sudhir also bites his babysitter when she asks him to put away his iPad.
- Antonio bites a classmate who sits too close to him during circle time.
- Melanie bites classmates when the fire alarm sounds or her older sister plays music loudly.
- Jennica bites her father's arm when he wears long sleeve dress shirts.
- Mitchell's teeth are coming in and he has been seen biting a plastic hanger.

As you can see in each of the examples above, the same behavior (biting) occurs in very different contexts and likely serves very different functions. In some instances, the motivation may be to get or keep a preferred item or activity, whereas in other instances, the child is trying to avoid or escape something they do not like. We hope you can appreciate that a "sensory" explanation based on the fact that they are biting would miss the mark in most or all of the examples illustrated above.

So the first takeaway message is that not every behavior problem should be assumed to have a sensory basis; in other words, sensory stimulation may not be the relevant motivation. So if we mislabel certain behaviors as

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#### "sensory," the recommended sensory intervention will not address it properly.

Secondly, we should differentiate between a sensory need and a sensory preference. A hand washing example may illustrate this distinction. Both April and Alice engage in high rates of hand washing.

- April washes her hands every time she touches a doorknob, wet surface, or uses the office phone. She reports that she is worried about germs and will often appear agitated if hand washing is delayed (e.g., she is in a meeting or there is a line to use the restroom). From a behavior analytic standpoint, hand washing in this instance may serve as a negative reinforcer, because the behavior terminates the discomfort that April associates with unwashed hands. April might say, "I really *need* to wash my hands and feel so relieved after I do so."
- Alice, on the other hand (no pun intended), also washes her hands a few times per day. She is a huge fan of a "high-end" salted caramel hand soap that is in the restroom two floors above her office. She will happily wait in line to access this restroom. From a behavior analytic standpoint, hand washing here serves as a positive reinforcer because of the resultant access to an item that she enjoys. Alice might say, "I really *like* to wash my hands with this particular product. I hope I get this for my birthday."

As you can see, April has a "need" and Alice has a "like." To make this distinction more relevant to autism, we could substitute the use of swings here. Like many children, some children with autism often appear to enjoy swinging, may be willing to work hard to earn it and demonstrate pleasure while swinging, whereas other children may start off agitated and appear calmer following swinging, but it is not necessarily an experience they would choose (children experiencing pain relief from taking aspirin may also benefit from it but not necessarily choose it).

#### So the second takeaway message is that not every sensory-seeking behavior reflects a "need."

Let's examine the misuse of the term "sensory need." It is not unusual to see a person with autism engage in unwanted behaviors such as biting which cease when a vest is applied or a tantrum that stops after a cookie is delivered. In both cases, something was missing from the person's immediate situation. In both cases, the behavior is likely to decrease once the vest or cookie is delivered. This is evidence that these items may be functioning as reinforcers and the function of the behavior is to access them. Why is it that in the first case (engaging in biting to get the vest), it's often concluded that the child's behavior is due to "sensory needs," however, in the second case (engaging in a tantrum to access a cookie), it is rarely said that the child has "food needs?"

Activities stimulating the senses can serve multiple behavioral functions, depending on the motivation. Jumping on a trampoline is likely to be repeated because of its reinforcing vestibular effects — it is fun. This leads to the question, "Do I jump on the trampoline because I need to jump on the trampoline, or because it's fun?" Either way, I am going to do whatever I can to get the opportunity to jump on the trampoline (thus, attesting to the reinforcing value). Again, the responses one engages in depend on the history of reinforcement and punishment, verbal repertoire, social contingencies and perhaps the level of deprivation or strength of the motivation. That is, if I had been jumping on the trampoline for extended periods of time, I may be less motivated to continue jumping, and less likely to engage in behaviors that will allow me to jump.

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Lastly, any discussion on "sensory issues" would be remiss without some mention of sensory hypersensitivity. We have also observed individuals with autism who have extreme reactions to sensory input (e.g., loud noises, bright lights) and there are those who are extra sensitive to textures or certain clothing (e.g., the tag in the back of a shirt or particular food). These children/adults learn to engage in behaviors that reduce the aversive nature of such stimulation. But this isn't exclusive to autism – there are also people without autism who are sensitive to certain stimuli as well.

There are some who experience extreme discomfort when exposed to situations which would be considered typical to most of us (e.g., loud music). Some people with the requisite skill-set will engage in behaviors that relieve the anxiety, such as escape behaviors (leaving the situation), avoidance behaviors (skipping the situation entirely), or engaging in some incompatible behaviors (practicing relaxation techniques). In these cases, sophisticated repertoires of skills are in place. Rarely will an adult (who does not have autism) run and scream from a room or become aggressive when confronted with an uncomfortable situation. Most of us have a sophisticated verbal repertoire allowing us to compensate or better negotiate the situation in a more sociallyaccepted way.

Unfortunately, many people with autism do not have the repertoires to engage in the sociallyaccepted methods that relieve the anxiety or discomfort. However, many other non-socially accepted behaviors have been shaped over the years and have proven to be effective in removing the aversive stimulation. If we were in a room where the music is too loud, we would leave or ask for it to be turned down. If those behaviors are not

possible, we may have to tolerate the situation. We have learned that behaviors such as biting will result in undesired social consequences. But what if:

- We did not have the language to ask for the music to be turned down?
- We did not know that leaving was an option, or did not know how to ask, or were forced to stay?
- We didn't value the social consequences as most people? That is, we don't care how others perceive us or if we get invited back.

If all that were true, we might engage in biting to get the music turned off or get removed from the room.

Now, suppose we do have those skills, and we can always find a way to get out of situations that cause stress or sensory overload; or we tough it out because of the social contingencies that have been shaped up over our lifetime. Chances are, no one would suggest we had sensory issues and put us on a sensory diet or prescribe sensory integration therapy. However, a person with autism who may have the same level of discomfort and escapes the situation in the only way he or she knows how, is often said to have "sensory issues" when perhaps it would better to say they had skill deficits.

# So a final takeaway message is that "sensory" concerns have profound implications for the teaching of new skills, skills that can be targeted through behavior analytic strategies.

In summary, we are not suggesting that your son's biting behavior lacks a sensory basis. Our point is that perhaps there may be other explanations that would emerge during a functional assessment, and that these alternative explanations

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need to be carefully considered. In order to develop the most appropriate, and individuallytargeted treatment for your son, one must analyze the function of the behavior, evaluate whether the behavior has a sensory basis (and whether it reflects a "need" or a "like"), and identify skill deficits (e.g., manding) that may either compete with and potentially replace the biting behavior or provide him with coping skills to better negotiate his environment.

We would like to thank Different Roads to Learning <u>www.difflearn.com</u> for permission to reprint this adapted response from an article written by the first author that appears here <u>www.difflearn.com/category/expert-articles</u>.

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## **Clinical Corner**

## Explaining Applied Behavior Analysis to Parents and Colleagues

By Patrick O'Leary, MA, BCBA

Despite Applied Behavior Analysis (ABA) being at the forefront of scientificallyvalidated treatment options for individuals with autism for more than 30 years, there remains a need to help parents and consumers at large better understand the principles that underlie this science. Doing so not only alleviates misconceptions about ABA but also makes it more approachable when people realize the are using these principles in their everyday lives! In this Clinical Corner, Patrick O'Leary does exactly that by sharing consumer-friendly explanations and examples of several basic ABA principles that providers can use to demystify and promote ABA among those with whom they work and live.

Nicole Pearson, PsyD, BCBA-D Clinical Corner Coordinator

im a newly-minted BCBA, working in a public school. I really love my job and the students with whom I work. A concern I have is how to help parents and others understand what it is that I do, especially as it relates to some of the more fundamental principles that underlie our work, such as reinforcement and punishment. How can I best explain some of the basics of applied behavior analysis (ABA) to others?

Answered by Patrick O'Leary, MA, BCBA

his is a great question, and something with which the field of behavior analysis has historically struggled (Bailey, 1991). Consumers can indeed be intimidated by our use of terminology. We have a powerful science in our hands, and we need to make it approachable and understandable to those with whom we work. The principles of ABA are evident in how the environment – including the social setting – impacts our behaviors. Parents and colleagues may hold the false belief that these principles only apply to their classroom instruction. They may not appreciate that these same principles of behavior are at play, regardless of the individual, the setting, or the behavior of interest. Let's take a brief look at some well-known, though often misunderstood, principles of behavior.

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#### **Positive Reinforcement**

A hallmark of ABA, positive reinforcement is a principle of behavior stating: "a behavior occurs and is followed by the introduction of something to the environment, which subsequently increases the likelihood that the behavior will occur again in the future" (Cooper, Heron, & Heward, 2007). A typical example in teaching situations involves the delivery of praise (e.g., "Great job saying blue!") following a student correctly labeling a blue ball. Assuming social praise is positively reinforcing, correct responding will likely increase in the future.

But when we look at the definition, we see that this doesn't necessarily only relate to classroom instruction. Take for example, a 30-somethingyear-old male who is hungry for breakfast. He walks into the kitchen and opens a cabinet that contains a variety of cereals. The next morning, he finds himself hungry again and wanting cereal. He opens the same cabinet and is rewarded with cereal. What has happened? We see the same behavior in both scenarios, opening the cabinet. Opening the cabinet changes the environment in a way that cereal is introduced. We see in the second part of the scenario that "opening the cabinet" was reinforced - the behavior occurred more often in the future as a result of the positive reinforcement, the introduction of cereal.

#### **Negative Reinforcement**

Negative reinforcement is often considered synonymous with punishment; however, like positive reinforcement, negative reinforcement also increases the frequency with which a behavior occurs (Iwata, 1987). The difference can be subtle, but it is quite important. Negative reinforcement is also unique in that there are two aspects: escape and avoidance.

In the typical negative reinforcement example, an unpleasant situation is present. A behavior occurs and the unpleasant situation is removed. The behavior is likely to occur again in the future. It was reinforced by the removal of the unpleasant situation. We refer to this as "escape" because the unpleasant situation is removed as a consequence of the behavior. Contrast this with "avoidance." If we use the same example, the behavior occurs prior to the unpleasant situation occurring. Thus, the behavior results in an avoidance of the unpleasant situation altogether.

In a typical teaching example, a student with an autism spectrum disorder (ASD) is assigned a work to complete at her desk. The worksheet is difficult for the student, and she doesn't wish to continue work. Self-injury occurs, after which the teacher removes the task and presents a break. Self-injury is thus reinforced by the removal of the unpleasant task. In the future, self-injury may re-occur during similar, unpleasant tasks. The task is presented, self-injury occurs, and the task is removed.

Now, take the following example as an instance of avoidance responding. In this example, the teacher enters the classroom while carrying a box of teaching materials. As the teacher approaches the student, the student begins to engage in selfinjury. The teacher hasn't even begun teaching yet! Following the start of this self-injury, the teacher pivots away and directs her attention to another student. What happened? The teacher's presence (paired with the box of materials) signaled to the student that work was about to begin. The student engages in self-injury, to

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which the teacher removes the opportunity to do work. The student has avoided work. The unpleasant situation (work) is avoided following an instance of self-injury. Assuming self-injury increases in the future in similar scenarios, we see negative reinforcement (in the form of avoidance responding) at work.

Again, these principles are in play throughout our daily lives. For example, I recently purchased a new car. In the past, I rarely wore a seatbelt. This new car took care of that. Not only is there a red seatbelt icon on the dashboard, but a repetitive, loud beeping noise that occurs until the seatbelt is put on. Oh, it was so unpleasant! To escape from this unpleasant situation, over several days, I found that I put my seatbelt on shortly after starting my car, in order to "escape" the incessant beeping. Shortly after that, I began putting on the seatbelt prior to starting the car, in order to avoid the beeping in the first place.

#### **Positive Punishment**

Positive punishment is described as an introduction of something into the environment (think positive = addition = introduction), following a behavior, which is followed by a future decrease in how often that behavior occurs (Cooper et al., 2007). An example, used in most schools, is a reprimand. "Don't do that!" or "Stop talking!" It is easy to imagine the behaviors that are occurring prior to these statements: a classmate pulling another's hair, high school students texting during a lecture, etc. The reprimand, following the behavior, often immediately stops the behavior. In the future, the behaviors are less likely to occur because they have been followed by the reprimand (assuming the reprimand functions as a punisher).

Again, we can see this principle play out in our day-to-day activities as well. For example, a young woman is hiking in the woods. Though repeatedly told by her husband to stop shuffling her feet when she walks, she continues to ignore his request (a failed attempt at positive punishment). The environment will take care of that! While hiking on a rocky trail, she painfully stubs her toe. Pain was introduced after the behavior of "feet shuffling." In the future, she no longer shuffles her feet. The introduction of pain reduced how frequently she shuffled her feet in the future.

#### **Negative Punishment**

In negative punishment (think negative = subtract = removal), a behavior occurs and is followed by the removal of a pleasant situation (Cooper et al., 2007). As a result, the behavior occurs less often in the future. A common example can be found in the use of time-out. In time-out, a behavior occurs and the student is removed from an enjoyable activity. For example, a student playing a soccer game swears at a peer. As a consequence, the teacher removes the student from the game and he sits on the bench for a period of time to watch. In this instance, time-out has the desired effect in that the student swears less often in the future.

A great example of this concept in daily life is the use of fines, particularly for breaking the law while driving. An individual is driving a car at 75 mph, where the speed limit is 55 mph. A police officer pulls the individual over, and provides a \$75 ticket. The individual loses a portion of a pleasant stimulus (money) following a behavior (speeding). The individual is thus less likely to speed in the future.

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#### Extinction

This one is easy, right? We just have to mention dinosaurs, and it'll clear everything up. Just kidding! Extinction ties in with the principle of reinforcement. The phenomenon of extinction occurs when reinforcement of a behavior is withheld and, as a result, the rate of the behavior decreases (Lerman & Iwata, 1996). Let's look at our typical teaching scenario. A student in our classroom has learned that talking out in class will result in teacher attention. The student talks out during a lecture (imagine a "class clown") and the teacher provides a light-hearted reprimand. Talking out is thus reinforced. Our teacher, after learning of the principle of extinction, decides to withhold her attention the next time the student talks out. Notice that she did not remove her attention: that would indicate that she was giving him attention in the moment and then stopped. She withheld her attention; she ignored his talking out.

Before moving on to our daily life example, it is important to touch on another aspect of extinction: the "extinction burst." An extinction burst is basically an increase in some aspect of the behavior, which occurs soon after the behavior undergoes extinction (Lerman & Iwata, 1996). Basically, the student has learned that the behavior no longer works, and they "up the ante." Let's go back to our class clown. He has learned that, in the past, talking out results in teacher attention. But this time it didn't. What does the student do? Likely, some aspect of the behavior will increase. In our example, the student may talk louder, wave his hands in addition to talking, jump on his desk, or throw a pencil at the teacher. If the teacher attends to any one of these behaviors, we see that the new behavior is thus reinforced; the next time the student is looking for teacher at-

tention, he may simply try this new behavior, since he learned that it is more successful. It's easy to see how this can escalate quickly to inappropriate classroom behaviors.

A daily life example that explains this phenomenon well is when an individual is trying to get elevator doors to close. In the past, there is a history of reinforcement for pressing the "door close" button; the button is pressed, and the door is closed. Now, suppose the "door close" button is broken, or on the verge of breaking. A simple press no longer is successful; reinforcement is withheld. Pressing the button once no longer leads to the door closing. Here comes the extinction burst! Now, because pressing the button once doesn't work, the individual rapidly, and forcefully presses the button 3, 4, or 5 times. On the 5th time, it works! Pressing the button once was not successful, the "ante was upped", and the door closed only after the 5th forceful push. In the future, in similar elevator circumstances, the individual is more likely to press the button more than once, and forcefully.

#### **Motivating Operations**

In behavior analysis, motivation is an essential component that is often overlooked. The common definition of motivating operations includes two operations and two effects: the establishing/ abolishing operation and the evocative/abative effect (Cooper, et al., 2007). In terms of the establishing/abolishing operation, we are talking about an increase/decrease, respectively, in the effectiveness of some stimulus as a reinforcer. In terms of the evocative/abative effect, we are talking about the increase/decrease, respectively, in the class of responses that has resulted in the

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*(Continued from page 21)* aforementioned reinforcer. What does this mean?

We can analyze this in a simple, hypothetical scenario. Let's use sleep as our example. Last night, I slept a total of 2 hours. We can say that I am "sleep deprived." This state of deprivation has done something interesting. It has established sleep as an effective reinforcer. It's very easy to think of a night that you did not get much sleep. The stimulus that may be most reinforcing the next morning is an opportunity to sleep. Now that sleep has been established as a powerful reinforcer, what will I do about it? We will see an evocative effect, in that I am now likely to engage in behavior that has led to sleep in the past (e.g., staying in bed, taking a nap as soon as it's available, etc.). Note that these behaviors may or may not be socially appropriate.

Let's now turn to our second operation/effect: abolishing and abative. Let's use food as our example. I've just had a wonderful dinner. Steak, potatoes, Brussel's sprouts, bread, wine, and so on. I am stuffed! This feeling of being "full" has an interesting effect on food. Because I've just eaten all this food, the effectiveness of food as a reinforcer has been abolished. How likely is it that I will accept food at this point? We will also see an abative effect, in that the likelihood that I will engage in "food-seeking" behavior is reduced. For example, I am unlikely to drive to McDonald's, make a sandwich, or order chicken Alfredo from my local delivery restaurant.

#### Why Should We Care?

As a newly minted BCBA, problems such as these should prompt a look at our ethical guidelines. Let's do just that. While a full review of the guidelines is beyond the scope of this Clinical Corner, we can pull out some important specifics that will help. Several of the guidelines discuss the importance of talking to consumers in language that is easily understandable (<u>Behavior Analyst Certification Board Guidelines for Responsible Conduct</u> 1.04a; 1.05b; 1.05d; 2.04b; 3.03). That's great! But why does the BACB see this as an important part of our job? It can all go back to what behavior analysis fundamentally is: a science.

Applied behavior analysis has 7 dimensions, outlined by Baer, Wolf, and Risley in 1968. These dimensions outline what ABA is and does. However, there are some additional characteristics that are overlooked and yet of great importance. ABA should be public and doable (Cooper et al., 2007). What do these mean? When we say that behavior analysis is public, it essentially means that our methods are out there for the public to analyze. We don't sit in dark offices, manipulating the world to do what we want. Our methods are out there for the general public to see, analyze, and understand. Think about physics. The principles of physics are always acting on us. Though we may not fully understand all the details (physicists spend immense time learning those details, as do BCBAs for behavior analysis), the basic concepts are available for the general public to learn and understand. This takes some of the mystique of the science away. While sciences have made their mistakes in the past, they are ultimately available for the public to observe, analyze, and understand.

This feeds into our next concept: doable. We saw that physicists spend long hours learning the specifics and details of their science. BCBAs and BCaBAs do the same for behavior analysis. But this doesn't mean that the methods are mystical, beyond the understanding of any others. In fact, this Clinical Corner shows just the opposite! Of course, to fully understand and ethically engage

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in behavior analytic science, the proper training is required. However, the general principles are readily available for anyone to learn about. To fully "do" ABA requires extensive training and precise implementation, but an appreciation of key ABA principles is available to virtually everyone.

#### Conclusion

Since behavior analysis is the most widelyaccepted and scientifically-based treatment for individuals with ASD, it is important that consumers know what they are getting. The only way to truly garner informed consent for the work that is done is to inform. The best way to inform is to explain, in simple and non-technical terms, just what is actually being done. Think of a time that you spoke with someone who worked in a field that was completely alien to you. Listening to that person talk about their job may be interesting, but you likely will stop attending once you don't understand what's being said. We have a responsibility to disseminate behavior analysis to the general public and to the parents with whom we work. We should teach parents that the concepts we are using in therapy are actually occurring all around us. This will help show consumers that we are not trying to hide anything, or use

some fancy procedure that no one understands. While it takes highly competent and trained individuals to ethically and appropriately apply these techniques in therapy, it can help show consumers that we have nothing to hide.

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## From the Archives What Autism Awareness Should be About

By David Celiberti, PhD, BCBA-D



The following article about autism awareness appeared in the Spring 2013 issue of Science in Autism Treatment. April is autism awareness month, and this installment of "From the Archives" outlines a different type of awareness, one that is multidimensional and nuanced. Although consumers, professionals, and the media are aware of the current prevalence of autism, this article proposes that deeper appreciation of science and broader application of scientifically-backed treatments for autism is needed to assure that individuals with autism receive the quality services that they deserve.

Patrick O'Leary, MA, BCBA SIAT From the Archives Coordinator

pril is Autism Awareness Month. The blue puzzle pieces will appear on thousands of Facebook pages and billboards, and the media will give greater attention to, and information about, autism. Further awareness is a wonderful thing, as detection and diagnosis are necessary first steps to accessing help in the form of treatment, information, and support. With over 400 treatments from which to choose, parents of children with autism need guidance, tools, and accurate information to make the best possible choices for their children; choices that will undoubtedly have a profound impact on both their current quality of life and their children's future.

Clearly, autism spectrum disorder (ASD) is no longer the rare diagnosis that it once was. With the incidence of one in 68 children and one in 42 boys, our own families, neighbors, and coworkers are all touched by autism. In fact, the sheer numbers have heightened awareness of autism in and of themselves. This awareness is essential: it promotes early detection, and with early detection, we hope for a relatively clearer course toward effective treatment and better outcomes. Sadly, however, the early detection of autism alone does not always mean a seamless path to intervention. Furthermore, families whose children are diagnosed with autism are still not

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able to expeditiously access the most effective science-based treatments available. Instead, families often have to sort through over 400 pseudoscientific treatments until they arrive at the most effective and research-proven intervention in addressing the complex disorder of autism. We must do better!

"Autism awareness" should be about more than just detection and diagnosis. It has always been ASAT's hope that the conversation around autism awareness would be broadened to focus upon the obstacles that separate individuals with autism from effective, science-based intervention and distract their families, caregivers, and teachers from accurate information about effective autism intervention. Below are 10 ideas about what Autism Awareness should be about, along with ways that ASAT can assist families and providers in navigating the complex maze of autism treatment options.

#1 of 10 ideas about Autism Awareness: "Autism Awareness" must differentiate effective treatments that are scientifically validated from the plethora of "therapies" and "cures" lacking scientific support. Such a distinction is critical.

Autism treatment is a multi-million dollar industry with 400+ alleged therapies and interventions. For the majority of these methods, science is overlooked in favor of pseudoscience, and they are marketed with heart-wrenching testimonials or poorly crafted surveys, anecdotes, slow-motion video montages, and inaccurate and even outrageous claims that are touted as evidence of effectiveness. Aggressive marketing of these so-called "therapies" and "cures" is absolutely overwhelming and it drowns out accurate information for parents who are desperate to help their children.

For most other medical conditions, a provider who disregards proven intervention in favor of using a "fringe" treatment could then be sued for malpractice! Such safeguards do not exist for autism treatment. We do no favors for children with autism, their families, and those charged with providing effective services when we ignore the quackery and do not counter baseless claims. Families deserve better. Visit our website to learn more about the <u>scientific support behind various</u> <u>autism treatments</u> well as <u>the pitfalls of testimonials</u>.

#### #2 of 10 ideas about Autism Awareness: "Autism Awareness" must recognize the responsibility to make sound choices.

Decision-making power comes with tremendous responsibility. There are myriad stakeholders whose decisions have profound implications for children and adults with autism - not just parents, but siblings, teachers, treatment providers, administrators, program coordinators, and taxpayers.

- Scientists need to take responsibility in making their findings about an intervention's effectiveness clear, unambiguous, and unexaggerated.
- Administrators and program leaders need to take responsibility in identifying internal and external training opportunities that further their staff's competence with evidence-based practice. Additionally, they should make sure their staff receives the support needed to sustain these efforts and to continually engage in data-based decision making when both selecting and monitoring interventions. They must be savvy and selective in their selections of trainings for their staff and not fall prey to gimmicks, splashy sales pitches or fads.
- Providers need to select procedures which are based on published research, adhere to their (Continued on page 27)

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discipline's ethical guidelines about evidencebased practices, and maintain a commitment to ensuring that parents have truly been given the opportunity to provide informed consent. For example, if there is no scientific evidence to support an intervention that one is using, then it is ethical obligation of the professional to inform parents of this. Please see Principle 1 F of the Ethical code for occupational therapists, section 2.04 of the Ethical Principles of Psychologists and Code of Conduct, and section 2 of the Guidelines for Responsible Conduct for Behavior Analysts.

 Parents must continue to exercise caution in sorting through autism treatment options to make the best possible choice for their children, particularly since many providers do not make the path to effective treatment clear and simple.

There are far too many individuals with autism who do not have access to effective treatment, are receiving ineffective treatment, or are subjected to treatments which are, in fact, dangerous. Every minute of ineffective intervention is one less minute spent accessing effective intervention. Every dollar spent on an intervention which does not work depletes resources available for interventions that do work. For questions to ask to make sure that the individual with autism in your life is receiving science-based treatment, read more about the following three phases of inquiry about particular interventions and their associated questions and considerations in *The Road Less* Traveled: Charting a Clear Course for Autism Treatment:

- Phase I: Exploring the viability and appropriateness of a particular treatment approach.
- Phase II: Assessing the appropriateness of an intervention under the supervision of a specific service provider for a specific individual with autism.

• Phase III: Monitoring the implementation of the treatment and evaluating effectiveness.

#3 of 10 ideas about Autism Awareness: "Autism Awareness" must alert and remind the community that available information on the Internet (and actual information from providers) varies greatly in accuracy, and, in fact, can be completely wrong. This cannot be overstated.

As we know, not all information on the Internet is reliable and accurate. You have probably heard the term, *caveat emptor* ("Let the buyer beware"). Consumers must also practice *caveat lector* ("Let the reader beware").

Often Internet information is deemed equivalent in relevance, importance, and validity to research published in peer-reviewed scientific journals, but it is not. Testimonials and uncontrolled studies from so-called researchers can lead parents astray and be a tremendous source of distraction. Parents of newly-diagnosed children may be particularly vulnerable. Know the red flags to avoid and learn how to evaluate research by visiting our website. Our library of articles highlights scientific concepts and methods as they relate to potential autism interventions, with the goal of providing families, educators and clinicians with the information they need in order to be savvy consumers of marketed treatment products and therapies.

#4 of 10 ideas about Autism Awareness: "Autism Awareness" must include responsible reporting by journalists who fully embrace their role as "public educators" and who are committed to spreading accurate information.

There are scores of "miracle cures" and "breakthroughs" for autism which receive wide-(Continued on page 28)

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spread media attention (e.g., print and online news outlets, radio and television programs), even if they have not been shown to be beneficial through published research. Unfortunately, effective treatments typically receive less press because their providers are often focusing more on outcomes than on garnering media attention. Things are not likely to improve in terms of access to effective treatment for the autism community without more accurate representations of autism treatment in the media.

The media have a responsibility to scrutinize sensational claims related to a proposed treatment, and to be knowledgeable enough to report on those treatments with the most scientific approach. Such scrutiny can be accomplished by asking important questions such as:

- Are there any published research articles in peer-reviewed journals documenting the efficacy of the intervention method? If not, why not? If so, are the studies well designed? Have they been replicated by others?
- 2. Who am I interviewing for this story and what are his/her qualifications? Is he/she making claims of efficacy/effectiveness that are not supported by scientific data? What does he or she stand to gain by this interview? *Who* may benefit financially from my article?
- 3. How much does the intervention cost? Are these costs reasonable? How is it paid? Is there any evidence of harm imposed by this intervention? What are the risks?
- 4. What kinds of training and supervision do treatment agents need to have before implementing the intervention? If none or very little, have I explored the ethics surrounding this and if there is adequate protection for consumers, particularly for those with autism?

- 5. What position statements have respected professional organizations generated which support, or do not support, this intervention method? Are there science-based interventions (such as applied behavior analysis) which are recommended by these organizations?
- 6. Have I consulted with an unbiased entity for their input?
- 7. Have I taken necessary steps to avoid putting caregivers and treatment recipients at risk?

To support accuracy in the media, ASAT has developed resources for journalists. For examples of accurate and inaccurate reporting, please visit our <u>Media page</u> and learn more about our Media Watch efforts.

#5 of 10 ideas about Autism Awareness: "Autism Awareness" must recognize the critical need for newly-diagnosed children to access effective treatment ASAP. We know that early intervention makes a huge difference.

For many conditions, such as Lyme disease and breast cancer, awareness is essential because awareness promotes detection, and with detection comes a well established set of treatment options. Furthermore, optimal prognoses are often associated with early detection. Within a few short weeks of proper diagnosis, individuals have opportunity to receive the best treatment that science has to offer. If their conditions are not detected early, then access to such treatments is delayed and their conditions will likely worsen.

With autism, the story is too often different. Unfortunately, at the time of diagnosis, many children with autism are not accessing the best that science has to offer, and their families are bombarded with solicitations to partake in any num-

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# Receiving a diagnosis of autism was hard

Choosing amongst hundreds of possible treatments and fads for your child is absolutely overwhelming

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ber of the 400+ autism treatments, most of which lack even an iota of scientific support.

While individuals with autism learn and progress across their life span, it is widely understood that the earlier intervention begins, the greater the potential for an optimal outcome. It is also important to remember the limited window of time there is to prepare children for the "least restrictive setting" once they enter the public school system. Investment in effective early intervention saves a tremendous amount of resources over an individual's lifespan. These cost savings should become an integral part of conversation about intensive early intervention. Children's futures hang in the balance, which is clearly a function of their early intervention experiences. Please see the following articles on the ASAT's website:

- Early Detection and Intervention
- Teaching an 18-month-old
- <u>Summary of research on early intensive behavioral intervention</u>

#### #6 of 10: "Autism Awareness" should also instill hope for a better tomorrow for those individuals who are not part of the "best outcome" group.

With the right treatment, all individuals with autism demonstrate improvement, and many go on to lead happy, productive and fulfilling lives. Much of the conversation about treatment, however, focuses on "best outcome" and this is often defined as entering "mainstreamed" education settings or losing the diagnosis of autism altogether. This may delegitimize the significant progress made by most individuals with autism, whose outcome may be different, but nonetheless important and meaningful. We know, for example, with intensive intervention which is based on

applied behavior analysis (ABA), individuals with autism learn to work in the community, access faith communities, enjoy a range of recreational pursuits, become independent in their self-care needs, have meaningful relationships and are active, contributing members of their communities. The importance of such gains for individuals with autism must be recognized as a significant benefit of effective treatment. Autism awareness should definitively include a celebration of a broad array of outcomes!

Please visit our <u>website</u> for more information on teaching procedures using the principles of applied behavior analysis. You may also consider reviewing our library of responses in the <u>Clinical</u> <u>Corner section of the website</u>.

#### #7 of 10 ideas about Autism Awareness: "Autism Awareness" must mandate accountability from all treatment providers.

Accountability involves a shared commitment to clearly-defined targets, participation in data collection, respect for the scientific method, and proper solicitation of informed consent. It should be every treatment provider's obligation to objectively measure outcomes. No one should be permitted to boast claims which are unsupported by data. No one should get a pass on accountability, transparency, and objectivity just because they come from a particular discipline which has not proven their methods through research.

Providers using interventions which lack scientific support have an ethical obligation to share this fact with consumers, and to exercise caution in making claims about outcomes. Far too often applications of interventions which lack any scientific support are carried out in a manner devoid of transparency and objective measures to substantiate claims of the treatment's success. This *(Continued on page 31)* 

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must not be tolerated. They must make sound, scientifically-validated decisions and recommendations. Please encourage all members of your team to <u>subscribe</u> to our free newsletter, *Science in Autism Treatment*. We also have more information on <u>Ethics and Evidence-based Practice</u>.

#### #8 of 10 ideas about Autism Awareness: "Autism Awareness" must involve recognition that an abundance of clinical research already exists, and this body of research matters.

In the world of autism intervention, peerreviewed research which should guide and inform treatment efforts is too often disregarded or ignored. Imagine a world in which it was deemed acceptable for mainstream cancer providers to treat childhood leukemia with methods they preferred without consideration of existing research. Sadly, that is the reality of autism treatment, as many providers use their unresearched but personally-preferred methods, often divorced from scientific support and carried out without any objective means to assess benefit.

There are thousands of published research articles which can guide autism treatment. Published research exists which documents effective interventions to address a broad range of issues related to autism such as improving conversation skills, promoting academic skills, reducing challenging behavior, and developing tolerance for health care procedures. These peer-reviewed studies are often not accessed by treatment providers and caregivers. Thousands of researchers, experts in their fields, have published their findings in peer-reviewed journals, yet their findings are often overshadowed by a media which emphasizes sensationalism about the "next big thing" in autism treatment over objective scientific research. Please visit our website often to

read <u>research synopses</u> and our vast library of <u>treatment summaries</u>.

#9 of 10 ideas about Autism Awareness: "Autism Awareness" should help us identify and overcome the barriers that families and children face even within their own communities.

Not every child with autism is invited to birthday parties. Not every faith community welcomes families of children with autism. Not every school provides meaningful contact between students with autism and their typically-developing peers. Not every community provides recreational and other important opportunities for individuals with autism.

Like all families, those with children with autism want to be able to live comfortably and fully within their community. That may mean simply going to the park, attending religious services, going to the movies, or eating at a restaurant. Unfortunately, many families are not able to access these activities because the social community is not sufficiently informed or prepared to include individuals with autism within these settings, and, in some cases, the children are not taught how to manage these situations well due to ineffective treatments. As a result, families of children with autism are often isolated. This lack of opportunity is both a function of misinformation about autism and the lack of awareness about the successful efforts of those who have overcome such barriers. With 1 in 68 children being diagnosed with autism, every facet of society needs to be informed of the supports necessary for individuals with autism to succeed within their communities. Our website contains information on how to successfully include children with autism in the classroom and including people with autism in the workforce.

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#### #10 of 10: "Autism Awareness" should be about the reality that the hundreds of thousands of children with autism will soon become hundreds of thousands of young adults with autism.

When children with autism turn twenty-one, funding for services drastically changes. As a result, there are very few quality programs for adults with autism. We are facing a crisis in the field, with a scarcity of services for adults with autism and the absence of a clear strategy for closing the gap between the ever-increasing need, and an unprepared supply of resources. Quality science-based services for individuals with autism must continue into the adult years. Research indicates that interventions such as applied behavior analysis (ABA) can effectively help adolescents and adults with autism realize their fullest potential. The conversation about "cure" often delegitimizes and derails important conversations about how we can help individuals with autism to live and work independently, develop meaningful relationships, reduce challenging behaviors which may limit opportunities, access faith communities, and enjoy the array of recreational pursuits which are available within their communities. Those are important conversations to have.

ASAT is committed to broadening our scope so that we can be a part of this important dialogue; an essential dialogue to be had. In response to this need, we are developing a webpage to address <u>lifespan</u> topics. Learn about maximizing employment opportunities, strategies to support older learners, and a guide for transition to adulthood.

We are expanding our collection of synopses of research including <u>adolescent and adult participants with autism</u>. Finally, we have written about

this extensively within Media Watch. Please see the following examples:

- ASAT <u>responds to MSNBC's</u> "1 in 3 autistic young adults lack jobs education"
- ASAT <u>responds to Triblive.com's</u> "Pa. Autism Services Hope to make inroads in workplace"
- ASAT <u>responds to Portland Press-Herald's</u> "Graduating to an Uncertain Fate"
- ASAT <u>responds to News.com.au's</u> "Cost of autistic children cripples parents up to \$50,000 a year"
- ASAT <u>responds to FoxPhilly.com's</u> "Parents Of Autistic Children Worry What Life Will Bring When They're Adults"
- ASAT <u>responds to TheStar.com's</u>
   "Groundbreaking adult autism survey reveals mountain of unmet needs"

We hope these ideas have furthered your appreciation of the complexities and nuances surrounding autism awareness. We all play a role in bettering the lives of individuals with autism and helping their families and supporters becoming skilled and savvy consumers. Embrace that role with an eye toward identifying what additional steps you can take to become a contributor to important conversations and an even bigger part of the solution for there is much more important work to be done.

For more information on how to join ASAT in being part of the solution, please visit our website. On <u>this page</u> you will learn more about how to become a sponsor, volunteer, or extern. Or you can make a donation. Join us in making a difference in the autism community! ONOR WALL 20

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## **Article Summary**

## The Persistence of Fad Interventions in the Face of Negative Scientific Evidence: Facilitated Communication for Autism as a Case Example<sup>1</sup>

By Alice Bravo, MEd.

<sup>1</sup>Lilienfeld, S., Marshall, J., Todd, J., & Shane, H. (2015). The persistence of fad interventions in the face of negative scientific evidence: Facilitated communication for autism as a case example. *Evidence-Based Communication Assessment and Intervention*, o6–101. DOI: 10.1080/17489539.2014.976332. Available free for a limited time: <u>http://goo.gl/o7DqGn</u>

#### Introduction

ith the multitude of marketed interventions for autism spectrum disorder (ASD), identifying which to pursue and which to avoid is a common struggle for families of children with ASD, as well as the providers who serve them. Researchers have subjected many of these interventions to scientific scrutiny. Unfortunately, even after being found to be ineffective by scientific research, some interventions continue to be marketed and implemented. In a significant article published in the journal Evidence-Based Communication Assessment and Intervention, Lilienfeld, Marshall, Todd and Shane (2015) - researchers from Emory University, Eastern Michigan University and Boston Children's Hospital - discussed reasons why interventions that have been deemed ineffective by scientific research continue to be utilized. In tackling this important and relevant topic, the authors used

facilitated communication (FC), a practice targeting expressive communication among nonspeaking individuals, as a case example.

#### **Facilitated Communication**

Facilitated communication is a practice involving two people: the non-speaking individual and a "facilitator" - an individual who supports the hand and/or arm of the non-speaking person as he or she uses a keyboard or similar device to type a message. The goal is that this supported use of a keyboard will allow the non-speaking individual to communicate. This approach to expressive communication intervention gained popularity in the early 1990's, but by the mid- to late-1990's it had been discredited by research and was thus rejected by the scientific community. This was largely due to the replicated finding that facilitators tended to have control over the actual communication. While facilitators were often convinced that they were simply supporting an individual's hand, rigorous studies tested this by asking questions to FC users in two conditions; in one, the facilitators did not know the answers to the questions, and in the other, they did. The studies demonstrated that FC only "worked" when the facilitators knew the answers to the questions posed. Additionally, numerous abuse allegations against FC users' caregivers emerged through communication supported by facilita-

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tors, the majority of which were never substantiated. Yet despite all of the evidence against FC and a previous decline in its use, FC use has persisted and even appears to be making a comeback, sometimes under a new name (e.g., "supported typing").

#### "Fad" Treatments

Lilienfeld et al. (2015) analyzed what could lead to the persistence of "fad" treatments such as FC; a fad treatment being one that has "short-lived enthusiasm" and a "rapid loss of popularity" (Best, 2006). Two typical routes that fad interventions tend to take were described: 1. They are demonstrated as ineffective by scientific studies and subsequently abandoned, or 2. They are validated by research and thus adopted by clinical professionals (Overholser, 2014). In their analysis, Lilienfeld et al. (2015) identified a third route of fad interventions: once deemed unsuccessful by scientific research, the fad treatment "goes underground" and remains utilized within various professional communities, where it acquires enough respectability to be sustained. In this situation, there are too few researchers concerned with the treatment's credibility and, as a result, the scien-



tific community fails to speak out against its continued use.

#### Rationale for the Persistence of Fad Treatments

What causes an intervention to take this third route? One reason such treatments seem to attain a strong footing is due to "naïve realism" – the belief that our subjective experiences regarding treatment effectiveness outweighs that of data gathered through controlled studies (Ross & Ward, 1996). Consequently, when an individual hears about or sees what appears to be successful implementation of FC, he or she may believe that this single experience negates the findings of scientific research.

An additional factor is "confirmation bias," which leads us to pursue evidence that confirms our existing beliefs and to disregard or explain away evidence that does not (Nickerson, 1998). Confirmation bias may lead individuals to focus on the few studies that demonstrate success of FC, while ignoring the considerably larger number of studies demonstrating otherwise. In FC's case, not only are there more studies disproving its effectiveness, but also the better-controlled studies have reported the least cases of support for FC (Mostert, 2010).

A third element potentially contributing to the persistence of fad treatments is the "familiarity backfire effect." This is a phenomenon in which an individual believes something to be true and/ or effective simply due to hearing about it multiple times – that is, being "familiar" with the treatment. For this reason, Lilienfeld et al. (2015) argued that one of the important aspects of combatting a scientifically debunked and yet persisting fad treatment is to provide a replacement treatment. In the case of FC, this involves the promotion of scientifically supported augmenta-*(Continued on page 36)* 

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tive and alternative communication (AAC) methods and applied behavior analysis (ABA). Both of these treatment methods are supported by scientific research and can be used to target expressive communication, as FC was originally meant to do.

#### Conclusion

The widespread promotion of evidence-based interventions for ASD and related disabilities can provide parents with a genuine hope for supporting their loved ones. Lilienfeld et al. (2015) encourage researchers in the fields of communication disorders, psychology and education to become more involved in speaking out against fad interventions that have been discredited, and simultaneously to actively promote scientifically supported interventions. In addition to conducting research, scientists play an important role in *disseminating* their findings in order to ensure that unsupported interventions are permanently put aside in favor of ones that are backed by science.

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## **Research Synopsis**

## Evaluation of Early Intensive Behavioral Intervention in Community Settings: Public Preschool and Kindergarten

This study compared Early Intensive Behavioral Intervention (EIBI) based on the UCLA model developed by Lovaas and colleagues with an eclectic treatment.

We hope you will find it informative!

Sharon A. Reeve, PhD, BCBA-D Research Synopses Coordinator

Eikeseth, S., Klintwall, L., Jahr, E., & Karlsson, P. (2012). Outcomes for children with autism receiving early and intensive behavioral intervention in mainstream preschool and kindergarten settings. *Research in Autism Spectrum Disorders*, *2*, 829-835. doi: 10.1016/j.rasd.2011.09.002

Reviewed by: Casey L. Nottingham, Caldwell University

#### Why research this topic?

Early and intensive behavioral intervention (EIBI) is widely implemented with individuals with autism spectrum disorder (ASD) as in-home or center-based specialized settings. Several studies support the use of EIBI for improving academic and adaptive behaviors. However, limited research exists on the effectiveness of EIBI implemented in community settings such as preschools and kindergarten classrooms. This may be because EIBI is intensive and comprehensive and trained instructors and supervisors are necessary. Additionally, caregiver involvement is typically required. To add to the evidence of the effectiveness of community-based EIBI, the authors compared EIBI in public preschools or kindergarten classrooms to treatment as usual in these settings.

#### What did the researcher do?

Participants included 59 children who were diagnosed with autism and had not previously received EIBI services. Thirty-five participants received EIBI services in mainstream classrooms. Twenty-four

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received treatment as usual. All children received services in their local, publically funded preschools or kindergartens. Children in the EIBI group also received services at their homes.

Most of the EIBI therapists had no prior training or experience. Their supervisors had a minimum of a bachelor's degree, some had master's degrees, and one was a Board Certified Behavior Analyst. EIBI was based on the UCLA model developed by Ivar Lovaas and colleagues. This model begins with highly structured, one-to-one teaching such as discrete trial training and gradually moves toward more child-led interactions and inclusion in group settings. Although the curriculum is standardized in a manual, the intervention goals are individualized for each child. Treatment intensity ranged from 15 to 37 hours per week of intervention for the EIBI group (average = 23 hours per week), and weekly supervision meetings were held that included the child, primary therapist, caregiver, and supervisor.



In the treatment as usual group, the primary therapists were special education teachers who had a minimum of a bachelor's degree; teacher assistants sometimes also provided intervention. Treatment in this group was eclectic including alternative communication (e.g., signs, symbols), sensory-motor therapies, behavioral analytic techniques, and procedures that the special education teachers created based on personal experience.

The authors measured adaptive and interfering behavior with the Vineland Adaptive Behavior Scales (VABS) and the Childhood Autism Rating Scale (CARS). These assessments were given at the start of the study, after one year of treatment, and (for the EIBI group only) after two years of treatment.

#### What did the researchers find?

The researchers found that the EIBI group and treatment as usual group did not differ in the adaptive and interfering behavior measurements at the start of the study. After one year of treatment, the

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children receiving EIBI showed larger gains in adaptive behaviors and greater reductions in interfering behaviors and behaviors characteristic of ASD than did the children receiving treatment as usual. The EIBI group continued to improve from Year 1 to Year 2, although the improvements were smaller than those seen from Intake to Year 1.

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

Several limitations exist in the current study. First, the individuals who completed the assessments for children in EIBI were the therapists providing services. Because the therapists were responsible for the outcome of the children, they may have been inclined to assign lower scores on the intake assessments and higher scores on the later assessments. Second, the participants in the study were not randomly assigned to either the EIBI or treatment as usual group. This is a problem because although the two groups did not differ with regard to their adaptive and interfering behavior scores at the beginning of the study, they might have differed on other variables; random assignment to groups would allow for greater confidence that the groups were comparable. Nevertheless, the study does add to the limited evidence of the effectiveness of community-based EIBI and suggests that public school educators can deliver EIBI effectively.

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