



Letter from the Co-Editor

It is my absolute pleasure to join Dr. David Celiberti in co-editing Science in Autism Treatment. The quarterly newsletter is how I first learned about the Association for Science in Autism Treatment and immediately identified with its mission. Over the years, I participated in proofreading the newsletter so I could read it as soon as possible and learn about the latest research, coherently summarized for all audiences, Clinical Corner, answering questions we practitioners deal with frequently, Book Reviews, and among many other features and columns, Media Watch, responding to journalists' portrayal of autism and autism treatment in the media, one of my favorite ASAT initiatives.

In 2011 I was invited to join the Board of Directors and the Newsletter Committee, where I worked closely with a wonderful team, chaired by Dr. Celiberti and Dr. Joshua Pritchard. This is my second issue co-editing and I continue in love with our newsletter. I get to work with an incredible team of busy bees, who help us coordinate an impressive amount of quality content we carefully prepare for our more than 9,000 subscribers all over the world. It is with great pleasure that I collaborate on this work, to bring families and practitioners information that is scientifically accurate yet written by their peers, in straightforward, concise, user-friendly terms.

I am happy to bring you the Fall 2013 issue and I hope that you enjoy. To help us continue to spread the word and reach even more people, toward a future when all families have enough information to help them navigate the very complex systems to diagnose and support their child's development and maximum potential, while avoiding the pseudoscientific promises and products that can severely delay access to appropriate interventions and cost so much in financial and emotional currencies. Please share our newsletter with friends and colleagues and help us reach our goal of 10,000 subscribers!

Sincerely,

Daniela Fazzio, PhD, BCBA-D

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Clinical Corner

Recent advances in genetic research has led to greater understanding of possible genetic causes and risk factors associated with autism spectrum disorder (ASD). For parents who have a child with autism, this research can provide valuable insight into the potential recurrence risk of having another child with ASD. In this issue of Clinical Corner, Dr. Scott Meyers updates us on the latest research regarding recurrence risk and offers helpful recommendations for parents about genetic testing and counseling.

Nicole Pearson, Psy. D., BCBA -D

"I am a parent of a young boy with autism. I don't know of any other individuals in my family with an autism diagnosis but am considering having more children. How likely is it that I could have another child with autism?"

Answered by Scott M. Myers, MD, FAAP, Neurodevelopmental Pediatrician, Geisinger Autism & Developmental Medicine Institute, Lewisburg, PA.

This important question is asked by many parents who are considering having more children. The answer depends greatly on whether a specific genetic cause of your child's autism spectrum disorder (ASD) has been identified. Currently, genetic testing can identify a specific cause in approximately 15% of children with ASD, and this information allows more accurate counseling about recurrence risk for the individual family. In instances where a genetic cause is unknown, different types of studies have found varying rates of recurrence risk.

Epidemiologic studies investigate the characteristics of diseases or disorders in large populations using rigorous statistical methods. These studies have found that 4-7% of families had more than one child with an ASD (Chakrabarti & Fombonne, 2001; Gronborg, Schendel, & Parner, 2013). The largest and most recent population-based

study, which included over 1.5 million children born in Denmark between 1980 and 2004, found an overall recurrence risk of 7% (Gronborg et al., 2013). This type of study has many advantages, such as avoiding bias introduced by increased parental awareness and differential participation when there is already

"...the short answer is that for a couple with one child with ASD of unknown cause, the current best estimate of recurrence in a subsequent child is approximately 10% based on the most recent and well-designed studies"

a child with an ASD in the family. However, this type of study design may lead to underestimation of recurrence risk because of missed cases in the populations studied and the tendency of couples with an affected child to stop having children, which is known as "stoppage."

Rather than including all children in a given region, some research focuses only on children with ASD and their siblings. Studies that include all siblings born before and after the child who has ASD have found the ASD recurrence risk to be 6-10% (Bolton et al., 1994; Chudley, Guitierrez, Jocelyn, & Chodirker.

1998; Sumi, Taniai, Miyachi, & Tanemura, 2006); however, like epidemiologic studies, they may underestimate recurrence risk due to stoppage. Studies that only include families with later-born siblings to avoid the stoppage effect have reported higher recurrence rates of 8-19% (Ritvo, Jorde, Mason-Brothers, Freeman, Pingree, Jones, & Mo, 1989; Constantino, Zhang, Frazier, Abbacchi, & Law, 2010; Ozonoff et al., 2011). The highest rate of recurrence, almost 19%, was found in a large, prospective study of younger siblings of children with an ASD who were recruited in infancy and monitored closely (Ozonoff et al., 2011). However, when families that already had two or more children with ASD were excluded, the recurrence rate was 13.5% in this study.

Therefore, the short answer is that for a couple with one child with ASD of unknown cause, the current best estimate of recurrence in a subsequent child is approximately 10% based on the most recent and well-designed studies. Because this is much higher than the 1% chance of any random couple in the general population having a child with ASD, the younger siblings of a child with ASD should be monitored closely and screened for ASD at well-child visits as recommended by the American Acad-

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Clinical Corner continued...

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emy of Pediatrics (Johnson, Myers, & Council on Children With Disabilities, 2007). If a couple already has two or more children with an ASD, the chance of a subsequent child having an ASD may be as high as 32-35% (Ritvo et al., 1989; Ozonoff et al., 2011).

Two other points related to recurrence rates are worth noting. First, some studies have suggested that the risk of ASD in later-born children is higher if the first affected child was a girl and lower if the first affected child was a boy (Ritvo et al., 1989; Jorde et al., 1991; Sumi et al., 2006). Conversely, other more recent studies have not found that the sex of the first affected child is associated with a significant difference in recurrence risk in subsequent children (Goin-Kochel et al., 2007; Constantino et al., 2010; Ozonoff et al., 2011). Thus, at present, the available evidence does not argue convincingly for adjusting recurrence risk based on the sex of the first child with ASD. Second, some studies have found that 20-25% of siblings who do not meet criteria for an ASD do have a history of language impairment or delay (Lindgren, Folstein, Tomblin, & Tager-Flusberg, 2009; Constantino et al., 2010). The risk of language delay in a subsequent child is not included within the ASD recurrence rate estimates reported above.

It is important to understand that the recurrence estimates measured in these studies are based on group averages and that

unless the specific genetic cause of the first child's ASD is known, it is not possible for a family to receive specific counseling about their individual level of risk. This is one reason why it is important that families be offered genetic testing for their child with ASD. When the physician does not suspect a specific disorder or syndrome based on examination, the current recommendation is to complete chromosomal microarray analysis and Fragile X molecular analysis (Manning & Hudgins, 2010; Miller et al., 2010). These tests, which are typically performed on a blood sample obtained from the affected child, identify a specific cause in approximately 15% of individuals with ASD, and this number is likely to increase as newer technologies such as whole exome sequencing and whole genome sequencing become more widely available and utilized for clinical purposes (Abrahams & Geshwind, 2008; O'Roak, et al., 2012; Sanders et al., 2012).

For families in which a genetic cause of ASD has been identified, the recurrence risk varies significantly depending on the type of genetic problem found. For example, the risk could be as high as 50%, as in the case of a child who inherits a specific extra segment of DNA on the 15th chromosome (15q11-q13) from his/her mother. Or, the recurrence risk could be as low as 1% or less if the child has a small "missing" or "extra" section of DNA (called a microdeletion or microduplication) that is not carried by either parent. *(Continued on page 16)*

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Book Review

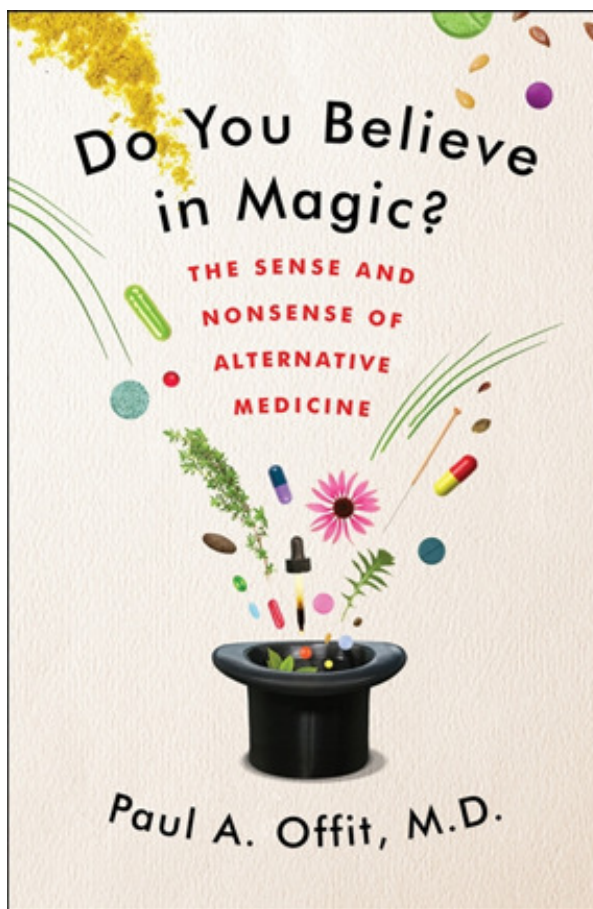
Offit, P. (2013). Do you believe in magic? The sense and nonsense of alternative medicine. New York, NY: Harper Collins Publishers.

**By Lori Ernsperger, Ph.D., BCBA-D
President of Autism and Behavioral Consulting**

"What people **believe**, prevails over truth," is a quote written over 2,000 years ago by Sophocles, an ancient Greek writer, and is exemplified throughout the book, *Do You Believe in Magic?* by Dr. Paul Offit. Dr. Offit is the Chief of the Division of Infectious Diseases and Director of the Vaccine Education Center at the Children's Hospital in Philadelphia. You may be familiar with Dr. Offit's earlier works, which include *Autism's False Prophets* (2008) and *Deadly Choices: How the Anti-Vaccine Movement Threatens Us All* (2011). Dr. Offit has never shied away from controversy and in this book he challenges his readers to examine the field of alternative medicine through the lens of scientific methods and peer reviewed research. Dr. Offit fearlessly attempts to uncover the truth behind alternative treatments such as acupuncture, dietary supplements, chiropractic interventions, and various other unregulated cures for cancer, Lyme disease, heart disease, and autism. This important and well-written book makes a case for disseminating the truth and educating the public while attempting the difficult task of

combating what people choose to believe.

Dr. Offit provides readers with a detailed historical account of the Food and Drug Administration (FDA) and the pertinent federal regulations for



consumer protection which began to slowly evolve in the early 1900s. At the turn of the last century, there were no set regulations governing food preparation, food handling, or the accuracy of statements made by the food industry

regarding product safety and nutritional ingredients. Several laws, passed between 1906 and the 1960s, established some basic food industry standards, and stipulated that pharmaceutical companies had to actually prove that drugs did not cause serious harm, such as was the case with Thalidomide in the late 1950s and 1960s. By 1975, the FDA began regulating the pharmaceutical industry, but vitamins, supplements, and other herbal remedies were not under the FDA umbrella and thus, could continue to make false claims of effectiveness without publicly disclosing their ingredients or side effects. The Proxmire Amendment of 1975 was written specifically to prohibit the FDA from establishing standards to limit the potency of vitamins and minerals in food supplements or regulating them as drugs based solely on their

potency. The passing of the Proxmire Amendment gave vitamin and supplement manufacturers carte blanche to self-regulate and create what has become a \$34 billion

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Book Review continued...

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industry over the last thirty years. Even the most recent federal law, the Dietary Supplement Health and Education Act (DSHEA), passed in 1994, has done little to change this, as all vitamins, supplements and other dietary ingredients continue to go unregulated and manufacturers are still not required to label the ingredients or provide evidence of effectiveness. According to the New York Times, the DSHEA of 1994 should be referred to as the "Snake Oil Protection Act" (p. 260 Kindle Edition).

FACT: *As of 2013 in the United States, manufacturers can produce vitamins, herbal remedies, or other products and label them "dietary supplements" which then excuses them from any testing, data, scientific evidence, clinical trials or FDA approval for human consumption.*

Dr. Paul Offit details several important reasons why alternative medicine is not regulated and why Americans believe in its efficacy and are willing to pay for these expensive treatments. First, the role of celebrity endorsements has long been a tradition in supporting alternative medicines and scam treatments. Steve McQueen was an early proponent of alternative treatments for cancer and traveled to Mexico in his final days to receive laetrile which at the time was being touted as an alternative cancer cure made

from crushed apricot pits. Unfortunately, although his choice in treatment did not cure his cancer, it propelled laetrile into the mainstream medical community where vulnerable cancer patients requested this treatment from traditional doctors. Dozens of other celebrities have endorsed alternative cures and treatments including Larry King, Mike Wallace, Whoopi Goldberg, Mel Gibson, Regis Philbin, Steve Jobs, and the mega-alternative celebrity, Suzanne Summers. Ms. Summers has created a multi-million dollar industry built on attempting to turn back the hands of time with anti-aging compounds, creams, and bioidentical hormone replacement therapy despite a lack of peer-reviewed research proving these claims. Such celebrity endorsements have propelled the popularity of alternative medicine without any regulation or scientific proof of efficacy.

FACT: *51,000 supplements have been manufactured in the US over the last 10 years and yet only 0.3% have been tested and documented safe for human consumption.*

In addition to celebrity endorsements, the vitamin and dietary supplement industry has political clout. Politicians from Bob Dole, Orin Hatch, Richard Blumenthal, Joe Barton, and most recently, Dan Burton, have all supported alternative medicines and have blocked any legislation from restricting or

regulating this industry. Each of these political figures has taken great steps to ensure less regulation for alternative treatments without any regard to the scientific data or human sacrifice. For example, Joe Barton a politician from Texas, supported antineoplaston (urine) treatment for cancer and repeatedly stated, "FDA, go away." This is in the face of every clinical trial proving its lack of efficacy and denouncements from the American Cancer Society. Dr. Offit details the motivations of politicians which are often financial or based on personal beliefs and anecdotal cases from their constituents.

Unfortunately scam treatments and frauds have targeted one of our most vulnerable populations, children with autism spectrum disorders (ASD) and their families. The clash of ASD treatment and alternative medicine is a perfect storm rife with celebrity endorsements and political support. Dr. Offit spends several chapters describing the various fad treatments which have emerged in recent years claiming to "cure" autism including mega doses of vitamins, chelation, stem cells, chiropractic manipulations, digestive enzymes, secretin, hyperbaric oxygen therapy, and even coffee enemas. As Dr. Offit explains, "parents of children with autism will do anything to help their children" (p. 392 Kindle Version) and as a result, they subscribe to the unsubstantiated claims of

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Book Review continued ...

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celebrities like Jenny McCarthy who has led the charge towards alternative therapies and expensive interventions. A parent of a child with ASD who was interviewed by Dr. Offit shared, "I don't blame the parents for being susceptible to this. The culpability lies with the quacks who are preying on desperate families" (p. 400 Kindle Version). Dr. Offit offers credible scientific evidence to refute these treatments but this is an uphill battle, as detailed in his chapter entitled, "Charismatic Healers are Hard to Resist" which describes the fraudulent work of Dr. Rashid Buttar (www.drbuttar.com) and his "cure" for autism.

Scientific evidence, data, conventional medicine, and clinical trials sound old and boring. Dr. Offit points out that most traditional doctors often lack the magnetic personality, sales pitch, and rapid fire charm which are sold in a bottle of vitamins or a cure for autism using "natural" remedies and creams. The charisma of Dr. Oz and others in the mainstream media who report that acupuncture is 3,000 years old and based on wise Chinese tradition is filled with intrigue and hope. Dietary supplements and alternative treatments offer a cure for some of the most awful diseases and disorders that afflict millions of children and adults. Dr. Offit explains how the marketing of alternative medicine is based on fraudulent

snake oil salesmen who are not selling the truth but rather, what people want to believe.

FACT: *Natural does not necessarily mean healthy or safe.* There is a myth that if something is grown from the Earth it is healthy. Conduct a quick Internet search of "Earth, Nature, Green and Vitamins" and you will find dozens of highly lucrative manufactures who propel this myth. Unfortunately, it is a fact that there are hundreds of plants which grow from the Earth but have poisonous chemicals and should not be consumed by humans in dietary supplements.

Whether you are an advocate for scientific inquiry and empirical research on alternative medicine (e.g., BCBA) or simply want the facts on taking a daily multivitamin, this book will meet and exceed your expectations. Dr. Offit provides a fascinating and accurate account of the state of alternative medicine in the United States. He compels us to examine the statement posed by Sophocles: "*what people **believe**, prevails over truth.*" As scientists dedicated to promoting the truth about effective treatments for individuals with ASD, we must continue to assist and educate families in their beliefs about traditional and conventional scientific methods. We behavioral scientists, along with other professionals, must sell our evidence-based truth as strongly and charismatically as the charlatans who are selling a

cure in a bottle. Dr. Offit reminds us not to shy away from confronting those who wish to hide the truth and asks, *Do You Believe in Magic?*

References:

Offit, P. A. (2008). *Autism false prophets: Bad science, risky medicine, and the search for a cure.* West Sussex, England: Columbia University Press.

Offit, P. A. (2011). *Deadly choices: How the anti-vaccine movement threatens us all.* New York: Basic Books.

About the Reviewer

Dr. Lori Ernsperger is a Board Certified Behavior Analyst-Doctoral and owner of Autism and Behavioral Consulting. She has over 28 years of experience working in the public schools as a classroom teacher, administrator, and behavioral consultant. Dr. Lori currently provides professional development and conference workshops to school district professionals and parents. She is the author of three books: *Keys to Success for Teaching Students with Autism*, *Just Take a Bite: Easy Effective Answers to Food Aversions*, and *Eating Challenges and Girls Under the Umbrella of Autism Spectrum Disorders*.

Research Reviews

In the first summary, Eldevik and colleagues investigated the effectiveness of intensive behavioral intervention by analyzing the results from earlier studies. These authors also looked at the predictors of successful outcomes. Our second study is a summary on the research conducted by Woo and Leon on environmental enrichment as a potential treatment for those with autism spectrum disorder. We hope you enjoy reading these summaries!

Sharon A. Reeve, Ph.D., BCBA-D

Environmental Enrichment as an Effective Treatment for Autism: A Randomized Controlled Trial

Woo, C. C., & Leon, M. (2013). Environmental enrichment as an effective treatment for autism: A randomized controlled trial. *Behavioral Neuroscience*. doi: 10.1037/a0033010

Reviewed by: Antonia Giannakakos, Caldwell College

Why research this topic?

Researchers conducting basic research with animals have found that an enriched sensorimotor environment enables rodents to compensate for neurological deficits. For example, rodents with autism-like symptoms who are exposed to an enriched environment tend to show milder symptoms. More than 90% of individuals with autism exhibit sensory deficits (e.g., over selectivity, unresponsiveness); therefore, the researchers in this study sought to translate the findings by animal research into a potential treatment for humans.

What did the researchers do?

Twenty-eight male children diagnosed with autism, ranging in age from 3-12 years, served as the participants in this study. Participants were randomly assigned to a treatment group that received environmental enrichment or a control group that received no intervention. Children in the treatment group were exposed to a variety of smells, musical sounds, and textures by their parents for 15-30 minutes, two times a day, over a 6-month period. The sensorimotor tasks grew in

their complexity every two weeks and included such tasks as rubbing the children’s bodies with different textures (e.g., felt, fine sandpaper, aluminum foil), putting scented cotton balls in their pillows while they slept, and having the children draw shapes on a paper, while their parents drew imaginary shapes on their backs. All participants were tested at entry to the study and at the end of the 6-month period.

What did the researchers find?

Although children in the treatment and control groups were similar at entry in the study, children in the treatment group showed larger gains than children in the control group at the end-of study assessment on: (1) a visualization and reasoning test, (2) a test of symptom severity, and (3) parent ratings of symptom severity.

What are the strengths and limitations of this study?

A strength of this study is that the researchers randomly assigned children to two groups that appeared similar at entry to the study. However, a limitation is that the researchers did not describe how they selected the different sensorimotor activities, making it impossible to determine if there is any scientific basis for the selection. The researchers also did not provide a detailed description of the types of behaviors that were reported to decrease in severity, which makes it hard to discern precisely what the effects were. Finally, all of the children in the study were receiving other forms of intervention (e.g., applied behavior analysis, speech therapy, occupational therapy) and it is unclear whether the effects of sensorimotor enrichment would be the same in the absence of those other therapies.

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Research Review Continued...

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What do the results mean?

The results of this study indicate that sensorimotor therapy may alleviate some skill deficits associated with autism in some children. However, further research is necessary to test whether the results of this study can be replicated and maintained, and whether sensorimotor therapy can be used successfully on its own or needs to be combined with other therapies. Thus, sensorimotor enrichment is not recommended as a treatment for autism until further research has been conducted and the potential benefits of this treatment are fully investigated.

Using Participant Data to Extend the Evidence Base for Intensive Behavioral Intervention for Children with Autism

Eldevik, S., Hastings, R.P., Hughes, J.C., Jahr, E., Svein, E., Cross, S. (2010). Using participant data to extend the evidence base for intensive behavioral intervention for children with autism. *American Journal on Intellectual and Developmental Disabilities*, 115 (5), 381-405.

Reviewed by: Lauren Pepa, Rutgers University

Why study this topic?

Much research supports the efficacy of intensive behavioral intervention (IBI) with individuals with autism for improving intellectual functioning, adaptive skills, and other core symptoms of autism. Most of this research has relied on group designs, wherein behavior changes are combined across groups of individuals and compared to changes observed in other treatments. However, individual change as a result of IBI is extremely variable, and little research has focused on the individual factors that may lead to better outcomes. One way to

look at these factors is to examine the data for each individual participant in group studies and evaluate their level of change, and then to look at what factors predicted treatment success for these individuals.

What did the researchers do?

The authors looked at both individual change and predictors of change in IBI. The authors first identified research articles that evaluated IBI. This process yielded data for 453 participants from 16 studies, most of whom had been evaluated on standardized measures of intelligence and adaptive behavior. They then examined the degree of change in these measures from pre- to post-treatment and examined pre-treatment variables that predicted the amount of change made by individual participants. This was accomplished by calculating means (i.e., average) and standard deviation (i.e., variability) scores for all study measures based on the collected data from the samples. Reliable change was defined as an absolute change in index scores of 1.96 standard deviations, corresponding to a 27 point change in IQ and a 21 point change in adaptive functioning. Predictors of this change were examined using a multiple regression analysis which is a type of statistical analysis.

What did the researchers find?

Looking at individual change, the authors found that children who received IBI were more likely to show meaningful improvements in IQ scores and in adaptive functioning than those receiving no treatment and those receiving comparison treatments. Specifically, the proportion of children who achieved reliable change was 23% higher in the IBI group than in the comparison groups for IQ and 16% higher for adaptive functioning. Additionally, the number of individuals needed to observe a beneficial outcome in IBI was significantly lower than in the control group (i.e., those with no treatment) and

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Research Review Continued...

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comparison (i.e., those with alternate treatments) groups. Only five children were needed to achieve a reliable change in IQ with IBI and seven were needed for a reliable change in adaptive functioning. These findings extend previous reviews indicating that IBI is an evidence-based treatment for young children with autism. Looking at individual predictors, the authors found that higher intensity of intervention was associated with better outcomes for IQ and adaptive functioning. Lower adaptive functioning prior to treatment predicted greater gains in adaptive functioning post-treatment. Separately, higher IQ scores prior to treatment predicted more significant gains in adaptive functioning.

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

Overall, the authors demonstrated that children receiving IBI showed more significant individual gains than those receiving other treatments, or no treatment. There was considerable variability across studies in the size of the gains, but many of the studies contained small samples of participants. Further, the authors identified individual factors that may contribute to treatment success. Individuals receiving high intensity intervention, those with higher IQ, and those with lower adaptive functioning at baseline made the most significant improvements. However, by combining multiple studies to conduct a single analysis the authors cannot ensure the reliability and consistency of treatment implementation and data collection at each site. The possible variability between sites prevents the broader generalization of these findings without further investigation. Also, as the authors pointed out, many of the studies have methodological limitations that diminish confidence in the validity of findings. Nevertheless, the results contribute significantly to knowledge about the effectiveness of IBI by estimating the magnitude of effects and suggesting factors that predict response to intervention.

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Twins With Autism Prepare to Set the Pace for the New York City Marathon

By Ruth Donlin, MS

Alex and Jamie Schneider are 23-year-old identical twins with autism. They are also accomplished marathon runners who will be joining Team ASAT in this year's NYC Marathon occurring on November 3, 2013. Each of these young men has profound autism with limited communication skills or understanding of safety in the community. However, both are gifted athletes and love to run. This will be their first time participating in the NYC Marathon and first time fundraising for ASAT.

When the twins were 17 months old and still not talking, Robyn and Allan Schneider were very concerned. As is common for many families of children with autism, their pediatrician told them the boys were fine, and to "wait and see" how they progressed. Months later they sought a neurological evaluation and the brothers were then diagnosed. The Schneiders transformed the upstairs of their home into two therapy classrooms, where the boys were taught countless educational, social and self-care skills for years. Ultimately the Schneiders co-founded a school for children with autism, where the boys still attend their Day Habilitation Program at the Eden II/Genesis Programs located in Plainview, NY.

The twins have always had boundless energy – so much so that Robyn and Allan actively searched out mainstream activities to burn off some of the boys' extra vigor. They focused their attention on local sports so that the twins could enjoy the additional benefit of being more involved in their community and developing

connections with other local children. The boys participated in basketball, horseback riding, and swimming. However, none of these activities captivated their interest the way running did. They became very interested in running when they were 15-years-old. Finding individual volunteer coaches provided a new set of challenges for the Schneider's, especially for Alex, who is an exceptionally fast runner.



Alex and Jamie Schneider

Alex and Jamie's coaches quickly learned that the twins did not know how to pace themselves. Alex typically runs under a 7-minute pace for long distances. The twins do not understand how long or how far they will be running, and to this day, it is still not known how fast Alex can actually run. Alex's running coach, Kevin McDermott suffered a sports hernia after struggling to hold Alex back while trying to keep up the first time he ran with him.

The story of these amazing young men would be incomplete without sharing some more information about

their family who has faced other unexpected challenges and overcome so many difficulties over the years. Allan was diagnosed with Multiple Sclerosis in 1987, and Robyn survived the rarest form of breast cancer, which after treatment and chemotherapy in 2008, is now in remission. Due to the twins' severe communication challenges and difficulty in managing stress and anxiety, Robyn and Allan are frequently preoccupied about their sons' safety and behavior. Robyn has said, "Managing their behaviors is beyond a full-time job."

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Twins with autism in the NYC marathon continued ...

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Over the last several years, the family has watched Alex and Jamie successfully compete in more than 120 races. And they have faced some frightening experiences as well, such as the time when Jamie had a difficult run in 2007 and suddenly dropped to his knees, and while still bleeding, crossed the finish line. It was after this event that Robyn and Allan felt compelled to be even more involved in their sons' sport, and so they began running as well. Or the time in 2012 when on a training run, Alex misunderstood his coach and continued running on an unfamiliar path and got lost.

Despite these challenges, the twins have completed five marathons to date, including two Boston Marathons, two Hamptons Marathons, and one Marine Corp Marathon. This will be their first New York City Marathon and sixth overall. The boys thrive in the routine and repetition of running: with a marathon, there is a distinct beginning in lining up and waiting for the starting gun, and an ending marked by crossing the finish line, giving high fives to supporters, receiving a medal, celebrating, and going home.

However, nothing could have prepared them for what would happen in their second Boston Marathon.

The Schneider twins are still experiencing aspects of the trauma of running in the Boston Marathon this past April, where two bombs close to the finish line killed three people and injured more than 250 others. Alex had one of the best runs of his life, completing the race in 3:23:22. But after finishing and eagerly waiting for his brother to cross the finish line with their father, Allan, who was running with him, everything about the typical marathon routine dramatically changed.

Moments after going to their hotel room at the Westin to get a sweatshirt for Alex, Robyn heard the bombs go off. Looking out her window, seeing smoke, and sheer havoc at the finish line, she could not imagine what had happened. Alex could not understand why they had to stay in their hotel and were unable to go back down to the

race. At the 22-mile mark, Jamie and Allan were re-directed off the course with crowds of people into a nearby church. Seeing everyone crying and distressed was extremely upsetting and confusing to Jamie. Robyn waited anxiously before finally reuniting with Allan and Jamie hours later at 10 pm that night.

Since the experience in Boston, Jamie has had an increase in challenging behaviors including self-injury, a greater degree of anxiety, and a lower tolerance of loud voices or noises. Robyn and Allan have been careful to ease him back into racing as he is unable to cognitively or emotionally process or discuss how he is affected. Alex continues to run amazingly well.

Because Alex and Jamie are not able to run alone, they will be running with guides whose sole responsibilities are to set the pace, help the boys navigate the course and hydrate when needed. If not for the commitment and perseverance of the running guides, the Schneider twins would not be able to compete in these races.

Running is an activity that readily includes Alex and Jamie in the community, and inspires others to celebrate that their challenges are not greater than their triumphs!

Please support Alex and Jamie Schneider! Every penny they raise will go to the continued and exhaustive efforts to make the public aware of science-based interventions for autism, so that individuals like Alex and Jamie can thrive in developing their unique abilities and enable them to reach their greatest potential.

Cheer on the twins and Team ASAT at <http://www.crowdrise.com/ASATnyc2013>



Questions to Ask Marketers of Autism Interventions

By Daniel W. Mruzek, Ph.D., BCBA-D

Families with a member with autism know that there is a vast selection of potential treatment options. Some of these treatments are purported to address one or more of the core features of autism (e.g., a pill that supposedly improves spoken communication), while others are marketed as treatments for other difficulties commonly experienced by individuals with autism (e.g., exercises to reduce tantrums). Many of these interventions are expensive and time-consuming, and some are potentially dangerous (e.g., hyperbaric chamber). Like other “purchasing” decisions, families need to consider treatment options carefully.

How does one investigate these options? One way is to ask a trusted expert (e.g., a physician, psychologist, behavior analyst). Another way is to reference science-based “quick reference” guides, such as ASAT’s web-based *Summaries of Scientific Research on Interventions on Autism* (http://www.asatonline.org/treatment/treatments_desc). A third way to investigate the soundness of a potential autism treatment is to ask the marketer or practitioner polite but direct questions about the treatment that they recommend. Below, we have eight questions that you can ask the marketer of an autism intervention that might be helpful as you make treatment decisions.

Family members might be a little apprehensive about asking marketers of purported autism interventions direct questions about the state-of-the-science of their interventions; however, a legitimate interventionist will appreciate good questions and the resultant opportunities to partner with the family in the development of effective treatments. This process of direct questioning is one way we can practice *scientific skepticism* – a quality of the scientific process that makes it such a powerful means of positive change. Also, this process increases the likelihood that hard-earned family income is spent wisely in maximizing the independence of their member with autism.

Additional information on selecting treatments for your family member is found in an article entitled, *The Road Less Traveled: Charting a Clear Course for Autism Treatment*, authored by David Celiberti and colleagues and found at this web address: <http://www.asatonline.org/pdf/roadless.pdf>.

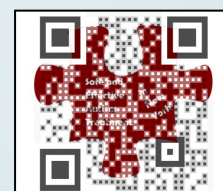
	Question	Notes
1	“What is the rationale or theory underlying this intervention?”	The marketer’s description of the rationale should sound reasonable. Be aware of scientific-sounding explanations that sound impressive but, upon consideration, are not plausible, logical or realistic.
2	“Do any scientific papers (e.g., peer reviewed journal articles) indicate that the proposed treatment is effective?”	Watch out for references to testimonials, opinion pieces, case studies and “articles” that have been posted without scientific peer review. They can provide an illusion of legitimacy and effectiveness when, in fact, no scientific evidence may exist.
3	“What should the benefits of the intervention look like and how will we monitor/measure these?”	The practitioner or marketer should be able to offer <i>specific</i> and <i>observable</i> potential benefits and an objective method of measuring for gains for your family member.
4	“Do you have (de-identified) data sets from your practice that suggests that this treatment works?”	If the practitioner cannot point to scientific studies supporting their proposed intervention, ask to see treatment data for other individuals with whom they have worked in the past. The practitioner should not provide you with the name or other identifiers of the individual they treated- just a good description of what they did and data that demonstrate functional improvement for the individual.

Questions to ask marketers continued ...

	Question	Notes
5	"What are the possible side effects and how will we monitor/measure these?"	Many interventions have potential unintended consequences that should be considered beforehand and, if concerning, monitored for during implementation.
6	"How much time does it take, and when will it be done?"	Even a brief intervention (such as a 10-minute exercise during the school day) adds up to substantial time lost for other, possibly important activities (e.g., skill building); therefore, one question to consider is what will <i>not</i> be done during implementation of the proposed intervention?
7	"How will we monitor treatment data for my family member?"	Watch for the use of objective (i.e., measurable) data to assess for possible treatment effectiveness. And, of course, objective data are of no use if the intervention team is not regularly reviewing these data and incorporating these data into treatment decisions. Will the data "pile up" in a folder or drawer, or will the intervention team maintain a schedule of ongoing review?
8	"How difficult is it to implement this treatment correctly?"	Beware of proposed interventions that require that they be implemented "just right" in order to be helpful. This quality can be an excuse that marketers use when unwary consumers question a lack of progress. Usually, an effective intervention is helpful even if not implemented with perfect fidelity.

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Safe and Effective Autism Treatment in New York (SEATNY) is a Facebook page that was started to raise awareness around issues pertaining to autism treatment in New York. Our primary goals are connecting parents and professionals with information about effective autism treatment, holding lawmakers accountable for fulfilling promises, and making sure that individuals with autism are treated by trained professionals who are appropriately monitored. We strive to provide quality information about autism treatment in New York, as well as to remind New Yorkers that our government needs to hear from us about what matters to us in autism treatment. The more people who "like" and "share" the SEATNY page, www.facebook.com/SEATNY, the more clearly our voice will be heard.



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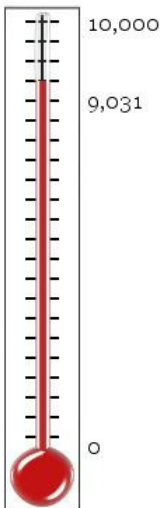
ASAT’s mission is to promote “safe, effective, science-based treatments for people with autism through: the dissemination of accurate, timely, and scientifically-sound information; advocacy for the use of scientific methods to guide treatment; and the countering of unsubstantiated, inaccurate and false information about autism and its treatment.” With this in mind, ASAT is striving to reach 10,000 subscribers by the end of the year. We are currently at 8,895 subscribers. Help us reach 10,000 subscribers by clicking on the following link: <http://asatonline.org/newsletters/signup>. You can also “like” ASAT’s Facebook page at <https://www.facebook.com/ASATonline?fref=ts>.

If you are a supervisor or administrator, please consider passing along a sign-up sheet to help us recruit new subscribers. We have an individual version and group version. After these are completed, they can be emailed to newsletter@asatonline.org or mailed to: ASAT PO Box 3250 Hoboken, New Jersey 07030.

ASAT would also like to recognize those individuals and organizations who strive to support our mission. Specifically, we would like to thank and send a “shout out” to:

- Victoria Blessing, Jennifer Bilby, and Mary Rosswurm of the Little Star Center for including our newsletter and website flyers in their family packets.
- Jennifer Cook and Tracie Linblad of Four Point Intervention Strategies, Inc. for sharing information about ASAT with their clients and at a local conference in Ontario, Canada.
- Spectrum Designs for quickly printing ASAT T-shirts for our NYC marathon runners.
- Jennifer Hieminga of the New Haven Learning Centre for sharing information about ASAT with her staff and families and for having her staff sign up for our newsletter.
- Kirsten Wirth from St.Amant in Winnipeg for distributing newsletter and website fliers at her workshops.
- Lisa Wajsblat of the Fay J. Lindner Center for Autism and Developmental Disabilities for sharing information about ASAT with the families who they serve.
- Suzanne Letso from the Connecticut Center for Child Development for distributing ASAT materials at her organization’s conference.

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Clinical Corner continued...

(Continued from page 3)

It is also important to understand that if a specific cause is not found upon genetic testing, it does not mean that the cause is not genetic, just that it cannot be identified currently using the tests that were completed.

In summary, for a couple with one child with an ASD of unknown cause, the current best estimate of the risk of a subsequent child having ASD is approximately 10% based on group averages. Any couple with questions about recurrence risk should pursue genetic counseling so that the information can be tailored to their specific situation. Because of the increased risk of ASD, all younger siblings of an affected child should be monitored through routine administration of ASD screening tools to facilitate earlier identification and intervention.

For a more detailed article on this topic, please see <http://asatonline.org/resources/clinician/morechildren.htm>

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- ⇒ All providers will be guided by science when selecting and implementing interventions.

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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.

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Coming up in the Winter 2014 Issue of *Science in Autism Treatment!*
This issue will be dedicated to the Little Star Center, 2013 Partner Level Sponsor

- ☆ Interview with Little Star Center Executive Director, Mary Rosswurm
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- ☆ Dr. Ricardo Dolmetsch will be discussing Stem Cell research and its implications for autism treatment
- ☆ Research Synopses
- ☆ Showcasing of our 2013 Accomplishments and 2014 Goals

International Interview: Pooja Panesar

By Nicole Pearson, Psy. D., BCBA-D

The advent of advocacy organizations like ASAT, Autism Speaks, Autism Science Foundation and the Organization for Autism Research have played a significant role in bringing autism awareness and treatment into the mainstream here in the United States. While there is still much work to be done here, in much of the international community, the understanding and treatment of autism is still in its infancy. In April of this year, I traveled to Kenya with the Global Autism Project where we worked at Kaizora Consultants, an educational program founded by Pooja Panesar that provides ABA-based services to children with autism and other developmental disabilities. Recently, I had the chance to speak further with Pooja about her organization and training experiences as well



as the current state of autism awareness and services in Kenya.

Let's start from the beginning, can you tell us about what led to your decision to pursue a career in autism treatment?

I actually never made a con-

scious decision to pursue a career in autism treatment. When I moved back to Kenya in December 2006, I started applying for jobs as a teacher or counselor at various schools and a parent



of a child with autism saw my resume and asked if I would work with her 7-year-old son at home. Up to that point, she had been unable to find a provider with any autism-related experience. I started his home-based program in 2007 and he gained many skills in such areas as communication, attending to others and using the toilet independently. As word of my work spread, I started working with several more children in their homes and by 2009, I could no longer sustain the traveling from home to home and decided to create a centre-based program which led to the founding of Kaizora Consultants.

That is such a common experience among service providers in underserved areas both here in the US, and abroad. Where did

you receive your training?

I completed my undergraduate studies in Canada at McMaster University with Honors in Psychology, Neuroscience and Behavior (major) and Biochemistry (minor) in 2006, before moving back to Kenya where I was born and raised. After doing the home programming work with children here, I began looking for a program to further my education and training. Despite impressing professors with my programs and data collection, there was no financial support at the time. Finally in 2011, I re-

ceived a scholarship from the University of Massachusetts, Boston to pursue my certificate in Applied Behavior Analysis (ABA) which I completed in 2012. I then enrolled in a Masters program in Education in which I completed in August with distinction. Next, I plan to sit for the BCBA exam in 2014. In terms of my work experience, I first learned about ABA during my undergraduate studies when I worked with the Behaviour Institute, running home-based programs for individuals with autism. I worked there until I graduated, after which I obtained a job with a rehabilitation centre where I worked with individuals with brain damage, and helped them re-integrate into

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Interview with Pooja Panesar continued...

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society. I did this until I moved back to Kenya.

You have the first behaviorally-based center in East Africa that provides services the children with autism. Can you share with our readers more about what autism treatment is like in Kenya?

Unfortunately, autism treatment first requires high levels of awareness and ,currently, many Kenyans are still unaware of the disorder or the needs of those who are affected by it. There are a growing number of organizations focused on creating this awareness so hopefully that will change. In terms of treatment, there are just a few professionals in the field at the moment and their availability is limited. Therefore, treatment access and resources are sparse and limited.

For those who are pursuing treatment in Kenya, which treatments are most popular?

Currently, many families who find out they have a child with autism pursue the gluten free/casein free (GFCF) diet intervention, as it is the most popular. Some recognize the need for speech and language therapy but few have access to such services due to the limited number of professionals and the financial constraints associated with paying for services.

What resources do parents turn to, in order to

learn about autism treatment? Do these resources recognize best practices based on scientific evidence?

For many, this depends on the financial resources of the family. For those who have Internet access, they rely on it as a primary source of information. In some instances this can be difficult as they aren't necessarily able to distinguish fad treatment options from evidence-based ones. For those without Internet access, they rely on whatever they hear from the doctors who made the diagnosis or on word of mouth. There are a few societies that have been established to promote autism awareness but not all appreciate the importance of evidence-based interventions.

Have the professionals in Kenya organized to advocate for evidence-based autism treatment? What about the parents? Are they organized or is everyone fighting on their own?

The professionals in the field of

autism in Kenya are few and not all of them advocate for evidence-based treatments though some do, myself included. While the professionals in Nairobi try to communicate with one another, they often end up working independently due to time and resource constraints. Moreover, most have differing training and tend to follow what they've learned. Currently, there is no other professional in Kenya, besides me, who is certified in ABA. On the parent side, it can be very challenging for them because, as you can imagine, they are willing to try anything out of desperation to help their child and as I've already mentioned, most have limited access to information.

As you know, there are several thousand BCBAs here in the United States. Are there any BCBAs in Kenya?

We're still waiting for the first one and I'm hoping to contribute to filling this gap very soon!!

We look forward to that! In terms of special education, the students who attend Kaizora receive ABA-based individualized instruction. What is special education like for children with autism who attend public schools?

Due to the financial constraints of families and limited treatment re-

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Interview with Pooja Panesar continued...

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sources in Kenya, few children receive any type of early intervention or other services prior to entering school. Some public schools have sectors or units that are dedicated to working with children with special needs. Others include the children with mild disorders in the classroom; however, the benefit in this is limited due to the high teacher-student ratios. There is a limited number of special education teachers and the training many receive is not always sufficient to handle the specific needs of these children. Often, children who are more severely affected and whom the teachers find too difficult to handle are simply sent back home. Most parents do try to put them in some educational placement but unfortunately, it doesn't always meet their child's needs.

From your standpoint, what help/information is most needed in Kenya?

In my opinion, the greatest needs are in promoting evidence-based practices and in helping parents get access to

this information. In addition, many families are in desperate need of financial support as they cannot afford to pay for behaviorally-based services and the government does not provide any funding. As a result, they are at a loss about how to help their children, which results in a loss of precious intervention time. If some of these factors can be fixed, there will be an increase in effective early intervention efforts which, ultimately, would give many more children with autism a better long-term outcome.

Is there anything that we, in the international community of parents and professionals who engage in science-based treatment, can do to help in your goals?

There is plenty to be done. First and foremost is helping create greater awareness and disseminate best practices in autism treatment. Then, support services both in terms of financial resources, as well in training service providers and parents to work with and advocate for their children. For exam-

ple, we have a team from the Global Autism Project that comes twice a year to facilitate trainings with Kaizora staff and help with other outreach activities. Consistency and sustainability are vital when it comes to help from the international community, to ensure that the assistance provided is meaningful and long-lasting.

Pooja, thank you so much for sharing your perspective and insight about the state of autism treatment in Kenya with our readers. From your work in establishing one of the first ABA-based autism treatment centers in Kenya to pursuing your board certification in behavior analysis, you're certainly making great strides in bringing greater awareness to the importance of evidence-based treatment to families and practitioners in Kenya.

We wish you the best and hope that practitioners and clinicians in our field will continue to support your very worthwhile efforts.

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