

Science in Autism Treatment

Newsletter of the Association for Science in Autism Treatment

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LETTER FROM DR. DAVID CELIBERTI, ASAT EXECUTIVE DIRECTOR

With 2017 well underway, I hope this new year has brought you good things. My hope is always that each new year will bring a deeper appreciation for the relevance of science in guiding autism treatment, greater

accountability across all treatment providers, more accuracy within media portrayals, and heightened awareness of the pitfalls and distractions of pseudoscience.

As you may recall, we shared details about some of our myriad accomplishments in the Fall 2016 issue of *Science in Autism Treatment* (SIAT). It is with great pride and optimism that I outline an array of goals and initiatives for 2017:

- Increase *Science in Autism Treatment* (*SIAT*) subscriber base to 12,000 with targeted focus on underserved areas in the US and throughout the world:
- Publish more synopses of recently published research to keep up with the growing number of studies on interventions for autism, considering requests from our website visitors:
- Create additional Public Service Announcements (PSAs) related to ASAT, our resources, and best practices in Spanish;
- Distribute our media resource booklet to international journalists;
- Create additional content for our comprehensive website as well as easier navigation across website pages and more comprehensive cross-listing of content;

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ASAT

Providing Accurate, Science-Based Information - Promoting Access to Effective Treatment

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- Continue to expand our website offerings for parents with a newly-diagnosed child, medical professionals, and members of the media;
- Increase our Facebook fans to 12,000, Twitter followers to 1,500 and increase ASAT's presence on quality autism community blogs;
- Increase reach to medical communities, particularly pediatricians and family practice doctors, sharing information about ASAT and science-based treatment;
- Increase ASAT's presence at state, regional, national, and international conferences;
- Increase grant proposal submissions to support our work;
- Provide information regarding ASAT and autism to faculty in ABA, special education, psychology, occupational therapy, and speech pathology programs nationwide;
- More extensively tap into the wealth of experience and expertise of our Advisory Board members;
- Recruit new writers and increase number of Media Watch letters and Media Alert posts in response to
 accurate/inaccurate portrayals of autism treatment, with heightened focus on international topics, biomedical advances and lifespan considerations;
- Continue to prepare new monthly blog posts with Different Roads to Learning; and
- Develop a 2017 strategic plan in preparation for our 20th anniversary.

As I did in my Fall 2016 column, I will end this letter with an appeal. The ongoing success of ASAT is predicated on the financial support and generosity of our donors. We are committed to maintaining and updating our website (asatonline.org) and to distributing this free quarterly newsletter; however, we cannot carry out our important work without your financial support, particularly in tough economic times.

If you support our mission, believe in the promotion of science, and recognize the need for accurate information about autism treatment -and we believe you do -, please join our efforts by donating today. We are so grateful to our 2016 donors listed on page 45.

In addition, if you are affiliated with an organization that shares ASAT's commitment to science in the treatment of autism, I invite you to consider becoming a 2017 Real Science, Real Hope Sponsor. Last year, 60 organizations became sponsors and our goal is to be even more successful in obtaining sponsorships in 2017. Please see page 42 for more information.

Warmly,

David Celiberti, PhD, BCBA-D

INTERVIEW

Lessons Learned, Lessons Shared: An Interview with Dr. Sabrina Freeman, Parent, Author, and Advocate David Celiberti, PhD, BCBA-D

David: Thank you for the opportunity to interview you about your experiences and the many lessons that you have learned parenting a child with autism over the years. I want to let our readers know that you are replying to my questions as an individual and that your view does not necessarily represent the views of our board. Having said that, I am looking forward to this interview as I know that your responses will be direct and unfiltered, yet thought provoking and insightful.

First and foremost, can you tell our readers a bit about you and your family?

Sabrina: I'm happily married with two children. I have a typically developing 18-year-old son, and an adult daughter with autism, both of whom live with us. We live in a small university town in the Pacific Northwest 30 miles south of the Canadian border. We moved from Canada to the USA in 2009. My responsibilities as a member of the adjunct faculty include teaching courses on research methods and organizations for the Department of Sociology.

David: Please describe your daughter's journey to diagnosis and ultimately to early intervention and some of the lessons you learned early on.

Sabrina: My 27-year journey has taught me many lessons that I'm happy to share with our readers. I was basically minding my own business, pursuing my doctoral degree at Stanford University, when my young child was diagnosed with autism. The diagnosis was confirmed one week before my first comprehensive exam. I had attended a *Mommy and Me* program with her and was blocked from enrolling her into a community center preschool at 3 years of age. The preschool teacher told me that my daughter should be in a special needs classroom because something was wrong. Since this was my first-born child, and I was never one to compare developmental dif-



ferences in children since I was a firm believer that children develop at different rates, I was quite shocked about this discrimination against my child. How, you may ask, do they discriminate against a three-year-old? Well, it's simple: they create a rule stipulating that a child who is not toilet-trained is not allowed into the program. That way, they can segregate a child without looking like it's discrimination based on disability. This technique may be used to block all children with special needs because it is unlikely they will be toilet-trained by 3 years of age.

Lesson No. 1: If your child is being blocked from a program, the rationale may look legitimate; however, chances are, they simply may not want your child.

At this point you have a choice: either challenge them by throwing financial resources at them and fight, or find a community or program more worthy of your child's participation. I put my child in the university preschool program where they were smart enough to avoid using that criterion to exclude children with special needs.

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After the preschool teacher delivered the bombshell about my child in an off-handed manner, the socalled experts in the community gave me the best place to get my child evaluated. The place they recommended had considerable prestige associated with it, but the clinicians were actually completely incompetent when it came to autism treatment options. The diagnostic team was acceptable, but larded down with professionals who have no role in diagnosis, such as social workers and occupational therapists. Although the multidisciplinary team made the diagnosis, we had to pay for the entire cast of characters! Unfortunately, they were wholly lacking in expertise when it came to advice on effective autism treatment. You have to remember that the year was 1991, and there was little quality research available on science-based interventions for autism. However, in 1987, Lovaas' first study was published; the psychiatrist in my daughter's evaluation team should have known about that treatment. Instead, he suggested play therapy that he was "qualified" to do with my daughter. Consequently, I spent four months and a considerable amount of money watching a psychiatrist crawl around the floor as my daughter completely ignored him. My most vivid memory of the play therapy sessions came when, after many sessions, my child tired of the psychiatrist attempting to join her in her selfstimulatory behavior. She took his hand and, using it as a tool, lead him to the doorknob and had him open the door. He dutifully opened the door and she pushed him out of the room. After months of play therapy, he actually saw this as a breakthrough! I had started doing research on my own regarding play therapy, and realized that there was no science behind the method. The studies that had been conducted were uncontrolled case studies, anecdotal in nature and completely unscientific in orientation. In short, play therapy was a waste of my daughter's time and my money.

Lesson No. 2: Credential does not guarantee competence.

That a professional has a PhD behind his name and is a fellow at a prestigious university does not mean he is competent and knowledgeable. In short, demand to see the data supporting the interventions being implemented. Do not rely solely on professional opinion. Make sure that the professional is, indeed, knowledgeable about the state of the science in autism treatment and that he or she can produce peer-reviewed journal articles regarding the technique he or she recommends

In 1991, the World Wide Web was not broadly available to the public; however, I had access to Medline and started to search there. I actually came across Lovaas' landmark autism treatment study but did not understand how to gain access to the treatment for my daughter. The treatment looked like it was still in the lab and not available to anyone outside of the Los Angeles area. The fact that my daughter was not toilet-trained actually saved her future. I asked the psychiatrist if he knew anyone who could help toilettrain her. He gave me the name of a woman who could do this. By this time, I was very jaded and felt hopeless (although thinking back, perhaps he knew that his treatment was quackery and steered me towards the treatment that worked without jeopardizing his position - we'll never know).

I phoned the woman the psychiatrist had recommended. She happened to be an incredibly talented behavioral consultant who had worked with Ivar Lovaas as an undergraduate student and knew his IBT protocol intimately. I was actually very terse with her when I asked, "Can you toilet-train my child?" She said, "Yes, I can, but I can do a lot more." At this point, I highly doubted that this was the case because I'd just spent four months seeing incompetence up close with play therapy. We arranged a time to meet, and this tall, gorgeous woman with long painted fingernails walked into our home with a big plastic crate full of kiddy toys. She sat on the floor of our living room and I offered her coffee. She politely declined, clearly ready to work. My child ran out into the living room and gave a fleeting glance toward this woman, at which point she said, "Good looking!" I thought to myself, "who cares?" that my child is cute. She has autism and needs to be toilet-trained! I did not understand that the consultant was using praise; behaviorally reinforcing my child's glance. Then she pulled out a toy that hurled pieces high into the air with the push of a button. My daughter was intrigued. After

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considerable prompting and back and forth, my daughter said the first words of her life: "Push Please." My spouse and I almost fainted! Our 3-year-old just spoke her first words! At that point, I understood that the very technique published in 1987 by Lovaas, was being used in my living room in Palo Alto. I quickly realized that I needed to do a lot more reading on how to set up and maintain an IBT program. In one session, my daughter had learned more than in 4 months of play therapy (which ended that afternoon by phone)! I immediately arranged for this professional to begin work with my daughter.

Lesson No. 3: Judge a consultant by the progress your child makes, not by his/her credential or fashion sense.

David: Thank you for sharing that. Your story is an all too familiar one, particularly with your experience contrasting behavior analytic treatment with the more traditional psychodynamic treatments that were prevalent at that time. What role did you play in your daughter's intervention as well as in promoting the generalization of skills? How has that role changed over the years?

Sabrina: Once I realized that a treatment able to maximize my child's potential existed, I very quickly became a student of the technique. I personally watched every therapy session for years, until I understood the field of applied behavior analysis (ABA) when applied to intensive behavioral autism treatment. I consider Lovaas' genius as taking the principles of ABA, the field of developmental psychology and psychopathology, and applying these principles intensively to children with autism. At the time, however, I had never even heard of ABA. I only knew about the research that had come out of UCLA under Lovaas. As I read more about the treatment method. I realized that the science demonstrates that intensity is key. Even great interventionists cannot develop the child's full potential without the appropriate intensity of the treatment. The literature is very clear about this point. Consequently, we had to ramp up treatment hours to make it intensive. I became my child's treatment team case manager, hired a team of therapists

and made sure they received high quality training. Luckily, my consultant lived in town and was able to take on a central role in assuring therapist quality. Once I felt comfortable with the competence of the therapists. I was able to leave during therapy sessions. Although I had a very competent team, as a first-time mother, I was extremely over-protective. Also, it took me some time to embrace behaviorism because I was dispositionally anti-behavioral prior to my child's diagnosis. I came from a very childcentered, child-led philosophy vis-à-vis child-rearing, which may be effective for typically developing children; however, I learned that allowing a child with autism to lead will impair development, despite how much we want to reject that notion. In short, I had to become open-minded very quickly. That said, once I truly understood how behavioral treatment was implemented, I embraced the technique wholeheartedly.

Even when the therapists left for the day, my husband and I had to follow through with behavioral techniques. To illustrate, all the language gains, self-help routines, and overall development did not generalize without our follow-through. If the child cannot get needs met outside of a therapy session, then the child has not actually gained the skill. The follow-through was very difficult for us at the beginning; however, we eventually adopted ABA as a lifestyle, not something done from 9 to 5. When I meet experts in the field, I remind them that they may do this for a living, but we parents live ABA, or in the words of a friend of mine who has a son with autism, "We're living La Vida Lovaas." Unfortunately, if you want your child's progress to continue unabated, you need to follow through 24/7. This lifestyle is hard, but does become easier over time.

Lesson No. 4: Adopt ABA as a lifestyle and your child will keep learning. There is no end to the progress your child will make.

Due to the behavioral techniques used with my child during all her waking hours, we managed to advocate for her to receive the same opportunities as typically developing children. That was very difficult because at the time, we were living in Canada, which is a country with no federal legal protections for people

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with disabilities (unfortunately, the Canadian Constitution does not do the job). Canada has no Americans with Disabilities Act (ADA), no Individuals with Disabilities Education Act (IDEA), and no Mental Health Parity Act (MHPA) to protect disabled children from government discrimination; therefore, the advocacy was much more difficult for us. I think it is accurate to say that Canada helped me tremendously in my metamorphosis from a mild mannered person to becoming a Mother From H*II. I cannot stress enough how important it is to be indifferent as to whether school bureaucrats like you or not. If you need friends, do not look for them in the school system. That may actually impede your ability to advocate.

Lesson No. 5: When advocating for your child, school staff members don't have to like you. They have to respect and, perhaps, fear you.

My child was accompanied through her education with a trained ABA aide and attended a two-year college program with an aide as well. That would never have happened without having lawyers on speed-dial. Unfortunately, the system is very good at outmaneuvering parents. Lawyers are crucial to even the playing field. The key is to write down every interaction with every school official, from the teacher, the resource specialist, the principal, and vice-principal to the district-level bureaucrats. Keep a journal by your phone and in your car. That will make it easier for your lawyers to make a cogent case in front of a judge if the need should ever arise.

Lesson No. 6: When advocating for your child, if you are in a school district that is not cooperating, have a lawyer in the background.

David: Thank you for describing the role you played, particularly with respect to the lifestyle changes that you and your husband needed to make. What is your daughter doing now? And how is she supported?

Sabrina: From an early age, my daughter lived in a world where music occupied every waking moment.

Although this sounds quaint, the incessant singing made it impossible to go into any public place, including restaurants, libraries, bookstores, or movie theaters. Although she had a repertoire of hundreds of songs that she sang with perfect pitch in several different languages (including Japanese and Hebrew), it was clearly perseverative behavior. I remember standing in a bookstore in Palo Alto, California with my two-year-old daughter in my arms singing and the student behind me made a comment that this was extraordinary since children this age do not sing so well! Little did I know that, indeed, it was extraordinary, but not in the way we thought. Once she started her IBT program, we also started working on channeling her love of music into socially acceptable venues so that she could participate with others in making music, learn when to sing and when to be quiet. This work on her strengths allowed her to attend a fine arts high school as a double music major and eventually attain her associate degree in music at the local community college. Although she is a talented musician who plays many instruments well, her competitive advantage in life is her ability to transcribe music. Today, our daughter works as a musical transcriber, transcribing original works from composers around the world. Composers send her full symphonies as mp3s and she manually transcribes each of the 18 to 30 instruments into notation software so that each musician can receive the score for their specific instrument and the conductor receives a score with all the instruments included. She is able to do this because she has perfect pitch and the musical education required to know how to communicate the rules of music to the musicians. She also has many clients who are budding musicians who do not know how to take their songs and notate them. Her website and public freelancing websites bring in the business. She does the work and I interface with and invoice her clients, since it would be very difficult for her to do SO

Lesson No. 7: When looking at your child's future, think about what gives the child joy, and then work on a way to develop the skill for integration opportunities. On occasion, these skills may be applied to earning money and participating in the economy.

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David: It sounds as if this has been a full-time role in and of itself, yet somehow you managed it, while continuing to pursue your career and author a number of books related to autism treatment. What led you in this direction and what were your goals when publishing these works?

Sabrina: As you can well imagine from what I just described, I was so outraged about the purgatory parents of children with autism have to go through just to get their child the help they need, that I had to do something! I'm a firm believer in the Pay It Forward philosophy; since people helped me, and I had so much knowledge to share to prevent heartbreak, I really felt that I had to write these books. I knew that the difficult lessons I learned would be of value to help parents of children with autism advocate for their children, and to teach the important language skills parents are desperate to have for their kids.

As a sociologist, I also knew too much about the scientific method to ignore pervasive quackery in the world of autism treatment. The books I wrote are a way to push back against bureaucrats and give parents important knowledge. The first book I co-wrote was, Teach Me Language that used the principles of ABA to improve language skills once children had reached a level where they could be integrated into the school system or were very successful in EIBT programs but needed more work to prepare them for school. The next book I wrote, Science for Sale in the Autism Wars, documented the tremendous advocacy effort by a large group of parents who took the British Columbia Government to court (all the way to the Supreme Court of Canada) to fight for the rights of children with autism to be part of the single-payer health care system in Canada. Many of your readers may be surprised to know that IBT is not included in the healthcare system in Canada. The book documents the way government-paid technocrats created junk science to exclude our children with autism from through travelling roadshows and word of mouth. the system for their core health need. At the same time, I was spending hours and hours every day speaking to parents about how to create a behavioral treatment program for their children. This was taking up so much of my time that I could not work! So I created a video/DVD called, Autism: Now What Do I

Do? Families for Early Autism Treatment of B.C. (FEATBC), established in 1997 when I moved back to Canada, would send new parents a complementary video and parent packet. When parents called back, the phone calls were much shorter and more efficient. Although this was more efficient, while speaking to literally 1000s of parents I kept having to explain to them the problem with quackery in autism treatment. I quickly understood that I needed to write another book to teach them about science-based treatment for autism. That book is called The Complete Guide to Autism Treatments and is an attempt to make parents savvy consumers. This latest book does the following: 1) describes the science (or lack of science) behind the various treatments presented as ameliorating autism; and 2) educates parents on the rules of the scientific method so that they can protect their child against the newest selection of bogus autism treatments introduced into the lucrative marketplace.

Lesson No. 8: If you have knowledge to help the next parent coming down the pike, help that parent and Pay It Forward.

David: It is unfortunate that you and others have had to work so hard to debunk quackery when the onus should be on treatment proponents to provide legitimate data to substantiate their claims. Nonetheless, I applaud you for taking the time to author so many incredible resources. In fact, I had the opportunity to review The Complete Guide to Autism Treatments, which is how we initially met (readers can find the review of the second edition here). What lessons should advocates of scientifically validated treatments of autism learn from the resilience of pseudoscientific treatments?

Sabrina: In the early 1990s, quackery in autism treatment was alive and well; however, there was no efficient way for quacks to advertise. The way people learned about the latest snake oil for autism was Someone would invite a speaker who would provide testimonials and pamphlets, but it was not efficient. The Internet changed all that. Now, a slick website with testimonials can hoodwink a desperate parent very easily. In addition, social media amplifies the

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ability for quackery to prevail. Unfortunately, dry, boring, peer-reviewed journals cannot compete with slick marketing. In addition, testimonials are actually anti-science, which makes it uncomfortable for those who practice the scientific method to showcase an effective treatment by having a parent talk about how well their child did even though there is an army of parents who can personally describe their child's progress.

Furthermore, not only are purveyors of fringe treatments utilizing the Internet to sell their latest quackery, there are also legitimate fields of inquiry, such as the Speech and Language and Occupational Therapy fields, that are providing purported treatments for parents of children with autism, yet their studies never compare techniques to best practices in behavioral treatment. In the same way as a new antibiotic must be compared to the best old antibiotic in order to be considered equal or superior, so must any new autism treatment be compared to behavioral treatment to judge its relative efficacy. These pseudo-scientific studies never seem to do so; rather, they compare their so-called treatments to ineffective special education, which does not have a good track record when it comes to treating children with autism.

Lesson No. 9: If the purveyors of the newfangled treatment do not compare their therapy to Intensive Behavioral Treatment, do not consider it best practice (and consider the term "promising practices" an abuse of the English language).

David: In your view, what can be done to weaken the influence of pseudoscience in autism?

Sabrina: Demand that all new treatment modalities be compared to the correct comparison group: the group of kids that receives IBT. Otherwise, call out editors of these journals as ignoring the generally accepted rules of the scientific method.

In addition, another group that needs to be critically supervised is the cadre of government funded epidemiologists and health policy professionals who create Clinical Practice Guidelines, that somehow always seem to support the rationing or elimination of access to IBT. In short, many tenured professors create junk science to block the funding of IBT for children with autism. This happened in Canada, and despite the obvious bias of these guidelines, as determined by a Supreme Court justice, these guidelines were shared around the world with other government bureaucrats attempting to block funding for treatment.

Lesson No. 10: Be wary of Clinical Practice Guidelines that are funded directly or indirectly by governments that have to fund the treatment.

David: What do you see as the most serious issue to combat in autism currently?

Sabrina: The "go along to get along" issue. There is considerable fatigue that has crept into the subfield of autism treatment. As the field matures, there are many parents and professionals who have simply become tired of the fight. It's much easier for everyone to get along; however, this tendency is dangerous to the future of children with autism. To illustrate, although I love the work that Autism Speaks has done on their Autism Votes advocacy, I'm troubled by their acceptance of treatments with no science behind them. They want to keep everyone happy; however, that can be potentially counter-productive to children with autism.

Lesson No. 11: Never trust an organization based upon its size, reach or fundraising ability.

David: Please tell our readers about your current role as a board member of ASAT?

Sabrina: My role is to be the crusty parent who is a constant reminder to the professionals at ASAT that we need to always remember that the parent is the front-line portal to the child receiving science-based treatment. Although ASAT does a spectacular job providing information to the many different professionals who see or work with children on the spectrum, or those who report on autism in the media, my role as a parent is to always make sure that they un-

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derstand that the parent is key in the endeavor. I'm happy that ASAT now has a comprehensive parent page on their website, but we always need to do more to provide parents with the best resources available on the web. That's my goal in being on the board.

Currently I am involved in two committees, the Newsletter and Website Committee and the Scientific David: What suggestions do you offer parents of Review Committee. We recently overhauled our website and I have been focusing on enhancing navigation across the various pages and developing pages for parents of newly diagnosed children as well as parents of older children and adults. I also serve on the Scientific Review Committee and have spent time updating the scores of treatment summaries that we showcase on our website

Lesson No. 12: Remember, we parents are the reason these professionals have jobs. They would be out of business if they had nothing to offer our children; therefore, expect results or find new professionals.

David: Sabrina, I cannot overstate the value of having a board member with your expertise in research methods and the parent perspective. I am very grateful for all of your efforts in making our website and newsletter offerings accessible to parents who are new to the autism diagnosis. In some of your prior suggestions you spoke about the importance of asking questions, actively participating in the carryover of skills, and in taking copious notes documenting communication. What other suggestions can you offer parents of young children?

Sabrina: Do not inherit tomorrow's problems. Get your child into a science-based treatment program as soon as possible. As of 2017, that program is IBT based on the principles of applied behavior analysis (ABA). This treatment protocol will realize the full potential within your child. In turn, the gains your child makes will translate into a life of dignity, surrounded by professionals with solutions for your child irrespective of whether your child becomes an independent adult or someone who needs assistance throughout the lifespan. Once your child is in a highquality program, then you can start thinking about their long-term future.

Lesson No. 13: Get your child Intensive Behavioral Treatment (IBT) based on the principles of applied behavior analysis (ABA) as soon as possible.

young adults and older individuals with autism?

Sabrina: There is a subset of parents with children on the spectrum who are faced with such issues as their children driving and going to college independently. Although this is where I see the lion's share of writing on adolescents and young adults, I worry that it may be relevant to a subset of children on the spectrum who have had quality treatment, and may not speak to the ongoing challenges facing the majority of adolescents or young adults with autism. We need to do more to help this latter group.

As a parent representing this larger group striving to create a life full of joy and dignity, as long as we can figure out a way to set up their lives, here is one option I've found: If your child has been in a program for some time, and you see that the future is going to include full time supervision, I urge you to look into an ABA teaching home.

The goal of the teaching home is to have the person always improve and ideally master the various skills they need for increased independence. In addition, an ABA teaching home means that your adult son or daughter with autism will always be surrounded by an educated group of professionals, thereby avoiding the nightmarish scenario of the typical group home, with insufficient supervision and uneducated workers. There are several ABA teaching home models in the United States and Canada, although these models have not been widely replicated. I would like to see this model become more easily accessible and prevalent.

What do we do for those adolescents and adults who have progressed significantly and are very capable but not able to live independently? For this group, appropriate living solutions appear to be elusive.

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This is where we, as a community, need to innovate our way towards the optimal, wonderful future for our loved ones. In the same manner as the ABA pioneers perfected Intensive Behavioral Intervention in the last part of the 20th century, we need to innovate to produce appropriate supported living options that are customized to our loved ones with autism. Although I've read about a variety of housing/living options, I have not yet seen an appropriate model for this subgroup. This is the Holy Grail of autism housing solutions.

Lesson No. 14: We need to innovate our way into planning safe, supportive living options for the tsunami of children with autism who will be reaching adulthood in the next few years.

David: What advice do you have for new professionals in the field?

Sabrina: Ideally, any professional who wants to be part of the solution should learn all they can about intensive ABA up to and including certification as a Board Certified Behavior Analyst (BCBA) or Board Certified Assistant Behavior Analyst (BCaBA). This applies as well for newly minted speech and language pathologists, regular and special educators, paraprofessionals, and occupational therapists.

For recent graduates in ABA, do not allow anyone, irrespective of credential, to pressure you into practicing anything but ABA with the highest fidelity. This is actually consistent with The Professional and Ethical Compliance Code for Behavior Analysts.

That means you must question and counter all the pseudo-science out there, some of which may masquerade as ABA. There are many diluted forms of ABA that do not yet have sufficient data to be used with children on the autism spectrum and it may be your role to ensure that the team understands this. In the worst case, be prepared to be fired or resign, rather than deliver anything other than the highest caliber of applied behavior analytic techniques. If you follow this advice – i.e., stay honest and true to what is scientifically validated – you will make a tremendous difference in the lives of children on the autism spectrum and send a clear message that science mat-

ters.

Lesson No. 15: Practice ABA with the highest fidelity possible with respect to behavior analytic techniques. Never allow anyone to dilute or distract from what evidence shows works best for kids with autism. No excuses!

David: We certainly covered a lot of ground and I appreciated how direct you were in expressing your views in this interview. More importantly, thank you for sharing your time, talent, and experience with us as a vital member of our board. It is deeply appreciated!

- ★ You can hear Dr. Freeman's daughter's music here.
- ★ Dr. Freeman also publishes a blog, Autism Pundit: www.autismpundit.com.

The New England Center for Children's ABA Software System



Proven Curriculum Proven Progress





2005 Award for Enduring Programmatic Contributions to Behavioral Analysis



2017 Award for the International Dissemination of Behavioral Analysis



CLINICAL CORNER

Setting Up the Classroom to Optimize Learning Opportunities and Effective Instruction

Melissa Taylor, BCaBA

In the issue's Clinical Corner, Melissa Taylor describes practical suggestions to consider when setting up a classroom for educating learners with autism. These strategies can help increase natural opportunities for communication as well as maximize instructional time and efficient transitions.

Amanda G. Fisher, PhD, BCBA-D Clinical Corner Coordinator

Question: I recently accepted my first teaching position. It's a new classroom for the district serving students with autism. I have lots of materials, but nothing is organized or set up in my classroom. What are some tips to set up and organize the classroom to optimize learning opportunities and effective instruction?

Congratulations on your first teaching position! This is a common question for new teachers. When we talk about classroom organization, there are several things to take into account. Good classroom organization effectively makes use of space and barriers, has accessible materials for instruction and data collection, and facilitates efficient time management. It is critical that when you set up your classroom, you review the needs of your individual students as well as make sure to address the core characteristics of autism. You probably already know that many of your students will present with deficits in social interactions and communication, including challenges with requesting items from adults and peers. It will be important to create an environment that makes it necessary for students to interact frequently with other people to increase communication opportunities. Once the environment is conducive to optimizing instruction, the instructors can implement effective behavioral strategies to teach desired behaviors.

Organizing the Space

Seating. When organizing a space, we want to make sure that the seating arrangement will allow students to access the materials needed for activities and respond accurately to instruction. For younger students, make sure the chairs allow their feet to touch the floor. Likewise, older students should be able to sit up straight with feet on the floor and legs at approximately 90-degree angle. Try to arrange seating so that you have space for group, as well as individual sessions. Also, allow enough room that additional support staff can sit behind students to make prompting less intrusive (e.g., sitting behind student and using physical guidance to help them learn the expected motor responses during the, "Wheels on the Bus" song).

Pathways for transitions. The furniture should be set up in a way that enables smooth transitions from one area to another without traffic jams. Walking between areas will be easier if there are not large dividers or barriers that slow down transitioning. Having open spaces and clear pathways between defined areas could

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also allow instructors to move quickly to different areas of the classroom if there is an episode of problem behavior or an unexpected opportunity to support a social interaction.

Defining areas. Some instructors find that using dividers helps clearly separate sections of the classroom. Keep in mind that every area should be open enough that the classroom teacher is able to see every student and classroom assistant. This will allow the teacher opportunities to provide immediate feedback to staff on interactions with students and to offer frequent student praise. Try to avoid tall dividers that make it impossible to see into the other areas and dividers that are easily knocked over. Shelving units, desks, carpets, and tables can create more natural space dividers that can help define the areas. Keep in mind the function and purpose of each classroom area, and make sure that the instructional materials needed are in the area and replaced as needed. For example, if students are going to be required to request items during circle time, those items should be easy for the instructor to reach during group rather than requiring the instructor to get up, leave the group and look in a cabinet for items.

Putting away preferred items. Children, including those with autism, are often good at finding and gaining access to the things they like without the help of other people. By keeping items out of reach, in clear containers that are difficult to open, and on high shelves, you can create new requesting opportunities and make communication with adults more valuable to students. Resalable plastic storage bags, totes, bins, shelving units, and aprons with pockets may all be useful to make it more likely that the students will need to request help from others to access the items they want or need. If the student already has a valuable item, you have lost an opportunity for communication. By restricting access to valuable items, teachers can prompt requests for specific items and deliver items to students. Furthermore, when delivering the item, the teacher becomes more valuable to the student, who learns the significance of communicating. When these types of natural communication trials with preferred items occur in areas where instruction will occur, it becomes more likely that students will approach instructors and instructional areas. One important consideration with using such materials is that, in some cases, direct visibility to highly preferred items can be distracting to students or result in attempts to retrieve items outside of appropriate or scheduled times. In such instances, evaluate the situation and determine whether moving the student's seat so that it is not facing those items or moving the items themselves will address the issue.

Organizing Materials

Materials for data collection. In preparing materials for instruction, we want to make sure that all instructors have easy access to necessary materials such as data collection tools and sheets. These items should be able to be easily accessed at any point of the day, so that instructors are more likely to capture all opportunities of the behaviors they are tracking. When data are recorded immediately following student behavior it is more likely to be accurate. Clipboards that have pockets attached to them are good for storing writing utensils, timers and additional data sheets. Student item lists, teaching stimuli, and data sheets can be kept in a cart with drawers to make it easily accessible during teaching. When collecting any type of data that require instructors to count the number of occurrences of a behavior, instructors can use clickers attached to their clothing with carabiner clips for convenience. Blank student specific datasheets can be carried on clipboards, kept in a drawer on a cart, or hung on bulletin boards in centers where instructional activities occur.

Materials for instruction. Pencil cases or small craft boxes help organize small materials such as pieces of edibles, small toys, pencils, highlighters, picture cards, visual schedules or index cards for instruction. For

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larger instructional items such as toys needed for teaching imitation skills, items needed for simple following direction tasks, or items needed to teach daily living skills, boxes, rolling carts with larger drawers, or labeled shelves can be used to organize materials by student or goal areas. Consider posting wall cues, table/ desk cue cards, or other reminders in places where staff will easily see them. These cues can be helpful to guide instruction without the need to flip through pages in consultation notes or program books to reference procedures. Types of items to post include specific teaching protocols and prompt hierarchies, reinforcement schedule reminders, behavior management strategies, toilet training schedules, reminders of how to teach play skills and student to student requesting, or other items that you want to generalize from one classroom area to another. Cue cards, wall cues, or student data sheets with specific targets listed can also guide instructor presentation during less structured teaching opportunities. For example, if the student has been working on labeling the picture of gloves, and during circle time the teacher is dressing a weather bear, the instructor can ask that student to label the weather bear's gloves. Additional targets to be posted for staff could include specific peer-to-peer requests or interactions (e.g., give item to peer, accept item from peer), specific motor skills (e.g., copying a line, opening a container), self-help skills (e.g., putting on shoes, washing hands), and other activities. This allows for easy implementation of strategies such as natural environment teaching and incidental teaching. Another point is to consider limiting other "wall clutter" that often serves as highly distracting stimuli to students. When possible, keep to salient items such as a classroom schedule, current student work or points of study (e.g., pictures of alphabet) but don't feel the need to cover every available inch of space with something!

Classroom Schedule

Time is valuable, and students with autism do not have time to waste. It is important to make the most of your day by having many opportunities to practice all targeted skills. Having a classroom schedule that allows for enough instructional time to make significant progress is critical. When creating a classroom schedule, make sure to address the who, when, what, and where questions. In other words, it should be easy to see who is working with a student at any given time as well as what skill they are working on and where they are working on that skill (e.g., red table, art table, hallway, etc.). Avoid unnecessary large chunks of non-academic or unstructured times. What each student will be working on should vary based on assessments conducted in the classroom. Instructors should consider posting the schedule on a wall, centrally located and large enough that all team members can see it. This will cut down on unnecessary talk about who is with specific students and what they should be working on, and allows supervisors to assess if assignments are being followed with a quick glance. Additionally, color-coding by students or staff will allow for staff members or administrators to easily follow from across the room. Staff should be assigned to students at all times. If a student is engaged in independent work, having a staff member still assigned to that child will help everyone know who is tracking data or responsible if an emergency occurs.

If you take all of these suggestions into consideration when you begin planning your classroom, you will be well on your journey to make a big difference in the outcomes of your students. An organized classroom allows teachers to focus on effective instructional strategies and behavior management strategies that are individualized to each child and not waste valuable time locating materials, guiding staff behaviors, and planning groups. We wish you well in your new teaching position for years to come.

DO YOU BELIEVE IN SCIENCE-BASED AUTISM TREATMENT? SO DO WE. JOIN US AND HELP KEEP SCIENCE IN THE FOREFRONT.

Alice Bravo Briana Tingler Cathy Curcio Past and Current ASAT Externship Co-Coordinators

Did you know that the Association for Science in Autism Treatment (ASAT) is primarily a volunteer-based organization?

The important work that ASAT does to promote science-based treatment for individuals with autism could not happen without our volunteers. Currently, ASAT has more than 60 volunteers working diligently to disseminate accurate information about science-based interventions for autism. Our volunteers come from a variety of backgrounds, including seasoned and young professionals, family members of individuals with autism, and students ranging from high school to graduate-level. We have international involvement of volunteers from all over the United States, Canada, India, Australia, and the United Arab Emirates.

Many of these volunteers are currently, or were previously, participants in ASAT's Externship Program, a structured, 150-hour experience that typically spans 12-15 months. Externs engage in a variety of activities, including but not limited to:

- Participating in teleconference calls; every third Tuesday evening (from 9:00-10:00 pm EST);
- Completing initial training modules on participation in social media, reviewing research, and international dissemination;
- Proofreading content for ASAT's newsletter, <u>Science in Autism Treatment (SIAT)</u>;
- Reviewing and proofreading existing website content;
- Writing two Media Watch letters for our Media Watch initiative;
- Engaging in our social media platforms (Facebook and Twitter);
- Promoting US and international dissemination by creating awareness among other organizations regarding our offerings;
- Soliciting subscribers for SIAT;
- Supporting ASAT's national and local fundraising activities; and
- Sharing progress toward individual externship goals with externship cohort at the 50-, 100- and 150-hour marks.

Additional opportunities available to externs include, but are not limited to:

• Writing summaries of published research related to autism treatments;

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- Participating in grant research and the writing of grant proposals;
- Writing new content for ASAT's website;
- Writing for **SIAT**;
- Reviewing biomedical advances;
- Participating in conceptualization and development of ASAT's marketing materials (e.g., posters); and
- Participating in the creation, piloting, and revision of extern training modules.

Interested in volunteering with ASAT, but perhaps the externship program does not sound like the commitment level you are seeking? We are also looking for volunteers to support our ongoing efforts. Opportunities for volunteers include, but are not limited to:

- Promoting our <u>website</u> and <u>SIAT</u>;
- Writing summaries of published research related to autism treatment;
- Monitoring and/or responding to misinformation from the media and promoting accurate information through our Media Watch initiative;
- Reviewing and improving our website content;
- Monitoring website navigation;
- Compiling and updating links and resources for visitors to our website;
- Creating databases and conducting internet research; and
- Participating in and assisting with fundraising activities.

If you would like to join ASAT as a volunteer or extern, please complete and submit the <u>ASAT Volunteer Application</u> or the <u>ASAT Externship Application</u> to <u>dceliberti@asatonline.org</u>. It is always important for potential volunteers to communicate their specific interests, so that their work with ASAT can be a mutually satisfying and meaningful experience. We are always looking for passionate individuals to join our team!

Here is what externs are saying about our program:

"Joining ASAT's externship program has given me the opportunity to disseminate science-based treatment for autism, work with wonderful professionals in the field, and build my professional experience. Being a part of a team that cares deeply enough to spend their free time advocating for individuals with autism has been empowering, and I've learned so many new skills that I'll be able to use going forward in my career."

~ Allison Parker (Summit, NJ)

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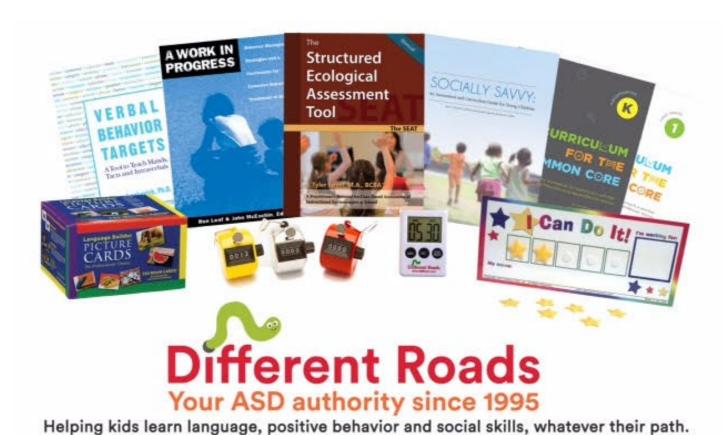
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"Joining ASAT has been an amazing experience for me. Having a brother with autism has made me want to reach out into the community and help others learn about authentic, science-based treatments for autism. ASAT has enabled me to do just that! I am currently learning about international dissemination of evidence-based practices regarding autism treatments, and am very excited about this. Through graphic designs that I have helped create for posters, flyers, and even bookmarks, I have been able to reach out to others. Although I am only in high school, ASAT welcomed me with open arms. The members of this group are very knowledgeable, passionate, and energetic, and are very inspiring models for me. I thank everyone, especially Dr. Celiberti, for allowing me to participate as an active member of this awesome group."

~ Alexandra Penzi (Manhasset, NY)

"Working with ASAT has been a great experience. I've had the opportunity to use my strengths and build upon them by writing in the newsletter, learning about the grant application process, and collaborating with other team members. Most of all, my experience has enhanced my skepticism and ability to look for the facts."

~ Alice Walkup (Los Angeles, California)



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IS THERE SCIENCE BEHIND THAT?

Bleach Therapy

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hroughout human history, the helping professions – medicine, psychology, education – have operated under many ethical guidelines and codes of conduct. But one singular, defining, and unwavering principle has been, <u>do no harm</u>. Providers of services understand that, fundamentally, we cannot behave in ways that will harm – physically, psychologically, or otherwise – the people whom we serve. This is part of the "DNA" of medical and social services.

This core value is lacking in the proponents of drinking bleach for a cure of or treatment for autism spectrum disorder (ASD). This treatment comes in different names: Miracle Mineral Supplement (MMS Healthy for Life, 2016), Master Mineral Solution (MMS Products International, 2016), or the Chlorine Dioxide Solution protocol (MMS Products United Kingdom, 2016). Different websites all market the exact same product. The promoters of this treatment prescribe that individuals with ASD (or individuals with a variety of other ailments as listed below) drink, spray on the skin, or administer as an enema, a mixture of water, chlorine dioxide (CI02), and citric acid (MMS Products International, 2016). The sellers assert that chlorine dioxide is different and safer than chlorine itself, and thus can be ingested or absorbed safely. They claim that although chlorine kills any germ or organism with which it comes into contact,"...Chlorine dioxide...has the amazing ability to remove electrons from diseased tissue and pathogenic stressors" (MMS Products International, 2016). They insist that this product is safe if used according to their directions.

A Review of its History of Development

Jim Humble, the originator of Miracle Mineral Supplements (MMS, 2016) and the Genesis II Church of Health and Healing, advocates for the use of bleach as a miracle cure (Genesis II, 2016). In fact, the primary activity of the Genesis II Church of Health and Healing is the promotion of bleach therapy (Genesis II, 2016). According to the MMS website, Humble is an aerospace engineer who worked on the lunar module and the atomic bomb. In 2008, however, Humble admits that he does not have an engineering degree (Project Camelot, 2016) and claims to be a billion-year-old god from the Andromeda Galaxy who was sent to protect and monitor Earth. According to Humble, he discovered the miracle of bleach therapy while traveling in South America. Members of his party became ill with Malaria and were allegedly cured within hours when Humble gave them a mixture of water and chlorine. The current formula has changed over the years to the concoction marketed today.

Its Purported Use – In Other Words, What is it Designed to Help Cure or Fix?

Miracle Mineral Supplements' (2016) website lists the maladies that can be helped by bleach therapy, in addition to autism. According to the website, MMS can treat and cure cancer, the flu, HIV/AIDS, herpes, malaria, problems of the mouth, gum and teeth, sinuses, constipation, burns, fungus infections, Ebola, staph infections, eczema, and cold sores. If reading is believing, bleach therapy can cure almost anything – a true miracle treatment, as the website name clearly states.

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Is There Any Research to Support This Therapy?

No. Besides reliance on testimonials (which are often used by promoters of fad treatments¹), there are no controlled research studies on this treatment due to significant risk of harm to the participants. **Chlorine is toxic and dangerous**, potentially causing a host of physical ailments and potential death. For one of dozens of articles on the dangers of chlorine, see Hattersley, 2000. Chlorine is used as an industrial cleaner and disinfectant. Indeed, it is doubtful that any Institutional Review Board (i.e., an organizational board that evaluates the ethics of research involving human participants and carefully assesses the risks involved) would be inclined to approve any study due to the toxicity of chlorine and the potential danger to human participants.

Position Statements Against the Use of Bleach Therapy

For more than a decade, organizations around the world have raised concerns about MMS:

- **A.** The Agency for Toxic Substances and Disease Registry (2004) warned about dangers to health when drinking bleach.
- **B.** The Food and Drug Administration (FDA; 2010) of the United States has clearly labeled this substance as dangerous to human health. The FDA emphasized that it has received several reports concerning serious side effects and warned consumers to stop using MMS immediately. It stated, "... This product becomes a potent chemical that's used as bleach when mixed according to package directions."
- C. Canada (Healthy Canadians, 2014) considers this concoction so dangerous that the government has seized these products from an online retailer, warned of its dangers, and pleaded with citizens to stop using it immediately.
- **D.** The Food Standards Agency of the United Kingdom (2015) has warned consumers to not use this product and to throw it away if owned.
- E. The National Autism Society of the United Kingdom (2016) rejects its use.

No autism treatment, with the exception of Facilitated Communication², has been so universally criticized. There is no reason for anyone to consider using this therapy. **It is potentially lethal**. The larger question to address here is, what is it about this therapy – and other fad treatments – that compel consumers to try it? Consider the following questions that may motivate consumers seeking treatment:

The Cause of Autism Is Unclear. Why Not Try Everything? What Is There to Lose?

When a child is diagnosed with autism, the family likely feels a sense of urgency to find a treatment, and understandably so. The variety of therapies has continued to increase over the past 50 years, since autism was first labeled (Jacobson, Foxx, & Mulick, 2015). Because we do not know the cause of autism, many families

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¹For more about the use of testimonials as evidence of a treatment see https://goo.gl/g49vnW

²See articles concerning Facilitated Communication at <u>asatonline.org</u>

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o autism treatment, with the exception of Facilitated Communication, has been so universally criticized. There is no reason for anyone to consider using this therapy. It is potentially lethal.

take the approach of trying anything and everything, regardless of how implausible or outlandish it may seem. After all, what have they got to lose? Unfortunately, the "everything but the kitchen sink" method has the potential to actually cause harm or, at the very least, perpetuate the current situation for which consumers are seeking treatment. In fact, research has demonstrated that "eclectic treatment" (i.e., a combination of treatment methods used with one individual) actually results in less improvement over time on key behaviors associated with autism when compared to using one scientifically validated treatment – specifically, intensive behavior analytic intervention (Howard, Stanislaw, Green, Sparkman, & Cohen, 2005). As described above with bleach therapy, the majority of the quick fixes, miracle cures, and breakthrough treatments available for autism have little to no sound evidence of effectiveness. Several have potential or known harmful side effects. Therefore, when deciding on treatment for an individual with autism, consumers must avoid pseudoscientific treatments and invest in treatments validated scientifically (Green, 1996). Silvestri and Heward (2016) state, "An extraordinary claim with extraordinary supporting evidence is a basis for best practice; an extraordinary claim based on anything but proportionally strong evidence should bring skepticism" (p. 150). Parents and consumers should seek out and demand extraordinary evidence that a treatment is successful before they invest valuable time and resources.

So, what is there to lose? The answer is time, resources, and potentially the individual's health and well being (Zane, Davis, & Rosswurm, 2008). Time spent implementing a pseudoscientific treatment is time that could have been spent implementing a scientifically validated treatment. Additionally, pseudoscientific treatments could actually interfere with the effectiveness of another treatment, thus further delaying improvement for an individual. Financial resources could be wasted on a treatment that is ultimately ineffective (Zane et al., 2008). Finally, side effects of dangerous treatments could lead to immediate or delayed ill health effects and cause other problems, as illustrated by bleach therapy.

Shouldn't a Treatment Be Believed if Based in Science and Logic?

There are several different ways in which a family or treatment provider may obtain information about potential treatments for autism including, but not limited to logic, authority figures, religious or spiritual beliefs, advertisements, testimonials, and/or experimental reports (Cooper, Heron, & Heward, 2007). When the claim is made that a treatment can help an individual with autism, the first question to ask is, "How do you know and what is the basis for this claim?" (Maurice, Green, & Luce, 1996). A pseudoscientific treatment is a treatment that seems to have a basis in science and logic when really there is little to no empirical evidence of effectiveness. A scientifically validated treatment is a treatment that has been shown to be effective through direct objective observation and measurement such that alternative explanations for the results are ruled out and the results can be replicated.

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Pseudoscientific treatments can be very persuasive for several different reasons (Levy & Hyman, 2008). First, these treatments may be more appealing than scientifically validated treatments. Often scientifically validated treatments are reported to appear cold and difficult to implement, while pseudoscientific treatments appear easier to administer, are cheaper, and seem more humane. However, consumers must keep in mind that appearances are not always accurate and more financial resources may be wasted if invested in pseudoscientific claims.

scientifically validated treatment is a treatment that has been shown to be effective through direct objective observation and measurement such that alternative explanations for the results are ruled out and the results can be replicated.

Second, pseudoscientific claims sometimes closely align with an ideology already adopted by consumers (Levy & Hyman, 2008). When the theory supporting a treatment matches with a consumer's pre-existing view of the world, that theory is much more convincing. For example, there is a common view that a positive attachment or bonding between parent and child leads to normal and healthy child development (e.g., Ainworth, 1969; Gutstein, 2009; Zane, Weiss, Dunlop, & Southwick, 2016). If one believes this, then pseudoscientific and fad treatments that flow from that belief – gentle teaching, holding therapy, and other relationship-based therapies – will be more attractive and believable (Smith, 2016). However, this should not be confused with scientifically validated information (Foxx & Mulick, 2016). When evaluating the validity of a treatment, scientific evidence should weigh more heavily than pre-existing beliefs or views of the world.

Finally, the repertoire or professional title of the person making the claim and/or simply the numerous amount of people making the same claim can make pseudoscientific treatments more persuasive. For example, in regard to bleach therapy, Dietrich Klinghardt, MD, PhD says,

"Kerri Rivera has done it...she has condensed and simplified the core elements of the biomedical approach, those that work 90% of the time on 90% of the children. Her focus on using a unified and affordable approach to reduce the body burden of chronic infections and infestations is addressing the very core issue of most autistic children and adults. It has made her method the most powerful tool to this day to help many children recover safely, inexpensively and solidly. Her research is validated by the enormously positive response from parents from all over the world." (http://cdautism.org/)

This statement is quite convincing. The speaker is a medical doctor who references a "biomedical approach," "research," and responses from parents "all over the world." However, regardless of who makes the claims or how many people agree with a claim, statements like these should always be questioned and investigated thoroughly. "The use of scientific language…does not add weight to evidence. Scientific language alone does not make a science" (Silvestri & Heward, 2016, pp. 149-150).

What Type of Evidence Should Consumers Seek When Validating a Treatment?

When attempting to avoid pseudoscientific treatments and find scientifically validated treatments, consumers should avoid *subjective* evidence and seek *objective* evidence. Subjective evidence is information that is based on a personal perspective that may be biased for any number of reasons. Proponents of specific autism treatments often offer testimonials speaking about the amazing improvements in behavior observed after

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hen examining claims about a treatment for autism, the goal should not be to identify professionals who may be qualified to recommend treatments but instead to identify the quality of evidence behind a given treatment.

implementing a given treatment. Unfortunately, whether a parent, a practitioner, a promoter of a treatment, or a well-trained scientific researcher, people tend to see what they want to see (Shermer, 1994). This makes subjective reports inherently biased and inconsistent. This is especially true when reports come from people who are predisposed (i.e., those with strong wishes or investments) to report a specific outcome.

The American Psychological Association set criteria for treatments to be considered evidence-based (i.e., valid). Specifically, two or more group studies or nine or more single-subject studies must be conducted providing objective evidence that a treatment produces superior or equivalent outcomes to alternative treatments already available (Hoagwood, Burns, Kiser, Ringeisen, & Schoenwald, 2001). To obtain objective evidence, precautions should be taken to minimize human bias. Conclusions should be drawn from evidence collected through observable and measureable events and outcomes should be replicable. Ultimately, the more objective and rigorous the means by which evidence is produced for a given treatment, the more confident consumers can feel about the degree to which a treatment is scientifically validated (Jacobson, Foxx, & Mulick, 2015).

Conclusion

The decision to implement a given treatment for an individual with autism is in the hands of the parent or caregiver. So much is still unknown about the cause of autism, making the treatment decisions more challenging. Therefore, when examining claims about a treatment for autism, the goal should not be to identify professionals who may be qualified to recommend treatments, but instead to identify the quality of evidence behind a given treatment. Personal accounts and promising claims are intriguing, but ultimately worthless for evaluating the effectiveness of a given treatment. Consumers should be wary of practitioners who make grandiose claims about their treatment and should instead demand experimentally-based evidence. Doing so may allow us to abolish such harmful treatments as MMS and promote the use of better, safer, and more effective treatments for autism.

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MEDIA WATCH UPDATE &

FEATURED LETTER

In this issue of SIAT, we are pleased to feature a notable Media Watch Letter written in response to The Atlantic's, "Is the Most Common Therapy for Autism Cruel?" In this letter, Emily Callahan, Executive Director of the Council of Autism Service Providers (CASP) and David Celiberti, Executive Director of ASAT, discuss why the article is misleading in its depiction of applied behavior analysis. We also recap the 9 Media Watch Letters that we published between August and December, 2016, all available from our website. These were written by ASAT Externs, Board Members, Media Watch Volunteers, and outside contributors. You can follow our posted Media Watch Letters and condensed "Media Alerts" on Facebook, and stay up to date on the latest responses to portrayals of autism and autism treatment in the media.

Renee Wozniak, PhD, BCBA-D Media Watch Lead

MEDIA WATCH FEATURED LETTER

Dear Mr. Gould,

We are writing in response to an article that was published about the use of Applied Behavior Analysis (ABA) for individuals with Autism Spectrum Disorders (ASD) on <u>August 11, 2016</u> on <u>theatlantic.com</u>.

With the growth of the number of individuals being diagnosed with ASD, this article discusses an extremely important topic, the effectiveness and accessibility of therapies for individuals with ASD. The author correctly identifies ABA as being the "best-established form of therapy for children with autism." Your readers should know that this level of scientific support is in sharp contrast to hundreds of touted therapies that lack any scientific evidence whatsoever. Unfortunately, the article is misleading about what ABA is and is not. It is important to note that while this article focused on individuals with ASD, ABA is used in business settings, educational and medical communities, with athletes and in a plethora of other areas to help solve socially significant problems. We would like to take this opportunity to outline a number of other concerns with this article, concerns that may inadvertently separate people with autism from effective treatment.

Much of the article focused on the premise that the primary goal of ABA and ABA therapists is to "normalize" individuals on the autism spectrum, which is incorrect. As articulated first by Baer, Wolf, and Risley (1968), at its core, the goal of ABA is to improve socially significant behavior to a meaningful degree. Whether that be through teaching basic self-care skills, safety behaviors, or how to complete a job application, one of the primary goals of any ABA intervention program is to help individuals become more independent, self-sufficient, and increase meaningful participation in their communities. There is also a signifi-

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Providing Accurate, Science-Based Information - Promoting Access to Effective Treatment

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cant improvement in the quality of life when individuals with ASD are able to overcome challenging behaviors. The empowerment that comes with the development of skills and the doors that opens for individuals is disregarded when the conversation is restricted to "normalization."

A large body of research in ABA focuses on decreasing dangerous behaviors and those that interfere with an individual's ability to participate in educational and employment settings. Recent research has indicated that individuals with ASD die on average 18 years before the general population (Cusack, Shaw, Spiers & Sterry, 2016). Research has also indicated that individuals with ASD exhibit higher rates of risk taking behaviors than their peers (Cavalari & Romanczyk, 2011) which can lead to significant injury and in some cases death. Failure to recognize dangerous situations, or to be able to communicate effectively during emergency situations is a significant concern for many individuals with ASD. There is wealth of literature illustrating the use of behavioral strategies for teaching safety behaviors and communication skills which can help address both of these issues.

The article also spends a significant amount of time discussing research that was conducted in the 70s and 80s. ABA programs have evolved and improved significantly since that time based on the cumulative efforts of hundreds of researchers who publish their work in peer-reviewed journals. The majority of the article describes only one approach used within ABA, discrete trial instruction (DTI). DTI is one of many approaches covered under the umbrella of ABA and the lack of a more thorough discussion or the current state of ABA research and practice is a significant failure of this article and does an injustice to the reader. It is akin to bastardizing the current field of medicine by hyperfocusing only on early research in one area of study (e.g., 1970s dermatology).

ABA is not prescriptive or "one-size-fits-all" as the authors describe. ABA programs rely on positive reinforcement, thoughtful selection from a broad array of techniques, careful individualization, and data-based decision making to create positive behavior change. The selection of goals and intervention targets is a collaborative and systematic process involving multiple individuals including the therapist, the individual, and the individual's family. Teaching techniques are also individualized, evaluated and modified based on individual preference and performance. ABA relies on systematic observation and data collection to help identify the strengths, weaknesses, and preferences of each individual to help customize teaching strategies. Individualization and client involvement are such important elements of ABA programs that they are actually written into the code of ethics for behavior analysts. Standard 4.02 requires that clients be involved in the planning and consent for any behavior-change programs and Standard 4.03 requires that those programs be tailored to the unique needs of each individual (Behavior Analyst Certification Board, 2016).

The lack of randomized control trials (RCT) evaluating the effectiveness of any intervention program is a recognized weakness in social services. However, the large number of peer-reviewed published studies using group designs along with the hundreds of single subject design studies carried out by hundreds of independent researchers demonstrating the efficacy of ABA cannot simply be ignored, particularly when contrasted with the dearth of research for most other interventions touted for autism. In fact, a report conducted by the US Surgeon General (1999) concluded, "Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and increasing communication, learning and appropriate social behavior." A criticism of the research underlying ABA falls flat when it fails to acknowledge that consumers are bombarded with false promises, dangerous treatments, and ineffective interventions that have never been tested scientifically.

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People interested in learning more about what ABA is and how it can be utilized can find more information on a number of well-respected websites such as <u>apbahome.net</u> or <u>bacb.com</u> or <u>asatonline.org</u> or <u>balcllc.org</u>.

Left without correction we fear that this article has the potential to cause great harm to children and families who may erroneously believe that ABA is cruel or detrimental. Please feel free to reach out to the first author via email ecallahan@casproviders.org if you would like more information.

Sincerely,

Emily Callahan, PhD, BCBA-D Executive Director, Council of Autism Service Providers

David Celiberti, PhD, BCBA-D Executive Director, Association for Science in Autism Treatment

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Cusack, J., Shaw, S., Spiers, J., & Sterry, R. (2016). Personal tragedies, public crisis: The urgent need for a national response to early death in autism. Retrieved from: www.autistica.org.uk/wp-content/uploads/2016/03/Personal-tragedies-public-crisis.pdf

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MEDIA WATCH QUARTERLY SUMMARY

ASAT Responds to The Hans India's "Stem cell therapy breathes life into 12 year old autistic girl" (August 1, 2016)

With the global prevalence of autism estimated at 1% of the world population as reported by the Centers for Disease Control and Prevention, it becomes increasingly important that we discriminate between effective treatments validated by scientific support and "therapies" and "cures" that overlook science. Reports such as yours claim that stem cell therapy causes marked improvement in children with autism; however, this is not corroborated by peer-reviewed published research.

ASAT Responds to The Atlantic's "The battle over a controversial method for autism communication" (August 14, 2016)

You accurately describe the dangers of using autism interventions that are not evidence based. As a best case scenario, these unsubstantiated treatments are a waste of precious time that could be spent making meaningful progress and acquiring skills via different and substantiated treatments and, as a worst case scenario, these unproven treatments may increase the likelihood that susceptible individuals incur possible harm and abuse.

ASAT Responds to The Atlantic's "Is the most common therapy for autism cruel?" (September 13, 2016)

The author correctly identifies ABA as being the "best-established form of therapy for children with autism." Your readers should know that this level of scientific support is in sharp contrast to hundreds of touted therapies that lack any scientific evidence whatsoever. Unfortunately, the article is misleading about what ABA is and is not

<u>ASAT Responds to Health Days' "Timing of autism diagnosis tied to choice of treatment"</u> (September 27, 2016)

Timing of diagnosis may be one of the most important yet overlooked topics concerning the assessment and treatment of ASD. As you correctly point out there are very effective behaviorally-based treatments, such as applied behavior analysis (ABA), available for ameliorating the core symptoms of ASD. However, without accurate and timely detection by frontline providers such as pediatricians, the full benefits of these evidence-based behavioral therapies will not be available to many families.

ASAT Responds to The Age's, "Autism cage details emerge as United Nations investigates abuse of children" (October 4, 2016)

In your article, you describe several cases of alleged abuse within Australian schools, which triggered an

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Australian submission to the United Nations Special Rapporteur on the Rights of Persons with Disabilities. It is extremely concerning to us to read that, of the 55 children alleging abuse, 93% had been diagnosed with autism. We agree with you that the use of restraint and seclusion with children with autism, in the absence of any appropriate behavior support plans or education plans, is disturbing.

ASAT Responds to Gulf News', "Reality of living with autism in UAE" (October 19, 2016)

We are grateful for your eye-opening accounts of some of the views on individuals with ASD in UAE, and the concerns many families face around the globe. The rise in autism prevalence worldwide, combined with an often limited understanding of autism by the general public, underscore the need for increased opportunities to advance universal autism awareness.

ASAT Responds to ABC News', "'Life Animated' parents describe how animated characters helped son with autism connect" (November 1, 2016)

The Suskind's story is one of positivity, persistence, and hope. It is important for families of people with autism to hear these messages. As importantly, we hope that Mr. Suskind and others describing Affinity Therapy or similar techniques, will take the mechanisms responsible for behavior change into consideration so that treatments incorporating the interests and passions of people with autism can be individualized and utilized in the most effective and efficient manner.

ASAT Responds to Spectrum News', "Exercise gives children with autism jump on social skills" (November 28, 2016)

The volume of research on this topic refutes the idea that "exercise is conspicuously lacking in traditional autism therapies such as ABA." In fact, a well-rounded behavior analytic program includes any skill important to the individual which may help them to be successful in everyday life.

ASAT Responds to The Indian Express' "Enacting Shakespeare's play helps autistic kid in developing communication skills" (December 15, 2016)

We are happy to read about the positive impact that the plays had for its fourteen participants. Being able to learn new skills in an enjoyable environment is the ultimate aim of any program designed for children with ASD. However, calling the Hunter Heartbeat Method a "novel therapeutic approach" is ill-advised as this is not corroborated by sufficient peer-reviewed research, nor are any limitations to the research mentioned in your article.

RESEARCH SUMMARY

Comparison of Verbal and Pictorial Naturalistic Communication Strategies on Spoken Language

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Characteristics and Quality of Autism Websites

In this issue of SIAT, we summarize two studies. The first compares the effectiveness of Pivotal Response Training to the Picture Exchange Communication System for increasing spoken language in young children with autism spectrum disorder. The second looks at the characteristics and quality of autism websites. We hope this information is helpful to you.

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



Schreibman, L. & Stahmer, A. C. (2014). A randomized trial comparison of the effects of verbal and pictorial naturalistic communication strategies on spoken language for young children with autism. *Journal of Autism and Developmental Disorders*, 44(5), 1244-1251.

Reviewed by: Mikala Hanson, Rutgers University

Why research this topic?

In recent years, a number of treatment models have built scientific support for teaching communication skills to children with autism spectrum disorder (ASD). Two commonly used models are Pivotal Response Training (PRT) and the Picture Exchange Communication System (PECS). PRT addresses communication deficits by targeting areas of development like motivation, responsiveness to multiple cues, and social interaction. PECS addresses communication deficits by teaching individuals to exchange picture icons to communicate. Both models provide natural opportunities for communication and use direct reinforcement to increase responding. PRT has been shown to improve speech imitation, labeling, spontaneous speech, and requesting in previously nonverbal children with ASD. PECS has been shown to increase requesting and other kinds of communication in the same population. The present study compared the effectiveness of PRT to PECS on the acquisition of spoken language by young, nonverbal or minimally verbal children with ASD.

What did the researchers do?

Thirty-nine children (ages 2-3) were randomly assigned to PRT or PECS groups. Participants received an average of 247 hours of treatment across groups. During the first 15 weeks, parents participated in two weekly, 2-hour parent education sessions with their child in the laboratory, and children received an additional five 2-hour sessions per week at home. This was followed by eight weeks of one 2-hour parent

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education session per week and two 2-hour sessions per week in the home. Researchers then measured the child's spoken language, spoken vocabulary, adaptive communication, and augmentative communication, as well as parent satisfaction in the two interventions.

What did the researchers find?

Results indicated that the children in both the PRT and PECS conditions made gains in spoken communication, and there was no significant difference between the two interventions. On average, children gained approximately 80 spoken words across the 6-month study period. Parents in both groups were satisfied with the intervention and reported progress in their children. However, parents reported PECS to be more difficult to implement in the home.

What are the strengths and limitations of the study?

One of the strengths of the current study is that it adds to the scientific literature on effective strategies for improving communication skills in individuals with ASD. In addition, the study demonstrated that there was no inhibition of spoken language in using either intervention. The primary limitation was that the study lacked a no-treatment control group for the purpose of comparison. Therefore, it could be argued that treatment gains may have been due to development rather than a function of either intervention.

What do the results mean?

The findings suggest that PECS and PRT have comparable levels of effectiveness for facilitating language. However, according to parents, PRT may be preferred because of easier implementation. To tailor interventions more specifically, further research is needed focusing on child characteristics associated with response to these treatment models. Overall, results point to the benefits of using both PRT and PECS to help build communication in young children with ASD who are minimally verbal or nonverbal.

Reichow, B., Halpern, J. I., Steinhoff, T. B., Letsinger, N., Naples, A., & Volkmar, F. R. (2012). Characteristics and quality of autism websites. *Journal of Autism and Developmental Disorders*, 42, 1263-1274.

Reviewed by: Briana Ostrosky, M.A., BCBA and May Chriseline Beaubrun, M.Ed., BCBA

Why research this topic?

Autism spectrum disorder (ASD) is a severe neurodevelopmental disorder that includes impairments in social interaction and communication, and repetitive patterns of behavior, interests, and activities. ASD is acknowledged as a major public health concern as its prevalence is on the rise (Johnson, Handen, Zimmer, Sacco, & Turner, 2011). For this reason, parents and providers alike are in great need of information about treatment. The internet is one of the most common resources for obtaining health-related information, using search engines such as Google and Yahoo. Unfortunately, there are conflicting reports regarding the quality of information obtained through search engines, with as many as 80% of websites about ASD including content of questionable accuracy. Inaccurate information may not only delay or affect treatment, but could also be unsafe. To date, there has been little guidance available for caregivers, educators, and professionals

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about how to locate websites containing high-quality information on ASD. Obtaining high-quality information is an important part of implementing evidence-based, effective treatment as soon as possible for optimal outcome.

What did the researchers do and what were the results?

The investigators evaluated the quality of autism websites using two studies.

Overview of Study 1: In the first study, they evaluated characteristics of the most highly ranked websites when a keyword search of the term "autism" was conducted using three popular search engines. The sample for Study 1 consisted of the top 100 websites located when "autism" was entered into the Google, Yahoo, and Bing online search engines. The researchers selected, defined, and coded the following website characteristics: advertisement (i.e., selling a product), attribution (i.e., references to peer-reviewed material), authorship (i.e., one or more authors of the information were specified on the website), copyright symbol (©), currency (i.e., evidence it was updated within 6 months), disclaimer (i.e., specifies information does not replace opinion of qualified professionals), disclosure (i.e., conflicts of interest or affiliations listed), a method of contacting an individual associated with the website (e.g., phone number, email address), product or service for sale, promotion of non-evidence based practices identified by the National Autism Center (2009), purpose of the website, reading level appropriate for consumers, seal from a health accreditation organization (e.g., HONcode), and top level domain (e.g., .com, .edu, .gov, .net).

Results of Study 1: Most of the 164 websites included in the study were registered using a .com or .org level domain. The most popular website purpose was to feature an organization or freestanding clinic. Two quality indicators were present on nearly all websites: all information was available without providing personal information, and a method of contacting the website was provided. Approximately half of the websites were current, provided author information, and/or contained a medical disclaimer. In contrast, about 21% offered a product or service, and 17% promoted a non-evidence based treatment. Moreover, 50% of the websites were written much higher than the average reading level of parents in the United States.

Overview of Study 2: Study 1 did not assess the quality of information, which was a major limitation. A follow-up study was, therefore, conducted which entailed 30 websites selected using the Google search engine. The websites selected contained information on one or more of the following topics: general characteristics of autism, signs of autism, symptoms of autism, causes of autism, and treatments of autism. This included university affiliated sites, ranked sites as well as sponsored links. Autism experts completed an online survey, evaluating website characteristics and quality. The 299 respondents rated the accuracy and currency of the information and were asked to whom they would recommend each website.

Results of Study 2: The following characteristics were statistically related to website quality: 1) whether the website offered a product or service for sale; and 2) whether the website promoted a non-evidence-based practice. Websites that had a .gov top-level domain were significantly more likely to have a higher website quality estimate than websites with a commercially oriented top-level domain (e.g., .com, .org). Higher quality indicators were also noted on most websites that had a seal from a health accreditation organization (i.e., HONcode, Utilization Review Accreditation Commission [URAC]). The two most frequently recommended websites were *The Association for Science in Autism Treatment (ASAT)* and *Wikipedia*, although the authors suggested using caution when using Wikipedia due to variable accuracy and utility in its other health-related research. Wikepedia articles are collaboratively written, and so it may be challenging to identify sources.

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What do the results mean?

Having informed consumers is a cornerstone of evidence-based practice (Reichow & Volkmar, 2011; Straus, Richardson, Glasziou, & Haynes, 2005). The researchers attempted to identify website characteristics that could lead consumers to websites with high-quality information on ASD. In Study 2, three positive associations between website characteristics and website quality were found. First, websites from universities and government agencies, which in the United States have a top-level domain of .edu or .gov, appear more likely to contain higher quality information. Second, websites with a seal from a health accreditation organization appear more likely to contain high quality information. Finally, websites that were coded as being a health information site appeared to be of higher quality than websites with more general purposes (e.g., blogs, forums, personal pages).

ASAT was one of the most recommended websites for academics, clinicians, and teachers while websites of government agencies were frequently recommended for parents. Although the World Wide Web has the potential to put consumers in contact with resources that are high quality, the investigators suggest using the internet as a supplement, not a replacement, for information obtained from professionals and experts in the field (e.g., pediatricians, psychologists, psychiatrists, special educators).

What are the strengths and limitations of the study?

Study 1 limitations included the examination of only the top 100 websites across three search engines. It's unknown whether this strategy provided a representative sample of all websites, making it impossible to generalize results of the analysis to the overall population of websites containing information on ASD. Although the evaluators addressed the major limitation of the first study (i.e., not measuring website quality), Study 2 also had limitations. First, although the 22% response rate of the survey is somewhat lower than ideal, it did provide the amount of data required to conduct the analyses. Second, the evaluators opted to use a small sample of websites (30) to obtain multiple ratings for each website. The small sample of 30 limits the ability to draw conclusions and generalizations to the larger population of websites containing information about ASD. Finally, to increase the response rate, the evaluators designed the survey such that each respondent only rated up to three websites. If participants had rated more websites, the ability to draw more definitive conclusions would have been improved with a larger sample size. This would increase our confidence in the website quality score estimates.

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A RESPONSE TO "APPLIED BEHAVIOR ANALYSIS, AUTISM, AND OCCUPATIONAL THERAPY: A SEARCH FOR UNDERSTANDING," AS PUBLISHED IN THE AMERICAN JOURNAL OF OCCUPATIONAL THERAPY BY WELCH AND POLATAJKO

Amy Stango, MS, OTR/L, MS, BCBA

n their (2016) article, "Applied Behavior Analysis, Autism, and Occupational Therapy: A Search for Understanding," Welch and Polatajko present a literature-based argument for the application of behavior analysis within the practice of occupational therapy. The authors acknowledge that despite the popularity of both occupational therapy and applied behavior analysis (ABA) as treatments for individuals with autism, there has historically been a separation between these fields. However, the authors note that there are many ways that occupational therapy may be enhanced from a behavior analytic approach.

Welch and Polatajko note that ABA has been demonstrated to be the most effective intervention for individuals with autism and that ABA practitioners have reported using sensory integration in their clinical work, although this practice has been discouraged by the behavior analytic literature and organizations such as the Behavior Analyst Certification Board (BACB) (Devlin et al., 2011; Matson et al., 2013; Schreck & Miller, 2010).

Although multiple studies of sensory integration approaches have been conducted by behavior analysts (Moore, Cividini-Motta, Clark, Ahearn, 2015, Sniezkyk & Zane, 2015), there has been little mention of behavior analysis in the occupational therapy literature. Welch and Polatakjo propose that this may be due to misconceptions that some occupational therapists have regarding behavior analysis. One such misconception is a belief that ABA is limited to one teaching strategy widely used with individuals with autism called discrete trial training (DTT), when as an applied science, ABA has a broad scope and a wide range of evidence-based strategies for decreasing problematic behavior and teaching new skills. Another misconception held by some occupational therapists is that behavior analysis does not produce generalization of acquired skills. However, generality is one of the defining characteristics of applied behavior analysis and there have been ample studies demonstrating generalization of skills learned through behavioral programming (Baer, Wolf & Risley, 1968). The third misconception described by Welch and Polatajko is that behavior analysis does not consider the unique desires and interests of clients. However, first, the ABA literature is rich in publications targeting preference assessments (i.e., ways to assess likes and dislikes of clients, from those able to communicate to those who have severe communication deficits). Second, ABA places a great emphasis on social validity of procedures, goals, and outcomes. In fact, social validity is another of the seven dimensions of ABA. The authors note that there are some shared commonalities between occupational therapy and ABA, including an emphasis on building and expanding upon a client's strengths, consideration of social and cultural contexts, and collaborative decision-making.

Welch and Polatajko conclude by suggesting several ways that occupational therapy outcomes might be enhanced by embracing ABA. They suggest, for example, combining sensory integration procedures and ABA procedures as described in the book, "Is it Sensory or Is It Behavior?" Welch and Polatajko

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acknowledge how the efficacy of behavioral procedures such as pivotal response training and the extensive empirical literature from the field of applied behavior analysis may have widespread applications to different areas of occupational therapy practice.

This article authored by Welch and Polatakjo is an important contribution to the occupational therapy literature, and the first article of its kind in the American Journal of Occupational Therapy. Applied

t should be noted that, given that sensory integration is not an empirically validated treatment for stereotypy (Mason & Iwata, 1990, Moore, Cividini-Motta, Clark & Ahearn, 2015) or challenging behavior (Devlin, Healy, Leader & Hughes, 2011), it is not advisable to attempt to combine sensory integration and behavior analysis.

behavior analysis is a science with many broad applications that may relate to autism and occupational therapy practice. Some of these applications include feeding (Paul, Williams, Riegel, & Gibbons, 2007), toilet training (Azrin & Foxx, 1971), play and leisure skills (Garcia-Villamisar & Dattillo, 2011, Machalicek et al., 2009, Blum-Dimaya, Reeve, Reeve, & Hoch, 2010), social interaction (Weiss & Harris, 2001), safe navigation within the community (Hoch, Taylor & Rodriguez, 2009), and work skills (Hume & Odom, 2007). Behavior analysis can also be utilized to effectively teach individuals with autism to tolerate nonpreferred stimuli (Koegel, Openden, & Koegel, 2004) and to replace repetitive, stereotypic behaviors with more socially appropriate behaviors (Boyd, McDonough & Bodfish, 2012). It should be noted that, given that sensory integration is not an empirically validated treatment for stereotypy (Mason & Iwata, 1990, Moore, Cividini-Motta, Clark & Ahearn, 2015) or challenging behavior (Devlin, Healy, Leader & Hughes, 2011), it is not advisable to attempt to combine sensory integration and behavior analysis. However, applied behavior analysis has many evidence-based alternatives to sensory integration that multi-disciplinary teams can use to assess and treat stereotypic or challenging behaviors. These evidence-based alternatives to sensory integration, along with an understanding of the contingencies of reinforcement that maintain problem behavior, can aid occupational therapists in viewing behavior from a broader lens. Other components of applied behavior analysis, such as operationalized targets, detailed, written treatment protocols, continuous, objective data collection, and the use of within-subject designs to study the effects of a treatment upon an individual's behavior, may also add value to occupational therapy practice. Collaborative work between behavior analysts and occupational therapists while applying evidence-based practices can provide the consistency needed to produce optimized outcomes for individuals with autism.

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THE ASSOCIATION FOR SCIENCE IN AUTISM TREATMENT: STANDING FOR SCIENCE, SUPPORTING APPLIED BEHAVIOR ANALYSIS

David Celiberti Patrick O'Leary Alice Bravo Sunita Chhatwani Melissa Taylor

How ASAT promotes the <u>field of applied behavior analysis</u>:

ASAT is committed to the promotion of evidence-based practices for individuals with autism. Applied behavior analysis (ABA) has consistently been shown to be an impactful, evidence-based practice enjoying abundant scientific support. It is part of ASAT's goal to ensure that disciplines with a high degree of support, such as ABA, are presented in objective, clear, and user-friendly manners.

- We embody the values of objectivity, a commitment to science, transparency, treatment fidelity, and data-based decision-making in all we do. We link these values to the core tenets of behavior analysis and urge members of other disciplines to embrace these same values in their work.
- We respond to accurate and inaccurate representations of applied behavior analysis (ABA) in the
 media. Approximately half of our <u>Media Watch</u> letters address ABA, and many others relate to ABA
 outside of the United States, such as in <u>Israel</u>, <u>India</u>, <u>Australia</u>, <u>South Africa</u>, and <u>Canada</u> to name a
 few
- We showcase diverse applications of ABA in our <u>Clinical Corner</u> column targeting a wide array of areas such as <u>food selectivity</u>, <u>articulation</u>, <u>toilet training</u>, <u>safety skills for adolescents</u>, <u>sleep</u>, and <u>play</u>.
- We review published research (using single case designs extensively) as part of our <u>Research Synopsis</u> effort, and highlight its relevance and importance within autism treatment.
- We interview prominent behavior analysts from across the globe around common themes of service delivery, dissemination, and access to behavior analytic treatment such as <u>Mickey Keenan</u>, <u>Bill</u> <u>Heward, Tristram Smith, Carl Sundberg and Genae Hall, Tom Zane and Suzanne Letso, Eitan Elder,</u> and <u>James Todd</u> as examples.
- We frequently write about the ethical issues surrounding the selection and implementation of evidenced-based treatment, such as the <u>limitations of testimonials</u>, understanding the <u>peer review process</u>, and obtaining <u>insurance coverage</u>.
- We are promoting the field of ABA worldwide by making our website content available in 39 languages.

How ASAT supports the interests of BCBAs and center-based ABA programs:

BCBAs are tasked with the service delivery of ABA in a variety of settings. With both the preponderance of evidence-based and non-evidence-based practices portrayed in the media and literature, ASAT makes it a goal to support BCBAs and agencies in accessing the appropriate methodologies.

(Continued from page 37)

- We provide resources to share with consumers served.
- We reinforce the messages of behavior analysts who attempt to steer consumers toward evidencebased practices and away from harmful or ineffective practices.
- We write about collaboration with related professions and highlight peer-reviewed research from other disciplines.
- We provide opportunities for young professionals to acquire valuable experiences via our <u>externship</u> <u>program</u>.
- We respond to media representations related to autism and ABA allowing BCBAs and center-based ABA programs the ability to interact with ASAT and share our media letters and alerts with their networks and communities.

How ASAT supports the interests of clients and consumers:

A Google search for "autism treatments" yields over 13 million results, some with supporting evidence and many without. Perusing the vast number of treatments available can be both daunting and frustrating for consumers, especially consumers with little background knowledge of autism. ASAT makes it a goal to ensure that consumers, both savvy and inexperienced, have access to the appropriate, evidence-based treatments that children deserve.

- We help to keep families and other subscribers in the know via our <u>quarterly newsletter</u> (we currently have almost 12,000 subscribers).
- We serve as a reliable and accurate resource for families of newly diagnosed individuals.
- Our written works continually reinforce the importance of asking questions to assess provider competency, credential verification, and goodness of fit.
- We help consumers become educated, skeptical, and savvy when it comes to evaluating various treatment options.
- We teach consumers to discriminate between science and pseudoscience.
- We explain behavioral concepts using nontechnical language.
- We help consumers remain apprised of the latest research in a consumer-friendly manner.
- Our articles often reference and explain the BCBA credential, and mention behavior analysts as professionals to whom consumers should turn to for various areas of need and support.
- We maintain an active <u>Facebook page</u> to help parents and other family members better understand the scope of what evidence-based practice represents.



aba-autism-conference-2017.eventbrite.com

2nd Annual CABA Autism Conference

Friday, April 28, 2017 Seal Beach, CA

Preserving Quality ABA and the Effective Implementation of Autism Treatment



Andy Bondy
What's the emperor wearing these
days? Communicating with PECs, SGDs,
and APPS



Peter Gerhardt

The role of aba in promoting socially important outcomes with adolescents and young adults with ASD: Ethical considerations in evidence-based practice



Sandra L. HarrisWorking with siblings of children with
Autism Spectrum Disorder



Raymond G. RomanczykAnxiety and fear in young children with autism: Concepts, assessment, and intervention



Florence D. DiGennaro Reed ABCs of staff support: Evidence-based performance management



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OUR REAL SCIENCE, REAL HOPE

2017 Professional Sponsorship Initiative

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, scientificallyvalidated 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 2017 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 2017 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.

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We thank 2016 and 2017 sponsors for their generous support of ASAT's mission and initiatives to disseminate science in autism treatment. Please click on the names to access their webpages.

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SOME CHAMPION LEVEL SPONSORS

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In 1994, Drs. McEachin and Leaf formed Autism Partnership to meet the tremendous need for comprehensive services to families of children and adolescents with autism. Based upon the founders' extensive and unique experiences in providing behavioral treatment to children, adolescents and adults, they have developed a comprehensive treatment program that provides a variety of services and serves as a model of excellence for the autism community.

Autism Partnership's senior staff started their work together back in the 1970's at the UCLA Young Autism Project. Under the mentoring of Dr. Ivar Lovaas, a pioneer in the treatment of autism, John McEachin, Ron Leaf, Mitch Taubman, Andi Waks and Tracee Parker learned their profession. They were

involved in all aspects of this ground-breaking project including development of curriculum and behavioral intervention strategies, implementing and supervising treatment, training therapists, teachers and parents, teaching classes, and conducting research. While at UCLA, they contributed to seminal works including books, research publications, and scientific conference presentations. They continue to speak at national and international conferences, have authored numerous research articles which have appeared in peer-reviewed scientific journals, and have published some widely used books including:

- A Work in Progress: Behavior Management Strategies & A Curriculum for Intensive Behavioral Treatment of Autism
- It's Time for School: Building Quality ABA Educational Programs for Students with Autism Spectrum Disorders
- Sense and Nonsense in the Behavioral Treatment of Autism: It Has to be Said
- Crafting Connections: Contemporary Applied Behavior Analysis for Enriching the Social Lives of Persons with Autism Spectrum Disorder

As knowledge about effective behavioral treatments continues to evolve, they continue to make advancements to improve effectiveness and increase accessibility to greater numbers of children. An important part of their work is to improve the efficiency of treatment methods that originated in a 1:1 format by extending the application to small groups and classrooms. Originally based in California, Autism Partnership has expanded throughout the world with offices in England, Australia, Canada, Hong Kong, Singapore, Seoul, Philippines and Kuwait. In 2013 they established the Autism Partnership Foundation whose mission is to support research and dissemination of information about effective autism treatment. An essential component of the Foundation is the non-profit Center for the Advancement of Behavior Analysis (CABA), a training institute which provides one-year internships and other training opportunities for aspiring professionals in the field of autism treatment. For more information, please visit www.autismpartnership.com and www.autismpartnershipfoundation.org.

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www.acenecc.org

The Ace ABA Software System: A Product of The New England Center For Children

The ACE ABA Software System is the premier educational system for learners with autism. Our educational package provides BCBAs and Special Educators the ability to assess, teach and evaluate progress using evidence based procedures. The Autism Curriculum Encyclopedia (ACE) is the culmination of over 40 years of research and practice conducted at The New England Center for Children (NECC), a leader in the fields of ABA and autism, and two-time SABA Award winner. The ACE provides an interactive database containing mobile data entry, assessment tools, lesson plans, teaching materials, graphs, and student performance reports for over

2,000 skills drawn from the curriculum used at NECC. Every lesson plan within the ACE can be customized to the learning profile of the individual student being taught. Thus, this web-based curriculum fills an enormous need for an easy-to-access, comprehensive and rigorously tested resource allowing teachers and schools to provide effective and individualized services to their students. www.neccace.org

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Torque Studio, in Pennsylvania, USA is a barre, spin, and TRX studio that focuses on providing an atmosphere where individuals can improve their overall well-being while becoming stronger and having fun in the progress. On Sunday, February 19th, Summer Fatzinger, owner of the studio, hosted an event that raised over \$250 for ASAT. A group of over 15 people gathered together on the indoor cycling bikes to raise money to promote autism awareness and science-based interventions. Riders arrived with their donations in hand to learn about ASAT's mission and to ride to Summer's upbeat playlist and motivating words. ASAT would like to thank all of the individuals who showed up to dedicate their time and energy. Special thanks to Summer for her effort in hosting this event and in raising money to support ASAT's initiatives!



The Association of Science in Autism Treatment is connected with AmazonSmile. AmazonSmile is the same Amazon you know. Same products, same prices, same service. Please support our mission to promote evidence-based, scientifically sound treatments for individuals with autism by choosing us one time and then supporting us every time you make a purchase through Amazon.

The link http://goo.gl/PgMQNT will allow you to make purchases through Amazon as usual while donating .5% of eligible purchases to ASAT. We greatly appreciate your participation! Remember: You shop, Amazon gives!

And there are other ways to support ASAT!

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