### **Science in Autism Treatment**



# Newsletter of the Association for Science in Autism Treatment

Volume 14, Issue 4 | Fall 2017

#### LETTER FROM DR. DAVID CELIBERTI, EXECUTIVE DIRECTOR

It is with deep gratitude and pride that I share with our subscribers this issue of Science in Autism Treatment. As 2017 draws to an end, we have the opportunity to reflect on our recent accomplishments. I would like to highlight some of them below. ASAT has:

- ★ Published four issues of *Science in Autism Treatment* (SIAT) covering topics of interest to families and professionals alike, and launched two new columns Is There Science Behind That? and Science Corner (for subscribers from over 100 countries)
- ★ Further developed website special pages and enhanced website readability for concerned parents, parents of older children and adults, faculty members, and journalists
- ★ Published several Media Watch letters and Media Alert posts in response to accurate and inaccurate news articles and broadcasts related to autism treatment
- ★ Expanded our Externship Program with Externs from Ireland, Brazil, Canada, Australia, UAE, and India with nine graduates in 2017 (seven of them assuming long-term roles within ASAT)
- ★ Added new committed members to our Board of Directors and to Professional Advisory Board
- ★ Increased social media to reach families and professionals with almost 12,000 Facebook fans and almost 1,500 Twitter followers

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- ★ Collaborated with Different Roads to Learning (DRL) to publish monthly blogs
- ★ Recruited 18 new sponsors from the US, Australia, and Canada
- ★ ASAT was represented in the Boston Marathon and at professional events such as ABAI, Autism New Jersey, and Eden II
- ★ Obtained the 2017 Silver Seal of Transparency from GuideStar

We will share our goals for next year in the Winter 2018 issue of Science in Autism Treatment. I would also like to take this opportunity to thank our volunteer board, externs, and committee volunteers for all of the work they do on behalf of ASAT. They do it because they believe in ASAT and want to further ASAT's mission.

I hope that you too will consider supporting ASAT. When selecting possible recipients of your year-end donations, I ask that you please give ASAT your fullest consideration.

<u>Donations</u> to ASAT help us to continue the important work that we do. By contributing to ASAT, you will increase the likelihood that the thousands of families with newly-diagnosed children, as well as the professionals that serve those children, will have access to clear, accurate and science-based information about autism and autism treatments.

Please support ASAT and help us keep science at the forefront of every single conversation about autism treatment. Individuals with autism deserve nothing less.

David Celiberti, Ph.D., BCBA-D

ASAT Executive Director
Co-Editor of Science in Autism Treatment

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#### **Perspectives**

#### 16 YEARS OF ABA COME TO AN END

#### Sarah Ziegel

Imagine having FOUR children with autism! In this installment of Perspectives, Sarah gives one of the best testimonials to the effectiveness of applied behavior analysis (ABA) I have ever read. She offers new parents a wonderful message of hope and demonstrates the value of perseverance with treatment that is science-based.

Franca Pastro, BA Perspectives Coordinator

ur youngest son, Marcus has just finished at mainstream primary school where he has been for the past 5 years with 1:1 ABA support. Prior to that, he started ABA at just 2 years old before he even got an official diagnosis. So that's 7 years clocked up for him alone.

His older three brothers all did full time (35-40 hrs. a week) ABA from their diagnoses. The twins, now aged 18, started at just three years old. Their younger brother, Hector, was six months old at the time. Two years later, he was also diagnosed and started ABA too.

For many years, I managed three full time programmes concurrently. A neat sentence to write which conceals eight very long years of incredibly hard work. It was hard work for me to manage it all. We had three tribunals to win funding along the way. It was hard to recruit tutors over the years – the hardest bit of any programme. It was hard to have people constantly in our house, in our space and it was hard to find the funding to pay for it all. At times, we had two lodgers living with us to fund it but that shows just how much we believed in it.

And, if it was hard work for us, it was equally hard work for our boys who had to learn to speak and to do so many daily activities that they were previously unable to do. Sometimes, simple things like getting dressed could take hours to teach. The boys had to get used to having someone who was not 'Mummy'



Sarah and her husband enjoying a meal.

with them for hours at a time. Sometimes, I felt compelled to let tutors go if I felt they were not compatible with my children. After all, the boys couldn't express in words if they were not happy but their behaviour displayed their thoughts at times.

I needed to be an advocate for them in so many ways. Choosing the tutors, choosing schools and nurseries and managing it all. It was a privilege in many ways to be allowed that level of control, to have a say in who I chose for my children. I was recently told by another mother that I have a reputation for only employing really good tutors. I am very proud of that, even if at times, it meant we had no tutors while I hunted for replacements. I feel my boys always deserve the best I can do for them.

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ABA worked best with people who had an open mind. Those who didn't necessarily follow all the rules. The ones who had the imagination to realise that a great social interaction in the playground between one of the boys and an un-



The kids together.

known child took priority over learning to read. After all, those skills are the ones we most want for our children. Social inclusion is vital and needs to start at an early age. I have written before about how, when the twins were diagnosed at age three, my wish for my boys one day would be for them to be able to go into a pub with friends and order a drink. Thomas achieved that this year. I did not wish for academic success, that was too tall an order but I did wish for them to be happy in social settings and we have managed that over and above my expectations.

It also worked best when everything taught was meaningful. Why would a child wish to know the names of kitchen items? If they wanted to know the names of every Thomas the Tank engine, that was what they learnt to begin with. In doing so, they learnt that language benefited them, it was worth learning. After a few years, we could teach them the labels for less preferred things, like items of clothing, still meaningful and useful but not quite so desired.

Without ABA, my boys would not be the socially able, happy and positive boys (or nearly men) that they are today. We were helped by the fact that we found a fantastic, inclusive primary school where they were allowed to fully integrate. They learnt academics but most importantly, they learnt to mix in mainstream society which has set them up for life.

I have never counted how many tutors we had over the years but there are many who have left an imprint on all our hearts, who we will forever be grateful to. Those who truly cared about our boys and their possibilities. Many of them we are still in regular contact with, many of them still visit the boys and the boys are so glad to see them again. They miss them still, which just proves how they felt those people were their 'friends' and not just tutors. We count those special tutors as friends too. In many ways they are like a second family for our boys.

Do I regret any of it? No. I just wish there had been more help in finding and recruiting and training tutors. I

also wish that there did not need to be the battles that also accompany running programmes. The unnecessary tribunals. For those who cannot afford to run a programme themselves for the time it takes to get to tribunal, life is hugely unjust and unfair.

We have living proof in all our boys of how life changing ABA was for them all. Happily, we are not part of a control study which might show how they would be without having had the benefit of it. I will never stop saying how important early intervention is and how we, as parents, should be allowed the choice to do therapies such as ABA.

Sarah Ziegel is a nurse and mother of four children with autism. She and her husband live near Richmond, Surrey, England.

You can follow Sarah's blog at <a href="https://sarahjziegel.wordpress.com/blog/">https://sarahjziegel.wordpress.com/blog/</a>

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#### **CLINICAL CORNER**

#### FIRST RESPONDERS EDUCATION IN AUTISM

Karen Parenti, MS, PsyD Executive Director, Melmark PA

In emergency situations, individuals with ASD can become confused and agitated, and when others do not understand their behavior the emergency can become even more dangerous. We must rely on first responders to help prevent or de-escalate these situations, but they can only do so with appropriate information about ASD and specific training. In this installment of Clinical Corner, Dr. Parenti, Executive Director of Melmark Pennsylvania, provides recommendations on

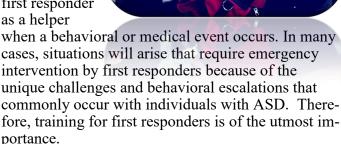
what training first responders should obtain regarding how individuals with ASD might behave in emergency situations, and the ways in which they can interact with these individuals.

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

am a parent of a young man with autism. I also work in the area of law enforcement. What are some important considerations when teaching first responders and law enforcement personnel how to interact with individuals with an autism spectrum disorder?

This is a very important question and one on which many local communities are focused. In addition, treatment of individuals with autism spectrum disorders (ASD) by law enforcement is a common worry for parents. As such, the topic requires training to increase awareness of ASD for first responders and local community members, as well as collaboration between service providers and law enforcement. As in any crisis situation, it is important to focus on positive and preventative approaches, as most behavioral crises with individuals with ASD can be prevented or lessened. In order to promote awareness on the part of first responders and prevent crises, ASD provider agencies should proactively prepare individuals with ASD for a possible encounter with emergency personnel and law enforcement using language they understand, pictures, books, or video models about emergencies so they know what to expect and how to respond. Additionally, building rapport and familiarity between individuals with ASD and local

police might help ensure the person with ASD perceives the first responder



Police officers expertly respond to a large number and variety of emergency situations on a daily basis. Each emergency situation has its own unique characteristics, and so do the individuals involved in that crisis. First responders and police receive standard and rigorous training on how to compassionately and effectively respond to emergencies. This training, while appropriate and efficient for the vast majority of situations, is not necessarily the best way to respond to a child or adult who is diagnosed with ASD. This can lead to an outcome such as this ex-

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## Autistic 6-year-old shot, killed during police pursuit in Louisiana, report says



MARKSVILLE, La. — A 6-year-old boy was killed and his father critically wounded after marshals for a central Louisiana city fired at their vehicle as the father was trying to flee, officials said. The boy's grandmother said he was autistic, CBS

ample of how an unfortunate misunderstanding can result in tragedy.

Whether the emergency is a medical or behavioral crisis, understanding ASD and how someone with ASD might

behave is crucial to ensuring a favorable resolution to the incident. Individuals diagnosed with autism may have heightened emotional responses in these volatile and stressful situations. For persons with ASD, emergencies are difficult to comprehend. During these confusing events, a person with ASD may fail to respond to vocal directions, may exhibit a startle response when touched, may run when addressed, or may engage in self-injurious or aggressive behavior.

For emergency responders, interacting with individuals with ASD can be ambiguous and unpredictable. Therefore, it is essential that emergency personnel learn to respond as sensitively and efficiently as possible to individuals diagnosed with ASD, so attempts to speak with or care for the individual does not inadvertently cause the individual's behavior to escalate. As you may know, this is especially important during a medical crisis because individuals with autism cannot always communicate feelings of pain or discomfort. A person with ASD may already be feeling frustrated and possibly agitated by his or her inability to convey his or her experiences and needs, thus when approached that individual may respond in an unpredictable and unconventional manner. It is important that first responders be prepared for such unusual responses, incongruent emotions, and failure to respond to directives and questions.

In addition to providing police officers and first responders with information about autism symptoms more generally, an important next step is to teach first responders how individuals with ASD might

behave in a crisis. In particular, emergency personnel need to understand how individuals with ASD might act when they are agitated, confused, overwhelmed, or in pain.

## A Child or an Adult Diagnosed with an Autism Spectrum Disorder May:

- Avoid eye contact.
- Walk away from familial residence or a group home to local pools or other places they enjoy.
   They may wander into traffic, not understanding environmental dangers.
- Be overstimulated and not comply appropriately to police or first responders' instructions. For example, they may not respond to directives such as "get out of the street" or "let me see your hands."
- Become preoccupied with certain objects or interests, such as planes, trains, fire trucks, or movies.
- Repeat or echo phrases, words, or actions.
- Not know how to relate, talk, or play with others.
- Have sensory sensitivity, manifested by stereotypical behaviors which may include covering their ears, flapping their hands, spinning, toe walking, or making unusual noises among others
- Become agitated due to the disruption in their routine.
- Have unusual reactions to the way things in the environment look, feel, smell, sound, or taste.
- Be nonverbal and unable to communicate effectively.
- If verbal, may have difficulty understanding questions or may respond noncontextually. For example, they may simply script from a movie or speak about their special interests or ask repeated questions about the responder's personal life.
- Be unable to communicate that they are in pain.

A first responder will be able to interact more appropriately with a person with autism if he or she is able to recognize that the person may have ASD. Once the first responder has learned to make this identification, he or she should become familiar with the following crisis response and intervention safety habits.

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#### **Crisis Response and Safety Habits:**

- Take 30 seconds to assess the situation and the scene before responding.
- Remain calm.
- Use an even, controlled tone of voice with minimal directives, including simple phrases and visual cues such as pointing or using simple gestures that may be easily understood by minimally verbal individuals.
- Pay close attention to the person's body language, tone of voice, gestures, and any other signs of potential agitation.
- Practice trauma informed care and assume that everyone has experienced some type of trauma and is easily startled.
- Respect personal space, except when it is absolutely necessary to approach the person. Remember that getting too close may increase agitation in some individuals with ASD.
- Assess the situation objectively and ask the person or someone familiar with the individual with ASD what he or she wants/needs while maintaining a safe distance.
- Reduce stimulation and allow time and space for the person to process information and requests.
   For example, it might be helpful to clear the area of additional people, turn off the lights of the emergency vehicles, and eliminate other extraneous noises as possible.
- Be prepared and practice situational awareness.
   Know your surroundings and the location of the closest exit.
- Deflect aggression and block self-abuse when possible.
- If a physical intervention is necessary because the situation is unsafe, establish control in a safe, non-threatening manner. Remind the person that you are there to help.
- Recruit familiar and trusted persons to assist you in understanding how to approach the individual.

When police officers and first responders receive training in interacting and treating individuals with ASD, incidents in the community may be resolved quicker and more effectively. With quality training, headlines reporting distressing incidents, such as that above, may be a thing of the past. Instead, the type

of training discussed here, when offered regularly to our dedicated police officers and first responders, could result in positive approaches similar to this:

Autism awareness is essential for all members of the larger community, but is truly imperative for first responders. In the absence of information, first responders may misinterpret the behavior of a person with ASD, may ascribe hostile intent to agitated behavior, may inadvertently escalate the behavior of the individual, or may fail to safely calm the individual. In cases such as these, there can be dangerous consequences. An opportunity exists for ASD service provider agencies to provide specialized training to local first responders. Providers can contact law enforcement officials and other emergency personnel to offer informational training sessions on a local level. In our experience, the administrators are routinely grateful and accommodating about arranging such training.

First responders need a dual skill set. First, they need accurate information about persons with ASD, including their behavioral characteristics, and secondly, they must use skills to de-escalate the situation when they engage with a person with autism who is in a confused and agitated state. With community outreach, negative outcomes can be averted, bridges can be built, and wider acceptance of persons with ASD can become a reality.

The following resource provides additional information related to first responders:

• <u>Living with Autism - Autism Information for Law Enforcement and other First Responders</u>

The reader may also be interested in the following:

- Teaching Safety Skills to Adolescents
- Bolting and Neighborhood Safety

#### INTERVIEW

## WITH DEVON SUNDBERG, MS, BCBA, CEO of the Behavior Analysis Center for Autism (BACA) and Conference Director of the Women in Behavior Analysis (WIBA)

David Celiberti, PhD, BCBA-D

David Celiberti: How did you come up with the idea for *Women in Behavior Analysis*?

**Devon Sundberg:** A few years ago, I served as a cochair alongside Dr. Kim Zoder-Martell for the annual conference of the <u>Hoosier Association for Behavior Analysis</u> (HABA). When it came time to select speakers, we asked for suggestions from colleagues. Although all of the recommended speakers were fabulous, the majority were men. We learned that this is a common observation in the field (e.g.,

McSweeney, 2005), and yet, there are so many prolific women in the field of behavior analysis who are doing impressive and intriguing work! After the HABA conference concluded, we continued to have discussions about the contributions of women in the field of behavior analysis. We talked about ways that we could celebrate the women in our field and highlight their accomplishments. As early career professionals, we talked about ways to support others who are in an early stage of their career and decided that one way to do this would be through hosting a conference.

David: Thank you so much for that background. What were your goals for the first conference? Were you successful?

**Devon:** I don't think we ever formalized goals. We have our mission: "To empower, celebrate, and mentor women behavior analysts and highlight their contributions to the field. To engage both sexes in meaningful discourse on gender equality for the promotion of behavior analysis and professional growth of future generations."

I believe we did accomplish our mission at our first conference held in Nashville this past March of 2017. We had two keynote presentations, four other invited presenters, 15 breakout sessions, a poster session, mentorship opportunities, and an expert panel. We received primarily positive feedback from our

275 attendees and 10 sponsors. We have also pinpointed areas for improvement for our 2018 conference.

David: Those are impressive accomplishments for a very first conference.



What are your future plans?

Devon: Hosting this conference was an amazing experience. We took our time to review our feedback from the 2017 conference and have begun to plan for 2018. We hope to host this conference annually. The sky is the limit as to what goals we may be able to accomplish in the future, but for the time being we are focusing on making this effort sustainable and continuing to improve the conference. Our main goal is to engage more women of color and increase the presence of men at our event. We also heard loud and clear feedback that we need more presentations on the applications of behavior analysis to children with autism. Our vision statement includes:

- Hosting an annual conference that features notable contributions of women in the field of applied behavior analysis, ensuring that women are respected as scientists and leaders;
- Empowering early career behavior analysts through highlighting role models for those building their careers;
- Inviting male speakers who support the effort of gender equality in the field of applied behavior

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analysis; and

• Remaining informed of the current literature regarding the equitable representation of women in the field of behavior analysis.

David: As an organization focused on best practices, we appreciate the heightened interest in autism treatment. Gender differences are certainly observed in the lives of families touched by autism. There is some research that shows that autism impacts work opportunities differentially for men and women with women working less outside the home and men perhaps working more. What is needed to address that divide?

**Devon:** Consistently promoting gender equality within all groups or communities would address this divide. I think a win for any minority group benefits other minority groups. If we are promoting gender equality in the US within our profession, this will empower other minority communities to expect and advocate for the same right. Promoting gender equality within our own field would strengthen the access to this right for all. This would be an excellent presentation for the next WIBA conference and remind our attendees that we also need to advocate for gender equality for those we serve. Further, we should ensure that fathers are just as engaged in the treatment process of our clients as mothers. And we should be cognizant of how ASD may affect females differently than males in our graduate programs, applied services, and applied research. Gender and gender stereotypes influence every aspect of life and hopefully this conference will train us to watch out for such pitfalls and pigeonholing.

David: As a member of this field for 25+ years, I have seen that the majority of new behavior analysts are women. This is in contrast to other areas of science where there are fewer women. How do you respond to those who question the need for a conference of this nature?

Our response to this question is multifaceted. Many existing professions have networking opportunities and associations to celebrate, support, and empower women (a similar mission to ours) such as:

- American Business Women's Association;
- Association for Women Journalists;
- Council of Professional Women in Banking and Finance; and
- Accounting and Financial Women's Alliance

It's clear that these groups thrive due to their utility. Although the field is primarily female, women behavior analysts still benefit from training, support, recognition, and mentorship in a conducive environment. Additionally, the promotion of gender equality benefits other professions and societies. Keeping that notion at the forefront of our profession will promote equitable decision making and prevent covert discrimination for both males and females.

David: Do you think that our field is doing a better job than other fields with respect to hiring, promoting, leadership opportunities, and equal pay?

**Devon:** I think it's obvious that our field excels in hiring and promoting females. At our 2017 conference Melissa Nosik discussed, "Representation of Women in Behavior Analysis: An Empirical Investigation," where she shared data on female representation in publications, association membership, and editorial appointments. The data demonstrated that we are approaching a female led field. Amy Odom presented on "Women in EAB: Representation in the Journal of the Experimental Analysis of Behavior." She discussed women's participation as authors, editorial board members, and editors. She shared that the representation of women in EAB is low relative to women's participation in other areas of behavior analysis. WIBA hopes to promote more research like this to determine the direction of our field and pinpoint the areas that need strengthening to promote the sustainability of behavior analysis. Perhaps proper research would uncover gender gaps in pay or leadership opportunities.

David: Given the emphasis on science and technology within primary and secondary education today, it is wonderful that we are approaching gender equity within our own science-based discipline. Any advice for young women entering the field here in the US?

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**Devon:** Seek out supervision and mentorship. I'm fortunate to have many mentors that I can reach out to (some male; some female), but they all have valuable experiences to share with me, especially in their areas of expertise. Also, whenever possible, work for an established agency to better access supervision. Our field is wrought with ethical dilemmas and day to day difficulties in practice. It's too much for anyone to take on alone. Having the protection of an agency and their supervisors to handle the big problems can be invaluable and allow early professionals to focus on developing their clinical and professional skills. Clearly, the field of behavior analysis is predominantly female. We need to support these women through this paradigm shift and ensure that they are prepared to successfully navigate any discrimination based on their gender from others. Also, we need to protect our field from the pitfalls of being a predominantly female profession. A phenomenon of female led industries is that they may be prone to a gender pay gap (nursing, social work).

David: Any advice for women in behavior analysis residing in other countries, particularly those in which opportunities for women are more limited?

**Devon:** In these instances, I would suggest seeking out a female mentor. We are fortunate in the US that we've had leaders take on the fight for gender equality since the time of women's suffrage (early 1900s). This isn't the case in every country, so having a female mentor might protect and support women from other countries entering the field of behavior analysis.

#### David: Tell us about your plans for 2018.

**Devon:** We worked very hard on analyzing our attendee feedback and implementing it for the greatest attendee satisfaction. Our 2018 conference will be even more affordable, will feature inspiring leaders in our field, and allow for an open forum of discussion. Additionally, this conference is a fun and convenient opportunity to, not only be inspired by, but also get to work on, improving our applied and business skills by attending our Day 3 workshops; Sarah Trautman-Eslinger will be presenting a 3-hour workshop on "ABA Business Bootcamp."



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David: Thank you kindly for such a wonderful opportunity to learn more about your efforts. All the best with the upcoming conference.

#### IS THERE SCIENCE BEHIND THAT?

#### AUTISM AND TREATMENT WITH MARIJUANA

Kelley L. Harrison, MA, BCBA, LBA-KS
Thomas Zane, PhD, BCBA-D
Department of Applied Behavioral Science, University of Kansas

ver the past several years, there has been an increasing number of states that have passed laws making the use of marijuana legal (GCODP, 2011; Hadland, Knight, & Harris, 2015), either for medicinal or recreational purposes. Coinciding with this trend is the growing number of reports suggesting that this drug could be used to treat symptoms of autism spectrum disorder (ASD) and other developmental disabilities (Ellison, 2009; Miles, 2012; Young, 2013). However, there are no controlled studies evaluating the effects of marijuana on ASD. Currently, the federal government assigns marijuana and its related products as a "Schedule I" drug, meaning there is no formal recognition of accepted medical use, and it has a high potential for abuse (American Academy of Neurology, 2017).

Recent surveys show that marijuana is the 2ndmost popular substance used by adolescents, after alcohol (Sacco & Finklea, 2013). A popular belief is that marijuana is relatively harmless. Users of marijuana report euphoria, increased social interactions, increased appetite, increased insensitivity to pain and discomfort, and increased relaxation (e.g., Hadland et al., 2015). Unfortunately, researchers have identified several adverse effects of marijuana use, especially when used by adolescents. For example, adolescents are more susceptible to addiction. In fact, one in six teenagers who use marijuana will become addicted (National Institute on Drug Abuse, 2013). Marijuana also has effects on brain development in anyone under the age of 21 years, and is correlated with a lower IQ, an increased likelihood of dropping out of school, diminished life satisfaction and achievement, and an increased risk for the development of mental illness (Volkow, Baler, Compton, & Weiss, 2014). In addition, Ellison (2009) reported that tetrahydrocannabinol (THC), the active ingredient in cannabis, interferes with memory, concentration, and attention, which are the primary diagnostic indicators of Attention Deficit Hyperactivity Disorder (ADHD).

#### Composition of Marijuana and the Current Law

Marijuana is derived from the 'cannabis sativa'



plant that contains more than 60 compounds called cannabinoids (Hadland et al., 2015). The euphoric effect associated with marijuana use is activated by Delta-9-tetrahydrocannabinol (THC), which is considered a major psychoactive substance (American Academy of Neurology, 2017). Other compounds in marijuana do not have a similar psychoactive influence. Marijuana can be smoked, ingested, and 'vaped,' similar to e-cigarettes. Hash oil, which is a highly concentrated form of marijuana, contains a very high concentration of cannabinoids, and is illegal at the present time (Mehmedic et al., 2010).

As the federal government has relaxed the laws regarding the legality of marijuana, more states have been allowing it to be used for medical and recreational purposes. Initially, the laws permitted only adults to receive the drug. However, more recently, the United States Food and Drug Administration (FDA) approved synthetic THC-based cannabinoids for use by children as an appetite stimulant while receiving chemotherapy (Hadland, et al., 2015). However, it is important to note that these synthetic versions of the drug do not possess psychoactive properties, and thus are believed to be safer to use.

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## What is the Conceptual Link Between Marijuana and ASD?

There is some published research suggesting that marijuana can alleviate spasticity and general pain in adults (Koppel et al., 2014), and some doctors are starting to recommend marijuana for children for ailments other than physical ailments (e.g., Tourette syndrome, epilepsy, dystonia, seizures; Hadland et al., 2015). Anecdotal report suggests marijuana may increase sociability, heighten perception, give a sensation of slowing time, decrease aggression, and increase appetite (Hadland et al., 2015). Thus, on the surface, it appears marijuana may be appropriate for several behaviors typically associated with individuals with ASD (e.g., decreased appetite, severe problem behavior including aggression towards other or self, inappropriate social skills, inability to maintain attention; Autism Support Network, 2016). Additionally, proponents of marijuana use argue that marijuana is safer and has fewer side effects than other behavioral management medications. For example, Ritalin, the commonlyprescribed medication for ADHD, is associated with facial tics, stunted growth, depression, and insomnia.

## What is the Scientific Evidence of Marijuana Use for Autism?

Currently, only testimonials exist supporting the use of marijuana to treat ASD. For example, there are advocacy groups such as "Mothers for Medical Marijuana Treatment for Autism," "Mothers Advocating Medical Marijuana for Autism (MAMMA)," and "Pediatric Cannabis Therapy" claiming that marijuana can both reduce the likelihood of serious behavioral episodes and make the individual more social and more receptive to learning. However, these groups do not cite any controlled research to support these claims. Additionally, they report that marijuana improves sleep patterns and allows the individual to be more 'present' in their immediate contexts, also without any substantiation from research.

One can find videos on the Internet that suggest a relationship between the use of marijuana and significant improvements in behavior, sociability, and other developmental areas (e.g., <a href="https://">https://</a>

www.youtube.com/watch?v=ISJ0fsCacMA). A review of Internet searches will return hundreds of stories and testimonials supporting the hypothesis that the marijuana was the reason for improvements in individuals with autism. However, the fact of the matter is that there is simply no scientific evidence that this drug is causally related to any improvements in developmental, behavioral, or academic measures (Hadland, et al., 2015). That is, there are no controlled studies using sound and acceptable research designs assessing the impact of marijuana on any aspect of autism symptomology. Thus, it is clear that at this time, that marijuana has not been demonstrated as an effective treatment for autism.

## What are the Risks Associated With the Use of Marijuana to Treat ASD?

More disturbing than the lack of evidence to support the use of marijuana to treat ASD are the major concerns regarding whether or not marijuana can be considered safe at all. The case against using this drug is quite compelling. Many medical reports describe in detail the known harm of cannabis and the possible physical and psychological harm that it could cause (Hartman & Huestis, 2013; Hatchard, Fried, Hogan, Cameron, & Smith, 2014; Hill, 2014; Joffe & Yancy, 2004; Kashyap, 2016; Liu, 2016). There is such enormous concern about both the lack of research supporting its positive influence for ASD, developmental disabilities, and other pediatric behavioral disorders, and the potential for psychological and physical harm, that a number of professional organizations have published position statements asserting that marijuana should be considered a public health concern, and recommending that further legalization of the drug be delayed until further research is conducted (e.g., American Academy of Neurology, 2017; American Academy of Pediatrics, 2015; American Medical Association, 2009; American Society of Addictive Medicine, 2014; American Academy of Child and Adolescent Psychiatry, 2017). For example, the American Academy of Neurology, in its 2017 position statement on the use of medical marijuana for neurologic disorders, clearly states that there are no welldone, formal research studies that support the use of marijuana and its derivatives for improving various neurologic conditions.

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In addition, there are documented potential side effects, including dizziness, suicidal ideation, the sensation of intoxication, hallucinations, and mood changes, (some potentially irreversible; Hall & Degenhardt, 2009). Also, chronic use of marijuana outside the realm of medical necessity has also been associated with memory and verbal learning losses (Zajicek, et al., 2003), and disruption of concentration and executive functioning difficulties (American Academy of Neurology, 2017). Finally, the interaction between prescription drugs and marijuana has not been adequately investigated and could pose a risk.

#### What Is the Bottom Line?

Currently, there is no evidence to support the use of marijuana as a treatment for ASD. This, in conjunction with the possible negative side effects, strongly suggests we should not use marijuana for treatment of ASD, at least until the medical community first understands its safety. However, even if proven safe, then professionals will need to do well-controlled, high-quality research studies using marijuana as a treatment for ASD. These studies should evaluate the effects of marijuana on clearly defined and carefully measured behaviors to determine any positive and causal impact. Until that time, it is clear that the use of marijuana and other related cannabis products are contraindicated for treatment of ASD. Because there is no scientific evidence that marijuana may benefit individuals with ASD, parents and caregivers of children with ASD should strongly consider the adverse side effects that may occur when marijuana is used as a treatment.

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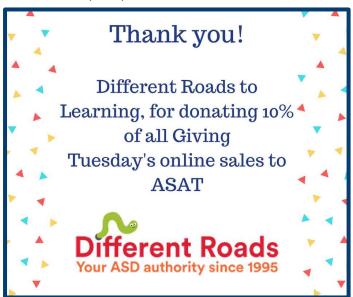
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#### CLINICAL CORNER

#### LEARNING TO MANAGE FEMININE HYGIENE NEEDS

Allison Parker, MA, BCBA

As girls with autism approach puberty many parents struggle with how to teach independence in feminine hygiene. In this installment of Clinical Corner, Allison Parker, our very own Externship Co-Coordinator and Caldwell University doctoral student, provides step-by-step recommendations on how to target management of female hygiene and important points to consider.

Kirsten Wirth, PhD, CPsvch, BCBA-D **Clinical Corner Co-Coordinator** 

**Ouestion:** I have a daughter with autism who is showing signs of puberty. I want her to continue to be as independent as possible and to be prepared for all aspects of her own feminine hygiene, but don't know where to begin with teaching her how to care for her menses. What is the best way that we can practice these skills before her menstrual cycle begins?

#### Answered by Allison Parker, MA, BCBA

uberty can be an anxious time for any parent, and feminine hygiene is a seldom discussed topic; therefore, your question is an incredibly important one. As behavior analysts and practitioners, we recognize that any skills related to hygiene that we teach girls with autism will equip them to have access to a higher level of independence, privacy, and dignity. We hope the following recommendations provide some guidance on helping your daughter become independent and confident with these skills.

#### Talking about Feminine Hygiene

As with any skill you teach children and adolescents, it is important to use plain language and to avoid abstract terms as much as possible. It is also important to become comfortable with all of the terms involved in feminine hygiene, such as period, pad, blood, etc. As uncomfortable as it may seem at first, speaking about these things becomes a normal part of the

teaching process over time. Due to the fact that taking care of your



period is a sensitive and private event, you may consider beginning by explaining to your daughter what it is and why you need to go over essential hygienic practices. Work a few basic facts into a conversation, or visual aid if you feel it will be helpful to your daughter's acceptance of the teaching program. Explanations may include a basic outline such as, "as we get older, our bodies change, and one day you will get your period. When you get your period, there will be blood in your underwear when you go to the bathroom. We are going to practice how to clean it up and take care of your period."

Because of the range in communication ability and level of understanding among individuals with autism, and accounting for family, cultural, and personal preferences on this topic, the advice here will need to be tailored to match your daughter's specific skillset.

#### **Materials**

*Hygiene products* 

As a caretaker, you will decide what products to use to teach your daughter to protect her garments from

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menstrual blood. Published research and clinical experience will limit my recommendations to the use of various pads, but other products available on the market include tampons, menstrual cups, and menstrual underwear. If you don't plan to use the same type or brand of your product on a permanent basis, then you will want to teach your daughter with a few different types in order to expose her to the different features and options these products offer. For example, have a few types and brands of pads available to use such as panty liners, thicker pads, and pads with and without wings. It is best to train your daughter to use a range of products and brands from the beginning to avoid potential issues should a specific product be unavailable or be discontinued by the manufacturer.

#### Purse and clean underwear

If your daughter does not carry a bag such as a purse or backpack with her, it is a good idea to begin teaching this skill right away. She will need a place to keep hygiene products and a change of underwear. She may also need to learn to keep track of her purse and keep it with her during trips to the bathroom. Make sure that hygiene products and a clean pair of underwear are always available in the purse, especially before each teaching opportunity.

#### Trashcan and hamper

Make sure a trashcan is easily accessible in the bathroom. Because most public restrooms have a waste disposal bin inside of the stall, it may be helpful to teach with a small trashcan next to the toilet. It may also be helpful to make a clothing hamper or basket available nearby the bathroom you're teaching in. Consider what you will want your daughter to do with soiled underwear in most conditions. It may be helpful to teach her to keep them in a plastic bag or to throw them away if a hamper is not available.

#### Fake blood

Finally, if you are teaching your daughter before her menstrual cycle begins, you will need to simulate this experience using fake blood. Be sure to use items that are safe for contact with genitals, and consult with your gynecologist to ensure that ingredients will not cause infection or irritation. A realistic and safe option may include a mixture of canned beats, prune juice, and water. Keep in mind that these foods are natural dyes and may stain surfaces and linens.

#### **Teaching**

There are a few different scenarios your daughter may encounter during her menses, so it is recommended that you teach for each of these scenarios. Recommended teaching conditions include what to do when:

- 1. The underwear is soiled with blood
- 2. Only the pad is soiled
- 3. Both the pad and the underwear are soiled, and
- 4. Nothing is soiled (both underwear and pad are free from blood).
- 5. Before approaching the bathroom to teach each scenario, place the corresponding items (including fake blood) on your daughter in another room so that the practice closely simulates a natural situation in which she goes to the bathroom to care for her menses.

Since these skills are complex and include many steps, it is important to break them down into smaller units. Create a detailed list of steps, otherwise known as a "task analysis", involved for responding to each teaching condition. A board certified behavior analyst can assist you with creating a task analysis based on the steps you want to teach, determining how to assist your daughter to complete each step (these are usually called response prompts), and teach you how to correct any errors she may make. Methods can be adapted from the study developed by Veazey, Valentino, Low, McElroy, and LeBlanc (2016). A sample task analysis is provided below for reference.

For example, you may want to wait a few seconds before each step to allow your daughter to complete it independently. If she does not move on to the next step, use assistance to prompt the correct response. If she completes the step incorrectly or goes to the wrong step, you should walk her through the correct step, and then allow her the opportunity to complete it herself. In a task analysis, each step serves as a reminder for what comes next, so it is important that your daughter experiences each step in the correct order. Provide specific praise such as "great job get-

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ting the clean pad from your purse" and preferred items for steps done correctly, especially those that are done independently. Remember to identify items that can be provided in the bathroom and will not interfere with the process, such as tokens or stickers that can be traded in for a favorite activity.

#### Task analysis for soiled pad

- 1. Walks into the bathroom
- 2. Pulls down underwear and sits on toilet
- 3. Removes soiled pad from underwear
- 4. Wraps toilet paper all the way around pad at least once
- 5. Disposes of pad in trashcan
- 6. Wipes vaginal area with toilet paper until clean to remove possible residual blood and drops paper in toilet
- 7. Removes sanitary napkin from purse
- 8. Opens clean sanitary napkin
- 9. Disposes of outer covering in trashcan
- 10. Removes covers from adhesive areas of sanitary napkin
- 11. Disposes of covers from adhesive areas in trashcan
- 12. Fastens sticky side of napkin lengthwise in underwear and presses into place
- 13. Wraps wings of sanitary napkin around underside of underwear and presses into place (if applicable)
- 14. Pulls up underwear
- 15. Pulls up and fixes outer clothing
- 16. Flushes toilet
- 17. Holds soiled underwear by the waist band and puts into laundry basket

18. Washes hands

#### **Additional Considerations**

Always keep in mind the teaching techniques that work best for your daughter. You may need to use visual aids or change instructions and prompts as necessary. You may find that you need to specifically teach these steps in school and in the community, so I suggest teaching in a variety of bathrooms from the beginning. You may also need to gradually remove yourself from the bathroom in order to teach independence with these steps. Gradually fade out your praise and proximity. Check to see if steps were done independently by making sure the clean pad is placed correctly, items are placed in the trashcan and hamper, and clothes are fastened correctly.

We applaud you for considering this important skill for your daughter, and hope these steps will assist in her self-care as she transitions into a young woman.

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#### Media Watch Featured Letter

ASAT Responds to The Washington Post's, "Nowhere to Go: Young People with Severe Autism Languish Weeks or Longer in Hospitals"

Justin DiScalfani, PhD, BCBA-D, LBA Erin Leif, PhD, BCBA-D

Through our Media Watch initiative, we provide written feedback to journalists and other media professionals who write about autism and its treatment. We strive to acknowledge the efforts of those individuals responsible for educating the public with sound, accurate information. When an autism intervention is portrayed inaccurately, we provide feedback to encourage correction and suggest consideration when writing future articles. In this issue we feature a letter to the Washington Post, about their piece addressing treatment of individuals who display severe behavioral challenges. You can check all past letters here: www.asatonline.org/for-media-professionals/media-watch/.

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



we are writing in response to your recent <u>article</u>, "Nowhere to go: Young people with severe autism languish weeks or longer in hospitals." We would like to commend you for highlighting an important issue, which is the extreme difficulties people with autism and their families encounter in crisis situations. Your article also highlights the current need for more appropriate supports for individuals with autism (and related conditions) who display behaviors of concern, especially in crisis situations.

At the beginning of your article, you state that there are currently not enough community resources available in most areas to adequately deal with severe behaviors of concern which pose a risk to the individual with autism and/or those around him or her (including family members). When these individuals and families are in crisis and people are in danger, emergency services may be a first port of call, regardless of in home supports. However, as you pointed out, traditional emergency rooms and psychiatric departments are ill equipped to manage most of these cases, sometimes leading to prolonged hospital stays without appropriate treatment. Without access to appropriate treatment, people with autism and behaviors of concern may be subjected to chemical and mechanical restraint, which are restrictive interventions that may not be necessary in a more specialized therapeutic setting.

Within the field of applied behavior analysis (ABA), a functional behavior assessment may be used to understand the reasons why individuals with autism and related conditions engage in behaviors of concern, prior to treatment. When the function of the behavior is identified, interventions can be designed that teach the individual to communicate or access his or her wants and needs in more socially appropriate

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ways. Hundreds of scientific studies have demonstrated the efficacy of function-based treatments, or those that link treatment to behavioral function, for reducing behaviors of concern in people with autism, without the use of restrictive interventions. Most medical and allied health professionals lack the training and expertise to conduct functional behavior assessments and write, implement, and monitor function-based treatment plans. Without proper training in evidence-based practices, professionals may resort to using restrictive interventions to respond to and manage behavior problems. Given the acumen required to conduct proper functional behavior assessments, medical and allied health professionals should seek support and supervision from a Board Certified Behavior Analyst (BCBA) when working with individuals with autism, especially individuals who display more severe forms of challenging behavior. Many states are now licensing behavior analysts in an effort to provide additional consumer protection and safeguards. The Behavior Analyst Certification Board (www.bacb.com), an internationally recognized organization, describes the education and training requirement to obtain the BCBA credential. However, even with more access to scientifically validated treatments and credentialed treatment providers, emergencies may still arise which necessitate calling 911 to maintain safety. Therefore, it would be beneficial to provide more educational programs to first responders and emergency department personnel on how to safely manage and de-escalate behavioral crises displayed by people with autism.

Thank you again for pointing out such an important topic. We hope that you will consider sharing our response to your article with your readers to help us disseminate information about evidence-based and humane strategies for safely and effectively managing behaviors of concern displayed by individuals with autism.

Sincerely,

Justin DiScalfani, PhD, BCBA-D, LBA & Erin Leif, PhD, BCBA-D Association for Science in Autism Treatment

#### RESEARCH SUMMARIES

PARENT-MEDIATED INTERVENTION VERSUS NO INTERVENTION FOR INFANTS AT HIGH RISK OF AUTISM

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PARENT-MEDIATED SOCIAL COMMUNICATION THERAPY FOR YOUNG CHILDREN WITH AUTISM (PACT)

In this issue of SIAT, we summarize two studies on parent-mediated interventions for young children. The first looks at the long-term outcomes of the Preschool Autism Communication Trial (PACT) on children with ASD. The second looks at the impact of a particular type of early intervention on infants at high-risk of ASD. We hope this information is useful.

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

Green, J., Charman, T., Pickles, A., Wan, M. W., Elsabbagh, M., Slonims, V., ... Jones, E. J. (2015). Parent-mediated intervention versus no intervention for infants at high risk of autism: A parallel, single-blind, randomised trial. *The Lancet Psychiatry*, 2(2), 133-140.

Reviewed by: Eileen M. Milata, Caldwell University

#### Why research this topic?

Studies have found that infants who have an older sibling with autism spectrum disorder (ASD) are also likely to develop ASD, and other social and communication disorders. The characteristics linked to a later diagnosis of ASD during an infant's first year of life are lack of attention to parent, poor eye contact with others, and difficulty shifting eye gaze between objects. During the infant's second year of life, the child may have challenges with visual attention skills and have more behavior issues than a toddler of typical development. The purpose of this study was to test whether early intervention to improve parent interaction and attention skills with infants at high-risk of ASD could reduce early signs of ASD and the risk of later ASD.

#### What did the researchers do?

The researchers compared a parent-mediated intervention to no intervention for 54 infants at high risk of ASD, ages 7-10 months. Twenty-eight infants

and their parents received intervention, and 26 did not.



The intervention was a modification of the Video Interaction to Promote Positive Parenting (VIPP) program. The VIPP used video feedback to help parents understand and learn their child's communication style, and then improve their child's social and communication skills. To measure infant attentiveness to parents, the researchers used the Manchester Assessment of Caregiver-Infant Interaction (MACI). An eye tracker system measured the infants' shift in attention between objects. An event-related-potential to speech sounds (ERP) paradigm measured whether they attended to speech sounds. Three standardized assessments were also used: a test of infants' early motor, language, and cognitive development, and parent reports of adaptive behavior (i.e., motor, communication, socialization, and daily living skills) and communication (vocabulary and gestures). The researchers then used a statistical procedure to combine the measures into eleven independent domains: infant attention to parent, infant affect, caregiver sensitive responding, caregiver interactions, parent-child mutual responsiveness, receptive skills, expressive skills, gestures, communication, socialization, visual attention skills, and recognizing unfamiliar speech sounds. They then

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compared change on these measures in the intervention and no-intervention groups.

#### What did the researchers find?

The researchers found that, compared to no intervention, the intervention increased infant attentiveness to parents, improved shifting attention between objects, reduced autism-risk behaviors, and enhanced parent-child interactions. Parents who received the intervention reported a positive change in their child's adaptive behaviors but a possible reduction in communication. The intervention and no -intervention groups did not differ on vocabulary scores, responsiveness to language sounds, or language development.

## What are the strengths and limitations of the study?

An important strength of this study is that it is the first randomized control trial study that examined an intervention beginning under 1 year in infants at high risk of developing ASD. Data showed a reduction in ASD-related behaviors, suggesting this intervention may prevent the short-term emergence of these behaviors during the child's early development and improve brain functioning. However, there are also a few limitations to the study. The participating families were self-referrals or clinic referrals and earned an above average annual household income. This makes it unclear whether researchers could replicate this study with a broader population and range of clinical settings, and still find similar results. Also, the sample size of this study was small for a randomized trial, so these findings should be interpreted with caution before making any definitive conclusions.

#### What do the results mean?

Overall, infants made gains in attentiveness to parents following parent-mediated intervention. This suggests that the VIPP program is a promising intervention for infants at high risk for ASD to reduce the early characteristics and risk for later ASD. Replications are needed to confirm the findings and determine the applicability of the VIPP program to diverse families in varying clinical settings.

Pickles, A., Le Couteur, A., Leadbitter, K., Salomone, E., Cole-Fletcher, R., Tobin, H., ... Aldred, C. (2016). Parent-mediated social communication therapy for young children with autism (PACT): Long-term follow-up of a randomized controlled trial. *The Lancet*, 388, 2501-2509. doi:10.1016/S0140-6736(16)31229-6

## Reviewed by: Nicole A. Pantano, Caldwell University

#### Why research this topic?

Few studies have looked at long-term outcomes of autism spectrum disorder (ASD) treatment such as changes in symptoms associated with ASD. The purpose of the current study was to measure the long -term outcomes of the Preschool Autism Communication Trial (PACT). This trial randomly assigned children with ASD, age 2-4 years at entry into the study, to receive either the PACT intervention or services available in the community ("treatment as usual"). The PACT intervention consisted of 12, two-hour parent training sessions for six months and monthly sessions for another six months, focused on social communication skills. Parents completed specific activities with their child for about 30 minutes every day.

#### What did the researchers do?

Originally, 152 participants received either PACT or treatment as usual. At follow-up, 59 PACT participants and 62 treatment as usual participants were assessed at an average age of 10.5 years. The assessors watched 8-min videos of parent-child naturalistic play to examine parent-child communication and child language. Parents reported on ASD symptoms including: restricted and repetitive behaviors, insistence on sameness, peer problems, and adaptive behavior outcomes. Also, the researchers evaluated whether any children had additional diagnoses.

#### What did the researchers find?

Children whose parents received PACT had fewer or less severe ASD symptoms and more communication with their parents at follow-up, but they did not differ from children in treatment as usual in their receptive or expressive language.

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## What are the strengths and limitations of the study?

A strength of this study was that assessors were unaware of which treatment the children received. This helped ensure that their ratings were unbiased (i.e., unaffected by expectations about whether one group would do better than the other). Another strength was that the study included a large sample of children diagnosed with ASD, most of whom took part in the follow-up assessment.

However, a limitation of the study is that, despite random assignment to groups, parents in PACT had more education than parents in treatment as usual. This imbalance could have contributed to the more favorable outcomes in PACT. Also, in their discussion, it would have been helpful if the authors could have done more to put their findings in the context of reports on long-term outcomes in intensive behavioral treatment, such as McEachin, Smith, Lovaas (1993).

#### What do the results mean?

Overall, PACT was superior to treatment as usual at a 6-year follow-up on most, but not all, measures. This indicates that a low-intensity parent training program can be effective in producing long-term improvements on core features of ASD. However, the finding of no group differences on some measures suggests either that PACT has limited effects on some aspects of functioning or shares common elements with treatment as usual. Replications are needed to confirm the findings, identify which components of PACT contributed to the favorable outcomes, and determine which children and families are most likely to benefit from the intervention.

#### Reference

McEachin, J. J., Smith, T., & Ivar Lovaas, O. (1993). Long-term outcome for children with autism who received early intensive behavioral treatment. *American Journal of Mental Retardation*, 97, 359-359.



#### HOW ASAT SUPPORTS PARENTS OF OLDER CHILDREN AND ADULTS

David Celiberti, Brian Fennell, Preeti Chojar, Franca Pastro, Sabrina Freeman, Mary Jane Weiss, and Vincent Winterling

s an organization, we have long been committed to the promotion of evidencebased practices for all individuals with autism across the lifespan. Because autism is typically a lifelong developmental disability, many individuals with autism have a myriad of needs that require attention across their lifetime. Determination of needs based upon severity and existing skill sets should be a crucial consideration in service planning. Parents understandably worry about the futures of their adult children with autism, as many individuals face a loss of services (i.e., receive minimal or no services through adult service agencies) when they graduate from school programs. Families also face difficulty in their attempts to identify providers, match interests to available programs and services, or understand how to navigate new and complex adult service delivery systems.

When families begin the process of arranging for services for their adult children, they face an immediate and sometimes overwhelming realization that much of what they know has become obsolete in this new environment and no longer relevant in the context of adult needs and service provision options. These concerns may be compounded by the reality that service provision for children in some countries may have been mandated by law for children (such as in the United States) and these entitlements and laws are no longer applicable in the adult services world. Thus, the need to remain a savvy and informed consumer as they attempt to navigate the adult world and a commitment to science remain paramount and continue to be the foundation of decisions and choices regarding programs. treatments, and other issues in the lives of adults with autism.

Although the research evidence continues to grow for best practices for young children with autism, the autism community is challenged by a shortage of professionals with expertise in working with adults, a lack of choice for employment opportunities, and a shortage of innovative living arrangements for the generation of people with autism now reaching



adulthood. Furthermore, while there is research literature to guide intervention planning, it too must be accessed by families to ensure successful implementation, as few studies have been published that focus on the issues facing adult learners with autism. Therefore, it is critical to learn about transition planning to ensure optimal success, the highest possible quality of life, and continued growth of individuals with autism throughout their lives. It is also important to share innovative data-based approaches to increase dialogue and highlight innovative models for intervention.

It is our hope that this article serves to provide a comprehensive list of resources offered to families and service providers of adolescents and adults with autism. We anticipate this list of offerings will continue to grow and with it an expansion of opportunities for adults with autism. The links presented here focus on solutions to a variety of challenges including increasing independence, developing safety skills, augmenting employment opportunities, increasing community integration, and managing sexuality, as well as other topics of interest to family members and service providers who work with this population of teenagers and adults. Increasingly, attention is also focused on outcomes such as happiness and quality of life which are difficult to define. In addition, in the future we

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very much look forward to sharing new, innovative ideas that are currently in development.

We would like to take this opportunity to share details about five important ASAT initiatives that may be helpful to you as a parent of an adult or an older child facing the transition to adulthood:

- ASAT publishes a quarterly newsletter, Science in Autism Treatment, containing reviews of published research, books, and consumer resources (e.g., training videos, websites, or resource lists like this one on 'bullying'), interviews with leaders in the field of autism treatment for older children and adults, as well as parent advocates, answers to questions about important clinical issues related to treatment, tips to differentiate evidence-based options from others marketed as panaceas, and more. In addition, you can find links to the current newsletter, Science in Autism Treatment, as well as past issues in the Archived Newsletters section. You can subscribe for free here.
- ASAT's website (www.asatonline.org) provides valuable information regarding how parents can evaluate the evidence supporting various treatment options. ASAT regularly updates treatment descriptions and research summaries so readers may access timely information about the current state of autism intervention research in an easy-to-read format. Our website also contains book reviews, interviews, topical articles, information to assist with a variety of clinical issues, and pages specific to parents of older children and adults. These Lifespan Suggested Articles include a review of bullying resources because individuals with autism may be effected by bullying even in adulthood, ABA for older learners, and messages of support from others on the same journey. You can also find a list of relevant books here. Some of these titles have been reviewed by us.
- ★ ASAT's Media Watch monitors mainstream media to identify published information about autism and autism treatments. Understanding that every media contribution has the potential to reach thousands of consumers and service providers, we support accurate media depictions

- of empirically sound interventions. We also respond to inaccurate information of proposed treatments reported and, at times, promulgated by news outlets. Parents can review our 150+ published letters as models of professional interaction with journalists and media outlets.
- ★ We maintain an active <u>Facebook page</u> to help readers better understand the scope of evidence-based practice available and to remain apprised of how autism treatment is being represented in the media.
- We offer Perspectives, which showcases articles and interviews from passionate and dedicated parents of adults with autism who relate their triumphs and challenges in implementing science -based treatment at home, school and in the community (for example, this web-based resource list for adults with autism). Readers can follow the journeys of parents as they share innovative ways to help their young adults with many common difficulties: transitioning to adulthood, developing vocational skills and creating novel models of employment, reaching greater community and school inclusion, dealing with safety issues, pursuing effective interventions as well as increasing awareness in their communities.

In the remainder of this article, we would like to highlight a few of our efforts in greater detail as they related to older children and adults with autism, as well as their family members and providers.

#### **Media Watch: Links to Adult Services**

As stated above, we respond to accurate and inaccurate representations of ABA in the media and endeavor to help consumers better appreciate the research evidence, relevance, and scope of science-based treatments. Many of our <a href="Media Watch">Media Watch</a> letters address older children and adults with autism, and focus on topics such as employment, transition from school, and other lifespan challenges. Below is a sample of some of the articles.

#### **Employment**

★ ASAT Responds to Triblive.com's "Pa. Autism Services Hope to make inroads in workplace"

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★ ASAT Responds to MSNBC's "1 in 3 autistic young adults lack jobs education"

#### **Transition from School**

- ★ ASAT Responds to FoxPhilly.com's "Parents of Autistic Children Worry What Life Will Bring When They're Adults"
- ★ ASAT Responds to Portland Press-Herald's "Graduating to an Uncertain Fate"
- ★ ASAT Responds to Psychologytoday.com's "NJ's I/DD community strongly opposes the state's transition plan: now what?"

#### **Treatment**

- ★ ASAT Responds to abc.news.go.com's "How A Child With Autism Became 'His Own Man' After Treatment"
- ★ ASAT Responds to Des Moines Register's "Autistic man struggles in Iowa's mental health system

#### Lifespan Challenges

- ★ ASAT Responds to TheStar.com's "Groundbreaking adult autism survey reveals mountain of unmet needs"
- ★ ASAT Responds to News.com.au's "Cost of autistic children cripples parents up to \$50,000 a year"

#### **Awareness and Advocacy**

- ★ ASAT Responds to The Washington Post's, "Nowhere to Go: Young People with Severe Autism Languish Weeks or Longer in Hospitals"
- ★ ASAT Responds to Gulf News', "Reality of living with autism in UAE"
- ★ ASAT Responds to niyitabiti.net's, "I Was Called a Witch and My Husband Quickly Divorced Me – Oritoke Aluko – Olukun"
- ★ ASAT Responds to Psychology Today.com's "Making Severe Autism Visible"

#### **Community Participation**

★ ASAT Responds to Good Housekeeping's, "Costco is Hosting Sensory-Friendly Shopping Hours for People with Autism"

## Clinical Corner and Research Synopsis: Focus on Adult Transition Issues

We discuss many clinical matters related to older children and adults in our <u>Clinical Corner</u> columns targeting a wide array of topics such as <u>promoting independence</u>, <u>IEP goal development for adulthood</u>, <u>employment</u>, <u>safety skills</u>, <u>bullying</u>, <u>addressing sexuality</u>, <u>participating in religious services</u>, <u>supporting siblings</u>, as well as general use of <u>ABA</u> for older children.

We review published research as part of our <u>Research Summaries</u> effort, and highlight its relevance and importance within autism treatment. Some examples related to older children and adults include:

- ★ Classroom application of functional analysis
- ★ Parent-assisted social skills training to improve friendships in teens with autism spectrum disorders
- ★ Post-high school service use among young adults with an autism spectrum disorder
- ★ Epidemiology of autism spectrum disorders in adults in the community in England
- ★ Cognitive behavioral therapy for anxiety in children with ASD

We interview prominent behavior analysts from across the globe around common themes of service delivery, certification, dissemination, and access to behavior analytic treatment. Recent interviews have included <a href="Linda Meyer">Linda Meyer</a>, <a href="EdD">EdD</a>, <a href="BCBA-D">BCBA-D</a>, <a href="And Jeffrey">And Jeffrey</a> <a href="Jacob">Jacob</a>, <a href="BCBA">BCBA-D</a>, <a href="And Jeffrey">BCBA-D</a>, <a href="And Jeffrey">And Jeffrey</a> <a href="Jacob">Jacob</a>, <a href="BCBA">BCBA-D</a>, <a href="And Jeffrey">And Jeffrey</a> <a href="Jacob">Jacob</a>, <a href="BCBA-D">BCBA-D</a>, <a href="And Jeffrey">And Jeffrey</a> <a href="Jacob">Jacob</a>, <a href="BCBA-D">BCBA-D</a>, <a href="And Jeffrey">And Jeffrey</a> <a href="Jacob">Jacob</a>, <a href="BCBA-D">BCBA-D</a>, <a href="And Jeffrey">And Jeffrey</a> <a href="Jacob">Jacob</a>, <a href="Backbard Horses">BCBA-D</a>, <a href="And Jeffrey">And Jeffrey</a> <a href="Jacob">Jacob</a>, <a href="Jacob">BCBA-D</a>, <a href="And Jeffrey">And Jeffrey</a> <a href="Jacob">Jacob</a>, <a href="Jacob">Jeffrey</a>, <a href="Jacob">Jacob</a>, <a href="Jacob">Jacob</a>

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<u>Penzi</u> and <u>Leigh Broughan</u>, and <u>Connor Archer and</u> his mother Jessica.

#### **ASAT Reviews of Transition Resources**

A series of reviews, previously published by ASAT, can be found with embedded links below. These guides can be a valuable tool for parents, care providers, and family members, as well as older individuals with autism as they seek to inform themselves of the crucial next steps to effective services for adults with autism. Beginning with an overview of the wide range of transition services, these resources can direct each reader in the direction that most suits their needs based on personal circumstances, topics of interest, depth of knowledge required, and current level of understanding.

- A review of Transition Resources for Adolescents and Adults with Autism: This article is a good jumping off point for parents with adult children on the spectrum or those who may be in the early stages of future planning. The links contained in this review are expansive and help start the process of information gathering across the vast field of transition services. These resources are provided by a variety of groups including Autism Speaks, US Department of Education, and many others.
- ★ A review of Life Journey Through Autism: A Guide for Transition to Adulthood: This article reviews the resources provided by the Organization for Autism Research (OAR) as a guide to parents assessing autism treatments based on research evidence. While this resource may be dated (it was published in 2003), the information about the scientific process and research, especially the glossary, are still helpful to increase understanding in this area.
- ★ A review of Working in the Community: A
  Guide for Employers of Individuals with Autism
  Spectrum Disorders: A resource published by
  The Alpine Learning Group, this document is
  billed as a guide to foster relationships between
  transition professionals and community
  businesses. Parents will find this resource helpful
  when working towards employment and/or

internship opportunities for their own adult with autism.

A review of Adults with Autism: The Journey Home: This documentary, produced by the Princeton Child Development Institute, tells the stories of four adults with autism receiving behavior analytic services. Through interviews with parents and individuals with autism as well as footage that depicts actual intervention from childhood into adulthood, this documentary celebrates a wide range of positive outcomes that are a direct result of scientifically validated ABA intervention and offers valuable insights for families.

We hope will find many of these offerings useful in this next chapter of your journey. Please be sure you are subscribed to our newsletter as we have much upcoming content related to older children and adults such as interviews, clinical corners responses, and research synopses. We also have a number of lifespan resources that we will be reviewing soon.

#### SUPPORTING ASAT WHERE YOU WORK AND PLAY!

#### Catherine Rooney, BCaBA

#### Support ASAT where you work

As you may recall, we published an article about **Monarch House** in the Winter 2016 issue of Science *in Autism Treatment*. ASAT is honored to continue to benefit from Monarch House and their employees' enthusiasm and generosity. They have been successful in raising over \$2,000 dollars towards ASAT's efforts to promote science-based autism treatment. With the support of businesses like Monarch House, ASAT has been able to further promote evidence-based treatments in autism.

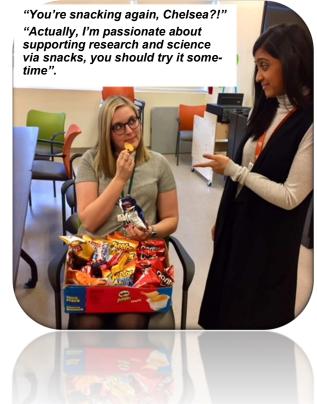


discover what's inside...

Monarch House staff continues to donate towards ASAT in two ways:

- Dress Down Fridays employees are asked to donate \$2.00 towards ASAT if they wish to 'dress down'
- on Fridays. This is where employees are permitted to where casual clothing in the workplace on a designated day when they contribute a designated donation amount.
- Monarch House Snack Food Box snack food/treats are bought wholesale and then re-sold to staff in their center with all profits going to support ASAT's mission to advocate for the use of scientific methods to guide autism treatment. This may also be known as a "tuck shop", one person can be responsible for buying the food items in bulk and then pricing them slightly higher to be sold back to the staff members when they need a delicious snack/drink. A big thank you to Jennifer Cook, Manager of Clinical Services and Research at Monarch House who devised these initiatives, and who continues to organize and track the collections during the year.

For more information about Monarch House, please visit their website.



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#### Support ASAT where you play

A big shout out and heartfelt thanks to Gold Coast Children's Center, a Patron level sponsor, who hosted a fundraiser for ASAT September 23rd at JoyRide in Darien, Connecticut. \$800.00 was raised with 100% of the donations given to ASAT. Mo Prester led the ride and a good time was had by all. Our deep appreciation to Lori Mastrogiacomo and Jessica Cordier of Gold Coast Children's Center for bringing this event to fruition and for being such enthusiastic supporters of our work.



For more information about Gold Coast Children's Center, please visit their website.

We are proud to organize this fundraiser for such an incredible organization.

ASAT has helped countless numbers of families of individuals with autism navigate treatment options, providing valuable information about what research has shown to be effective. This commitment to science is invaluable. We are thrilled to support ASAT in any way possible!"

 Lori Mastrogiacomo, Co-Director, Gold Coast Children's Center



#### **Benefits to Our Supporters**

ASAT appreciates our participating fundraising organizations and businesses. Proceeds from these fundraising efforts will directly support several important projects, including distribution of our free quarterly newsletter, Science in Autism Treatment, promotion of public awareness of science in autism intervention through our website, and expanding our outreach to the medical community.

We always reciprocate our gratitude for these donations. We do this by providing publicity and social media support to build awareness about the business. Your organization or business may be highlighted in the ASAT quarterly newsletter, which currently has almost 12,000 subscribers. We also make efforts to showcase your efforts on our Facebook page to further promote their business publicly.

If you are part of an organization that may want to follow in the footsteps of Monarch House and Gold Coast Children's Center, please write us at donate@asatonline.org.

It takes a village!

#### **ASAT**

#### LIAISONS, COORDINATORS, EXTERNS & COMMITTEE MEMBERS

In addition to our Advisory Board, a number of Coordinators, Externs, and other Volunteers lend their time and talents to support ASAT's mission and initiatives. These are our helping hands:

**Advisory Board Liaison** Allison Parker, MA, BCBA

Faculty Liaison Amanda Guld, PhD, BCBA-D

Fundraising Coordinator Catherine Rooney, BA, BCaBA

**Grant Research Coordinator** Carolyn Sniezyk, MS, BCBA

International Dissemination Coordinator Maithri Sivaraman, MSc, BCBA

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Newsletter Content Coordinator Caroline Simard, MS, BCBA

Social Media Coordinator Alice Bravo, MEd, BCBA

Sponsorship Co-Coordinators Melissa Taylor, BCaBA May Chrisline Beaubrun, MEd, BCBA

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Amanda Bueno dos Santos, BS, BCaBA Elena M. Escalona, MSEd Brian Fennell, PhD Karrie Lindeman, EdD, SBL, BCBA-D Laura Shay, MEd, SLPA

For more information about our Externship, please see: www.asatonline.org/description-application-process/#externship

Brizida Vinjau, MS, BCBA

## Thank You!

**Externs** 



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With CentralReach's <u>Behavioral Health Practice Management System</u>, we assist in providing, tracking and analyzing the care and progress of clients while also helping clinicians manage a business that requires billing, payroll, scheduling, documentation and so much more. Providers will be able to rely on one centralized system to keep their practice and their clients on the right track.

By creating and improving analysis tools, speedy <u>data collection</u>, continuous education and <u>learning resources</u>, we help to advance the field and assist medical and other health care professionals with collaborating in real-time - using our very own and expertly developed HIPAA-secured one-to-one or group chat application: ReachMe.

CentralReach incorporates its passion for autism advocacy and disability empowerment with meaningful technology that equips ABA and other developmental disability care practices with the technology and tools needed to help them grow and improve client care.

We take immense pride in knowing that our software is single handedly making a difference in the lives of over 40,000 clinicians and their patients nationwide.

This revolutionary approach to disability care begins with CentralReach's founder, Charlotte Fudge; MSN, RN, BCBA, CCM.

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#### **ASAT**

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As a practicing clinician and business owner, Charlotte was in the trenches, like many of CentralReach's clients today, providing care to clients, managing invoices, managing staff payroll, keeping track of CEUs, analyzing client progress and data...the list goes on. Charlotte quickly realized that there was not one effective platform that could meet all of the demanding requirements needed in the field and at the office. It was during that period that CentralReach was born – a company truly created by BCBAs for BCBAs and beyond.

Charlotte's passion for improving care does not end there. She and CentralReach entirely are committed to immersing our technology, company and values with our community. That is why one of CentralReach's most important line of work is our <u>ReachOut program</u>, which much to our delight, is gaining attention and inspiring others in the autism and ABA communities. A program that was created to employ adults on the spectrum and to begin filling the gaps of increased unemployment rates within this large group of able individuals.

The program, envisioned by our CEO and Founder Charlotte Fudge and managed by Senior Implementation Specialist Katy Han, started with the goal of hiring three adults in the implementation department. Today, the program employs four adults who perform data entry tasks for ABA billing and quality assurance tasks for CentralReach software. Data entry was selected as the primary job due to its repetitive nature. Furthermore, the many component skills involved in data entry allows Katy to assess applicants for other positions, such as performing user interface quality control for CentralReach software.

Community outreach and teamwork at CentralReach is paramount to creating innovation within our field as well as providing the service and support that care providers need to succeed.

We are continuously innovating and adding to our platform exciting new features that will continue to improve client experience - features like, a new app that includes:

- iOS (iPhone)/Android native application;
- Location-based time tracking; and
- HIPAA secure messaging (If you're using our ReachMe application)

With version 2 already close behind and including a powerful data collection module which will support offline data collection as well!

Additionally, we have new features such as, <u>Real-time insurance verifications</u> - a complete toolset and workflow designed to save staff time on benefits verification; plus, so much more on the horizon!

CentralReach is not just a software company. We are a group of passionate and experienced clinicians and we are relentless about our mission to equip each client of ours with the necessary training, <u>implementation and support</u>, tools and community reinforcement needed for them to continue to provide exceptional care to their clients. We hope to get the chance to serve you as well.

### Some of our Champion Level Sponsors (\$2,000)





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BCBAs and serving more than 400 students daily. Every one of our team members uses the ACE to provide a level of service that is unparalleled in the autism service community. Please visit ACE<sup>®</sup> ABA Software System on social media <u>Facebook</u> or on its <u>website</u> for more details.

Autism Partnership Foundation is a non-profit organization dedicated to expanding understanding of



effective and empirically-supported treatment of Autism Spectrum Disorder through innovative research, improving the quality of services through national and international training and consultation, and most importantly, increasing the availability of effective treatment to children with ASD and their families.

It is disheartening to know that the lives of thousands of children diagnosed with ASD could be changed forever with effective and intensive treatment; but quality treatment is out of reach for all too many children. Drs. Ron Leaf and John McEachin understood this too well. Playing an integral role in the seminal work of Ivar Lovaas on the UCLA Young Autism Project and continuing their work around the world for over 40 years, they had an unyielding hope of reaching those children and ensuring effective treatment could be accessible to all. It is this vision that led to the founding of the Autism Partnership Foundation.

Too many families are given false promises of interventions that simply have no empirical support. Without well supported research, dreams are lost on treatment that fails to produce meaningful change. Under the leadership of Justin Leaf, Ph.D., BCBA-D, APF's research department continues to discover and develop cutting edge treatment and ABA-based strategies that make a difference in the lives of children with ASD.

Autism Partnership Foundation is committed to broadening the community of skilled educators, service providers and family members. To further this mission, APF has founded the Center for the Advancement of Behavior Analysis, a training institute in Seal Beach, California, committed to furthering the field of Applied Behavior Analysis and autism spectrum disorder by promoting expertise in the application of behavioral treatment. APF is also proud to sponsor world-wide training, consultation and education promoting the understanding and implementation of evidence-based treatment of autism spectrum disorder. Please visit Autism Partnership on its website for more information.

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721 N Vulcan Ave., Ste.208, Encinitas, CA 92024 P: 760-634-1125 F: 760-634-1530 coyneandassociates.com Tiffany Bauer, April Worsdell, and Len Levin, the Executive Team at Coyne & Associates Education Corp., have been collaborating for the past ten-plus years to design and execute a model of excellence in the provision of early intervention services. The synergy between these three BCBAs and their talented colleagues at Coyne & Associates has driven the practice to the forefront of ABA service delivery in Southern California. Coyne & Associates has two distinct programs: Early intervention for young children under age three, mostly via IDEA Part C services referred to as Early Start in California; and ABA services for children diagnosed with ASD ages three through twelve. Both programs have a foundation in applied behavior analysis, using intervention

strategies that have empirical support and are based on the principles of learning. To serve the diverse population of at-risk and developmentally delayed infants and toddlers in the Early Start program, developmental specialists in areas such as speech and language, motor, and adaptive behavior skills are incorporated to support the scope and sequence of developmentally appropriate curricula objectives, to advise the ABA trained clinicians and the Early Childhood Instructors, and to provide direct services to children when needed. Some additional cornerstones of best practice prioritized at Coyne & Associates to achieve its mission include:

- Intensive, systematic staff training and performance management using Behavioral Skills Training, carefully developed job aides and supports, and ongoing coaching and shaping.
- Focus on parent-mediated intervention and support to achieve meaningful and long-term generalization and behavior change.
- Collaboration with relevant regional and national organizations to promote accountability and industry standards in child and family outcomes, employee satisfaction and retention metrics, key service delivery processes, and the standardization of staffing requirements via certification and licensure.

We are excited and humbled that in November 2017, Coyne & Associates was named a Top Workplace of San Diego. This distinction was awarded based on employee survey results on critical job satisfaction metrics. The successes and outcomes achieved at Coyne are completely dependent on the dedication and effort of our very skilled employees, so positive feedback and accolades from them, our most valuable resource, is greatly appreciated. Please visit Coyne on Facebook or on its website for more details.



Eden II Programs is a not-for-profit organization founded in 1976 and currently serving over 500 participants in New York City and Long Island. The mission of Eden II Programs is to support people with autism through service, science, and passion so they may achieve their full potential throughout their lives. Eden II Programs provides a variety of services

using the evidence-based principles of applied behavior analysis (ABA) to treat the delays and challenges associated with Autism Spectrum Disorder (ASD). Eden II is recognized nationally as a leader in working with individuals across the autism spectrum, including those with the most significant challenges.

Currently, over 130 families participate in full-day education programs from early childhood through adulthood on Staten Island. In 2015, Eden II opened a new, state-of-the-art autism center – the Honorable

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James P. Molinaro Center for Autism – which serves 68 participants, ages 8-21, in elementary and secondary education programs. The Autism Center also serves as the Agency's main headquarters for the administrative team. Eden II Programs educational programs in Staten Island also includes a preschool program, Special Education Teacher Support Services (SETSS,) Special Education Itinerant Teacher (SEIT) services; The Staten Island Adult Day Habilitation program serves over 90 individuals; and 39 adults with ASD live in our five community residences located on Staten Island.

On Long Island, Eden II's Genesis School program serves 30 individuals, ages 5-21, in elementary and secondary education programs. The Genesis Outreach Autism Center assists over 50 individuals across all programs. The Adult Day Habilitation program serves 34 individuals; and 12 adults with ASD live in our two community residences. Genesis has recently opened a new social enterprise called Seasons for a Reason. Individuals with autism create handmade seasonal items and autism jewelry for sale in a kiosk at The Broadway Mall.

Hundreds benefit from a variety of other services such as Community Habilitation, Respite, Afterschool, and a number of Family Support programs. Eden II also provides consultation support locally, nationally, and internationally. Please visit Eden II Programs on its website or Facebook page for more information.



**Melmark** is a multi-state human service provider with premier private special education schools, professional development offerings, and training and research centers. We are committed to enhancing the lives of individuals with autism and intellectual /developmental disabilities, and their families by providing exceptional evidence-based and applied behavior analytic services to every individual, every day. Please visit Melmark Pennsylvania on <u>Facebook</u> or on its website for more information.



#### **Lovaas Institute Midwest**

From its headquarters in Minneapolis, Minnesota, the Lovaas Institute Midwest provides early intensive behavioral intervention utilizing the principles of applied behavior analysis. The Lovaas Institute is committed to providing the highest quality treatment available to children who suffer from the symptoms of autism. They approach this treatment, one child at a time, by individualizing each child's program to meet his or her needs.

The Lovaas Model of applied behavior analysis has undergone rigorous research at UCLA under the direction of Dr. O. Ivar Lovaas, proving its effectiveness in treating children with autism, through long-term outcome data

published in peer-reviewed journals, and replicated by additional long-term outcome research as recently as 2006. The Lovaas Institute Midwest is currently organizing and analyzing its extensive body of multi-modal clinical data, which was collected on the treatment of over 200 children over more than a decade.

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#### **ASAT**

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

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Treatment follows the procedures described by Lovaas in his 2002 book, Teaching Individuals with Developmental Delays: Basic Intervention Techniques, as well as the latest innovations in the field of applied behavior analysis, as developed both at the Lovaas Institute and internationally. An extensive clinical management system ensures that each child's treatment is dynamically adjusted on a daily, weekly, and annual basis to result in the most rapid recovery from all of the defining symptoms of autism.

Intervention is based on shaping behavior through reinforcement of successive approximations, prompting and fading procedures, and use of positive reinforcers that are child-specific and functional (i.e., serve the intent of increasing behavior). Initially, powerful intrinsic rein-forcers are selected to maximize engagement and an acceleration in response to treatment. As intervention progresses, reinforcement is expanded, whenever possible, toward more natural and complex conditioned social reinforcers. The intervention is continuously modified so that appropriate behaviors are maximized through the most effective schedules of positive reinforcement. Debilitating behaviors are reduced by managing the schedules of reinforcement and teaching alternate, more socially acceptable means of attaining the child's needs.

At the Lovaas Institute, services are provided in four ways:

- 1. Direct Treatment services are provided to families in their homes and communities. A team of 3-6 staff members, extensively trained and supervised, provide the intensive, daily intervention. The focus of treatment is on training the parents to conduct the most effective behavior therapy 24 hours-a-day, 7 days-a-week. During this treatment a behavior analyst clinical supervisor is in the child's home for 8 hours a week.
- 2. Family Consultation services are designed to help remote families set up their own intervention programs, modeled after all aspects of the direct treatment service. During this treatment a behavior analyst clinical supervisor travels to the child's home for 12 hours per month.
- 3. Consultation services to behavioral treatment organizations on the latest innovations in the Lovaas model.
- 4. State-wide and National Advocacy services to assist families in gaining improved access to fully funded treatment services.

For more information, please visit the <u>website</u> of Lovaas Institute or the <u>Facebook</u> page of Lovaas Midwest.

#### RESOURCES FOR JOURNALISTS

#### TEN WEBSITES SUPPORTING SCIENCE JOURNALISM

Maithri Sivaraman, MSc, BCBA

eeping up with new treatments and studies related to autism spectrum disorder (ASD) and identifying reliable sources of information is a tremendous task for journalists. On the one hand, there is the creative challenge of making a story interesting and readable. On the other, there is the immense responsibility that entails being aware of what is at stake; these are not merely "stories" because important treatment decisions are likely to be made by families based on them. Given that the media is the most influential means of communicating to a large number of individuals, journalists could be among the greatest assets for promoting science-based treatments. It can be challenging figuring out where to start. Here are ten resources that can help fine-tune journalists' reporting and critiquing relevant scientific studies.



- 1. <u>Poynter Institute</u> This organization is a Florida-based institute which offers webinars, free training courses, and other links to effective science journalism. An article on the essential questions to ask about scientific studies succinctly summarizes the methods of identifying the credibility of a study. The <u>News University</u> associated with Poynter also provides <u>self-directed free courses</u> for journalists interested in effective science journalism in the digital era.
- 2.SciDev.Net This nonprofit group is a news analysis organization that provides information about science and technology for equitable, sustainable development and poverty reduction. An <u>online 'How-To' guide</u> about reporting results from a scientific study is provided on the website. It emphasizes the need for a journalist to read the research paper, speak to a large number of experts and non-experts, and be responsible in reporting results. It also includes a <u>final check-list</u> of things to be done before publishing a report.
- 3. The Open Notebook This is a not-for profit organization which features an essential guide to science communication within today's social media ecosystem. The website also offers advice on responsible journalism and <u>features articles</u> on pitching stories successfully for new journalists writing about science.
- 4.Showcase An initiative of the Council for Advancement of Science Writing (CASW), Showcase highlights award-winning science journalism. A <u>list of comprehensive resources</u>, including books, online guides that offer advice on reporting scientific studies, websites dedicated to discussing science journalism, and a list of fellowships providing journalists with training in specific areas of interest are provided.
- 5. The Science Writer's blog This blog offers essays regarding science journalism and information about the Science Writer's Handbook: Everything You need to Know to Pitch, Publish and Prosper in the digital age. The book provides information on developing an essay, researching reports for an essay, structuring an essay, and finding an audience.
- 6. <u>Australian Science and Media Centre</u> The organization offers tips on improving links between the media and scientific community and begins with addressing the prerequisites for a good science journalists' repertoire. Key information offering advice on obtaining evidence, choosing sources and critiquing an expert's

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#### **ASAT**

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

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study are provided. <u>Additional tips</u> on dealing with scientific uncertainty and peer-review are discussed as well.

- 7. <u>Journalists Resource</u> Based at Harvard's Shorenstein Center on Media, Politics and Public Policy, Journalist's Resource examines news topics through a research lens. Given the abundance of research output available through digital technology world every day, the website provides tools to verify information gathered from social media or content gathered directly from the user. Additionally, <u>The Verification Handbook for Investigative Reporting</u> that explores using databases and domain records, verifying data quality, and applying ethical principles to investigations is reviewed.
- 8. Knight Science Journalism Founded thirty years ago as an initiative from the Massachusetts Institute of Technology (MIT), this program seeks to nurture and enhance the ability of journalists from around the world to accurately document and illuminate the often complex intersection of science, technology, and human culture. The website offers a compilation of academic and other training <u>resources</u> for students and practicing journalists. It also provides a <u>list of councils/societies</u> for meeting other science journalists in a global forum.
- 9. World Federation of Science Journalists (WFSJ) WFSJ is a not-for-profit organization that aims to develop awareness about science journalism internationally and aid media professionals to engage in incisive, impartial and accurate reporting. The website lists 51 national and international associations of science journalists across the world and provides information regarding upcoming science journalists' conferences. It also outlines a range of resources including competitions for students of journalism, books, online courses and other websites that might be of interests to reporters.
- 10. Science Literacy Project The project that was launched in 1999 as an initiative of SoundVision Productions, underlines the need for a journalist to understand the science behind a story before reporting on it. In an attempt to help a journalist discern the evidence (or lack thereof) in complex scientific studies, the resources section on the website offers an extensive reading list on specific topics such as statistics, biology, physics and evolution. The online references throw light on the ethical codes that govern reporting of news and the use of accurate terminology when writing scientific stories.

## RETURN OF SCIENCE CORNER TO SCIENCE IN AUTISM TREATMENT Brian Fennell, PhD

he Association for Science in Autism Treatment is excited about the return of Science Corner as a regular feature in its quarterly newsletter.

Science Corner focuses on helping consumers better understand the scientific method and how these methods would reduce susceptibility to pseudoscience. The format for these articles will be shorter, precise pieces with a goal of bringing scientific understanding to non-scientists (e.g., individuals with autism, parents, siblings etc.) because a knowledgeable consumer makes informed decisions.

The ASAT team hopes you find this feature informative and engaging. We are all better served with greater knowledge of the science that helps improve the interventions, therapies, and programs for individuals with autism spectrum disorders.

In our first instalment to appear in the upcoming Winter 2018 issue, Dr. Beth Glasberg and Dr. David Celiberti will discuss the various sections of a published research article.

Brian Fennell, PhD Science Corner Coordinator

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### OUR REAL SCIENCE, REAL HOPE

#### 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, scientifically -validated interventions for their child.
- ★ The media will educate and not confuse parents by providing accurate information and asking the right questions.
- ★ All providers will be guided by science when selecting and implementing interventions and use data to demonstrate effectiveness.

## What It Means to Be a Sponsor:

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

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

#### Become a Sponsor Now!

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

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

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