This Summer 2015 is the 25th quarterly issue since the return of Science in Autism Treatment in the summer of 2009. This time has come and gone so quickly. Co-Editor Daniela Fazzio and I remain so grateful to our incredible newsletter team showcased on the bottom of page 44 and, of course, to the nearly 12,000 readers worldwide who are committed to ensuring that science remains in the forefront of every conversation about autism treatment. No sooner do we get one issue out we are beginning to put together another information-packed issue for the next quarter. We ask for your help in enabling us to keep science at the forefront of every conversation about autism treatment. There are a number of ways to support ASAT:

- Your financial support, however small, can make a big difference in enabling ASAT to continue its mission to disseminate accurate information about autism and its treatment, and to keep our resources free. Please make a donation at http://www.asatonline.org/donate/
- If you are affiliated with a professional organization that shares ASAT’s values, there is still time to become a 2015 Real Science, Real Hope Sponsor. Please see page 36 for more information or visit http://www.asatonline.org/direct-financial-support/#sponsors
- If you are a business owner, or know of one, and would like to become a Community Sponsor or help raise monies for ASAT through donation jars or customer appeals, please write us at donate@asatonline.org. We can provide you with information about how your business can take small easy steps to support ASAT. Please learn more at http://www.asatonline.org/fundraising/
- Finally, we have extended our online auction through Bidding for Good as we have some items awaiting bids, such as autism related items, hotel stays, amusement park tickets, recreational and sports tickets, and so much more! Please check it out at: http://goo.gl/jxWmJp

Please see page 45 to learn of the wonderful businesses, organizations, and individuals who have contributed great to the success of our 5th annual Rock’n 4 Autism Awareness campaign. We are so grateful for their support.

As we look to the last few months of 2015, we are proud to share that ASAT has had a very productive year thus far, with progress made on many of our goals. We will write more about our 2015 accomplishments in the Fall 2015 issue of Science in Autism Treatment and will share information about recent changes to our Board of Directors. We have seen some members leave and look forward to working with a group of new members each joining ASAT with an important role to fulfill.

Best,
David Celiberti, Ph.D., BCBA-D
Executive Director and Co-Editor of SIAT

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Interview

Robyn Schneider, author of
Silent Running: Our Family's Journey to the Finish Line with Autism
By Sabrina Freeman, PhD

Sabrina: First of all, I'd like to thank you for writing this book. I think that it is one of the most honest books I've read on autism in a very long time. I'd like to ask you a few questions, if I may, to let our readers know about this exciting book.

Robyn: Thank you so much for the compliment! I'm honored to be interviewed by you and to talk about my book with ASAT readers. I have been a supporter of ASAT for many years.

Sabrina: What motivated you to write this memoir, and open up your heart and your family's life for the world to see? Your candor is very refreshing.

Robyn: There were several motivating factors that led me to write my memoir. The first is a very personal and emotional one. I wanted to leave a legacy for my sons. Although they will never be able to read my book, nor will they know the significance of their story being out in the world, it is my gift to them, and that makes me incredibly happy. I also know that their story, and our journey, will inspire many people; not just parents of children with autism and other special needs, but anyone who has faced adversity in their lives. My hope is that my book will offer something of value to everyone. And lastly, I wanted to reflect on the moments in my life that were imprinted in my heart and mind, and by doing so I was able to honor the people that I care so deeply about, and to whom I am so grateful for their love and support.

Sabrina: What I loved about your book is that you describe the successes and the ongoing challenges of your journey. Did you have any hesitation here? If so, what was the internal dialogue or the conversations you had with your spouse about this issue specifically and about the issue of privacy for your sons? The reason I ask this question is that I grapple with these issues as well.

Robyn: I had many moments of hesitation. There were times I wanted to omit certain scenes that were heartbreaking and embarrassing. But I had two wonderful people working with me during the writing process. My husband was very supportive in agreeing to be as honest as we could. We committed to one another that it would be our story - the true story. The other person was Kate Hopper, an author, editor and teacher, who helped me to feel comfortable expressing my most inner thoughts and feelings and getting them down on paper.

Sabrina: Many parents of children with autism have interesting stories to tell; however, it's one thing to

(Continued on page 3)
have a story, and quite another to tell the story in a way that is compelling. How did you take your memoir and turn it into a page-turner? I felt like cheering with every race result you provided, and crying with every setback you experienced.

Robyn: Thank you, Sabrina! I felt that my life has so many unique twists and turns - a double diagnosis of autism, debilitating obsessive-compulsive disorder, extreme anxiety, multiple sclerosis, breast cancer, family relationships, celebrations and tragedies, running, and struggling to persevere through some of the most stressful times. Because of this, I thought my story would resonate and touch a chord with readers having experienced some or similar aspects of my story.

Sabrina: Did you ever think of giving up in the middle of writing your memoir? You describe a particularly hard time when you were hiding in the bathroom to avoid being injured. I can't imagine coping with this type of scenario and then being able to write my memoir about this experience.

Robyn: This was one of the scenes that I was hesitant about including in my book. At first, I didn’t want to expose my son Alex this way. It was hurtful enough living through that period in my life and I never talked very much about it. But I wanted to be truthful, and I felt that other parents of children with autism, particularly those with severe autism, could relate to these kinds of behaviors and the stress that families face on a day-to-day basis. But I also wanted others, who don’t necessarily have autism in their lives, to peek inside ours, see our reality, and understand our challenges. We are just trying to cope and make the best decisions for our sons while providing a quality life for them.

Sabrina: In your book you speak about the unsung heroes in your twin sons’ lives. How did you find these people? Was it difficult?

Robyn: I consider myself so very lucky that these kindhearted and selfless people came into our lives. When Alex and Jamie started running with the Rolling Thunder Running Club, we met some amazing running coaches. Kevin McDermott is the one that took Alex under his wing, tamed the “wild colt” and trained him to become the incredible runner he is today. Then, through personal contacts, we met other athletes who wanted to run with my sons, and these relationships have led to wonderful friendships. My husband and I are so grateful to them.

Sabrina: I know that you had both your sons in an intensive behavioral treatment program, and then in a school that uses Applied Behavior Analysis (ABA) to work with children afflicted with autism. Was this behavioral orientation at all relevant to teaching your sons how to run a marathon?

Robyn: Absolutely! I truly believe that the principles of ABA helped my sons “learn to learn” and enabled them to apply those same lessons to running. And their running coaches were able to use ABA teaching strategies in their training. It has had a remarkable effect on them.

Sabrina: What I particularly respect about your book is the fact that you were so forthcoming with (Continued from page 2)

Allan, Jamie, Robyn, and Alex Schneider

(Continued on page 4)
your family's experiences and what came across was that although you have invested in the best treatment available, your sons continue to face many of the significant challenges presented by autism. Was it difficult to paint your reality? Even though both your sons have achieved so much in life so far (and they've got much more that they will achieve in the future), could you address the difficulty in describing the day-to-day challenges as well?

Robyn: Once I committed myself to telling the real story of the challenges that we faced on a moment-to-moment basis, writing was cathartic for me and gave me a sense of peace. There have been many books written about children with autism who have overcome some or most of their symptoms. However, for those with severe autism who have not been so fortunate, I felt it was important for me to share our reality. And although Alex and Jamie have achieved so much through running, they have done so because of their early training in an ABA program. I hope that readers will appreciate our struggles and better understand the needs of children with severe autism.

Sabrina: Did you feel that the amount of work put into writing this book was worth the effort? If so, could you describe the reaction that makes you feel this way? What was your biggest challenge, and your biggest reward?

Robyn: It was an enormous amount of work! It took months and months of late nights, deadlines, and reliving all the moments of our journey. It was truly an emotional rollercoaster for me. The biggest challenge was carving out the time to write. I had many nights during which I was writing past 2:00 AM but it was worth every moment. Silent Running is the memoir I always dreamed of.

Sabrina: I don't have to tell you that, today, the publishing industry is full of books on autism. The fact that you found a publisher is amazing! Once you had this unbelievable true story, how did you actually find a publisher who was prepared to work with you? Also, how did you get into Good Morning America and into the New York Times? That's impressive!

Robyn: I am truly lucky to have found a wonderful agent that saw the potential in my story and believed in its power. Triumph Books believed in me and my story, and shared my passion and enthusiasm right from the start. As far as the media outlets are concerned, there has always been an interest in our story from the very first article I wrote for our local paper years ago when my sons participated in the 1500 meter race in the Special Olympics. Alex won first place and Jamie won second place. I was so excited that I had to write about it. Since then, we have been very fortunate to have had such wide coverage on my sons over the years. I am eternally grateful to all the media outlets that have featured my sons and our story so eloquently.

Sabrina: If you could give any advice to parents, what would it be? I'm sure many parents with children on the more severe end of the autism spectrum would be very interested in any words of advice that you may have.

Robyn: My advice is to keep hope alive and try to stay positive. Surround yourself with people who care, and professionals who can offer guidance and support. Follow through with recommendations. Explore activi-
ties that you believe may enrich your children’s lives and make them smile. And most importantly, be smart and do your research. ASAT is a valuable resource to ensure you are making decisions that are evidence based.

Sabrina: Is there anything you’d like to add that we have not yet covered in our interview?

Robyn: Sharing my journey with ASAT readers has been my pleasure! I only hope that my story can offer some insight, value and strength to families living with autism.

Buy the book: * Amazon- http://goo.gl/BNCtIU
Learn More: * You Tube: https://goo.gl/PLRDJR
  * www.autismrunners.com
  * www.robynkschneider.com

"My advice is to keep hope alive and try to stay positive. Surround yourself with people who care, and professionals who can offer guidance and support. Follow through with recommendations. Explore activities that you believe may enrich your children’s lives and make them smile. And most importantly, be smart and do your research. ASAT is a valuable resource to ensure you are making decisions that are evidence based.” - Robyn Schneider

We know we can count on you!
Click to learn how you can help Science in Autism Treatment

How You Can Help

This page contains information about the many ways you can get involved with ASAT; from volunteer opportunities, to supporting us on social media websites, to how your donations help our organization.

Get involved or make a donation today.
From the Archives

Tribute to Dr. Ivar Lovaas

As part of this tribute that appeared on our Fall 2010 issue, ASAT's Bridget Taylor and David Celiberti open with a few thoughts on Dr. Lovaas's legacy. This is followed by Josh Pritchard and Allyson Ross’s archived interview with Tristram Smith, who speaks of his involvement with Dr. Lovaas, then by the message from a parent who was deeply impacted, despite never having met Ivar Lovaas.

Patrick O’Leary, MA, BCBA
From The Archives Coordinator

Tribute #1

By Bridget Taylor, PsyD, BCBA-D and David Celiberti, PhD, BCBA-D

When on August 2nd, Dr. Ivar Lovaas passed away, the field of autism treatment and behavior analysis suffered a significant loss. Dr. Lovaas began his career when the psychoanalytic theory of autism was presumed valid, despite a grievous lack of supporting research. Flouting that unsubstantiated conventional wisdom, Dr. Lovaas changed the course of autism treatment by initiating a long-term program of targeted research. That research led to his seminal 1987 study, demonstrating that some children with autism can make significant progress with early intensive behavioral intervention. This indispensable work paved the way for additional empirical demonstrations and single-case subject designed studies, all supporting the central premise that, with behavioral intervention, children with autism can overcome many of the debilitating effects of the disorder and learn skills previously considered unattainable.

Dr. Lovaas’s practical manual, The Me Book, was one of the first volumes to put validated interventions directly into the hands of parents and practitioners. The Me Book charted a new course of treatment, and offered parents and teachers a road map of what — and how — to teach. It is an understatement to say that Dr. Lovaas was a pioneer. And while his work may have generated controversy and criticism, few great thinkers have followed such a visionary path without suffering detractors along the way. Today, thousands of children and families — whether or not they realize it — enjoy the benefits of the programs and strategies that Dr. Lovaas advocated. His work will continue, and his legacy will not be forgotten.
We chose, in this issue, to interview board member Tristram Smith, as he worked closely with, and knew well, the late Dr. Ivar Lovaas. We have the great fortune to have Tris’s contributions to ASAT through his active role on our board. We hope you enjoy this brief insight into his life and history.

Before we get into questions about your — “job” what kinds of things do you do outside of work, for fun? 

I’m mostly a home-body, spending time with my wife and 7-year-old daughter. My 18-year-old son recently started college. When I have spare time, I like to create family photo albums and scrapbooks, cook, read general science books, go for hikes, play chess, or collect ancient (but inexpensive) coins.

How would you characterize — “what you do” to people that ask? If you were to give a — “30-second elevator explanation” of your job.. what would it be?

I work with children with autism and their families. My work involves providing applied behavior analytic (ABA) intervention, consulting to community providers, and conducting research to test ABA and other treatments.

How did you first get involved with autism?

When I was in college, I had an opportunity to become a buddy for an adult with autism. He was a brilliant man in many ways. For example, he liked reading dictionaries, and he could always stump me with spelling or vocabulary words I had never heard of. He also routinely trounced me in checkers without even looking at the board or taking much time to think. However, he couldn’t hold down a job, had no friends, and lived in a supported care facility. This mix of extraordinary skills and challenges was fascinating and touching to me, and it sparked a lifelong interest in searching for ways to help individuals with autism.

What is your goal in your work with ASAT? How does it fit with your personal goals and interests?

My goal is to ensure that ASAT’s website and publications present accessible, up-to-date, and accurate information about research on interventions for individuals with autism spectrum disorders. This activity helps keep me from getting so caught up in my own research that I lose track of what else is going on.

How did you first hear about/ interact with ASAT to get involved?

Accepting an invitation from Catherine Maurice and Gina Green, I gave a talk at a conference in Pittsburgh in 1998, when the initial efforts to form ASAT were underway. I had contact on and off again with ASAT until I joined the Board of Directors in late 2005 or early 2006.

What, exactly, is/are your role(s) with ASAT?

I’m the Chair of the Scientific Review Committee, which reviews scientific research on autism treatments, works with other ASAT committees to disseminate research findings, and consults to ASAT members on scientific issues.
such as interpreting the validity of news items about autism treatment.

**What was it like to work with Dr. Lovaas?**

It was exhilarating. My first year of graduate school was the final year of data collection for Lovaas’s now famous 1987 study. For my master’s thesis, I scored the pretreatment videos, and I could scarcely believe my eyes when I saw how much some of the children had improved from these videos to the time I met them. I also had the extraordinary opportunity to witness these kinds of improvements firsthand as a one-on-one student therapist for a couple of the last children to enter the study under the direct supervision of Lovaas himself, and his superb team of more senior therapists and graduate students. Lovaas was inspirational—exuberant, outgoing, brimming with excitement about his work, teeming with ideas for new research projects, and always keen to sit down to work with a child with autism. He also was enormously generous. For example, he kept me on the payroll during an illness that otherwise would have required me to go on disability. He supported Annette Groen, Jacquie Wynn, and me as we conducted an outcome study in his clinic, diverting resources that he easily could have used for his own work. He went far out of his way to credit me and other graduate students for our contributions and to help us find jobs when we left.

**Wow, that does sound exciting! It seems like you had a perfect job and mentor.**

I have to say, though, that I also had to develop a certain amount of equanimity. Lovaas could praise me extravagantly on some occasions yet give brusque criticism at other times; tell me to insert a passage into a manuscript that he would later reproach me for, excite his whole team about a new project or idea only to abandon it at the next meeting, set an agenda but then spend an entire meeting talking about something else altogether, and appear at meetings in a jovial mood or livid because of a mistake or oversight on my part. These ups and downs could be difficult, but I came to see them as a form of creative destruction that would ultimately lead to an original, important contribution.

**What would you like to share with our readers that may be a little known fact about him?**

Although Lovaas’s critics often accused him of wanting to turn children with autism into drones who automatically obeyed orders, the opposite was really true. He was especially proud of the unique and unexpected achievements that his graduates went on to make—one boy who made the high school wrestling team, another who started a rock band, even the girl who was caught with her friends smoking cigarettes under the school bleachers (although he and his graduate students worked with the girl’s mother to put a stop to that one!). He spent a great deal of time reminding undergraduate and graduate students of the importance of preserving and respecting individual differences. He recognized that children in his clinic were required to comply with many demands from therapists, but he firmly believed that this requirement was the best way to help them pay attention to instruction and learn skills that they could use to develop into distinctive individuals.

**Can you briefly describe how you think he has most impacted the world of autism?**

Lovaas showed that children with autism did not need to be confined to institutions or segregated classes and that, on the contrary they could live, learn, and thrive at home, in their neighborhood schools, and out in their communities.

**Given the current state of the science, has much changed since his ground-breaking study suggesting that ABA can help children lose their diagnosis? What kinds of things are different between then and now? What has**

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stayed the same?

A generation after Lovaas’s (1987) groundbreaking study, his intervention remains the most studied and arguably most successful comprehensive early intervention program for children with autism. However, many other things have changed. In 1987, autism was considered to be rare, affecting about 1 in 2000 children; now, however, the prevalence is estimated at about 1 in 110 children. Accordingly, intervention programs need to be implemented on a much larger scale for many more children than anyone would have anticipated in 1987. Also, we now have much clearer information than we did in 1987 on what the defining features of autism are; this information may require revising curriculum content and possibly also intervention methods. Perhaps most encouraging for the future, after many years when Lovaas and a small handful of other behavior analysts were the only ones who were systematically studying interventions for children with autism, a large and rapidly growing number of researchers with a range of backgrounds have joined the effort to test interventions for children with autism and identify ones that are effective.

Again—thank you for your time! Your experiences and insight are very interesting and you have provided some great personal insight into a giant within the autism community.

Tribute #3
“Thoughts on Dr. Ivar Lovaas from a Parent”
By Harold Doherty

I never met Dr. Ivar Lovaas in person. My 14 year old son, Conor (diagnosed at age 2 with Autistic Disorder and profound Developmental Delays), was never a patient or a subject in a Lovaas study. Yet, when Dr. Lovaas passed away recently I felt that one of the most important people in my son’s life had been lost. Through his career and research he helped our family, our teachers, and autism service providers, teach my son and other children with autism. He proved to us that we could help children with autism learn to communicate, to overcome deficits, to grow, and to live more rewarding lives.

The importance of Dr. Lovaas in my son’s life stems from his research, reported in 1987 and 1993, which demonstrates that Applied Behavior Analysis (ABA) can help many children with autism overcome the cognitive, linguistic, and behavioral deficits which are often displayed in these children. Unfortunately, I cannot provide testimonial evidence that my son Conor, who is severely impaired by his disability, has recovered from autism because of ABA. This is partly because such services were not readily available in Fredericton (New Brunswick, province of Canada) where we lived at the time when Conor received his diagnosis. I did not learn about ABA until Conor was almost four years old, when the preschool development window was already closing for him. Therefore, he did not have the opportunity to receive 40 hours per week of discrete trial training between the ages of two and five. Notwithstanding the severity of my son’s condition, and his late introduction to the ABA principles that Dr. Lovaas demonstrated, he has been helped immeasurably by the effective autism intervention created through this research.

Dr. Lovaas’ work helped convince this father that ABA was the best bet on which to gamble my son’s valuable development time. That research provided me and my wife, Heather, with the confidence and the methods to help us communicate with our severely autistic son, and help him grow and develop. As parents, few gifts are greater than these. My knowledge of Lovaas and of ABA began when I attended lectures given by a clinical psychologist and University of New Brunswick (UNB) psychology professor emeritus, Paul McDonnell, PhD, who worked with children with autism and educated many parents about the Lovaas studies and about ABA principles in general.
In particular, Dr. McDonnell gave a lecture entitled, “Managing Problem Behavior in Autistic Children.” It is the only talk from the many, varied, and bewildering seminars given by various purported authorities in those early years that I can remember with any detail. It was the only presentation at which I was made aware of learning principles that would be helpful in dealing with the serious challenges a parent faces in raising a child with autism. I can still visualize a “Problem Behavior Extinction” Chart from that lecture, based on evidence, which showed how to eliminate problematic (including dangerous and self-injurious) behavior in children with autism. The effectiveness of ABA principles was not “pie-in-the-sky” nonsense. The claim of effectiveness was based on solid research, and in particular, on the research of Dr. Ivar Lovaas.

At the conclusion of that presentation by Dr. McDonnell, I immediately tried to use what I learned. That evening, in a crude application of ABA principles, I refused my son’s initial screaming for what I knew, from experience, was a favorite treat (an apple), until he started to ask for it by saying the word, “apple.” I repeated “apple” in two drawn out syllables, “Appp … pull.” Conor continued to scream. This process continued for almost 45 minutes until Conor finally said, “App.” I immediately gave him a bite of the apple. Each time he said, “App,” he got another bite. Then I insisted that he say “app-pull” to get another bite. After almost an hour and a half of this process, Conor had said “apple” several times, and without prompting.

This anecdote might not seem like much to many people, but to me it was the first time I was able to teach my son to say a word. It was the first time that I could communicate with him at all, in any meaningful way, other than by guessing what he was trying to say through his screaming. The process I just described was not easy for me to endure as a parent; to withhold what I knew my son wanted while he screamed in frustration. That experience, though, was the beginning of my ability to communicate meaningfully with my son with autism, and he with me. I was able to do it, I was able to communicate with him meaningfully, because the principles were sound and because I was convinced it would work. I was convinced it would work because of the research evidence in support of its effectiveness, especially the research by Dr. Lovaas.

Since that initial success there have been many others. Conor’s ability to communicate with us, and ours with him, has improved substantially. We used ABA principles at home and were successful at toilet training Conor well before he started school. Frustration-induced aggressive behavior toward others has been eliminated. Conor started his first year of high school, with his own curriculum and with ABA based instruction at school. Conor initially started school in a general classroom for the entire school day, but that resulted in some self-injurious hand-biting. It was resolved shortly thereafter by placement in a more quiet area for his ABA instruction, and the hand-biting disappeared. Otherwise, we have not had a single incident of aggression toward himself or others, nor problem behavior of any kind, reported to us by school officials. Conor loves attending our neighborhood schools, loves receiving his ABA based instruction, and is liked by fellow students and educational staff. I do credit Conor himself. Conor has always been naturally personable, and well liked by other children and adults, but his interaction with others has also been helped by the application of ABA principles to address his more challenging autism based behaviors.

It might surprise some to read that, here in New Brunswick, my son receives ABA based instruction in our neighborhood schools, but that has been the case for several years. The provincial government has provided ABA training to teacher assistants and resource teachers at the UNB-CEL Autism Intervention Training Program. The program is based on ABA principles and research, and has received external review by Dr. Eric Larsson of the Lovaas Institute who described it as “A remarkable and thorough program that has been developed to an exceptional level of quality in the context of limited resources. The province-wide model is one that many other provinces should adopt, as it carries with it many cost-effective features. The curriculum content requires little modification.”

(Continued from page 9)

(Continued on page 11)
The UNB-CEL program itself was based on ABA research, and includes instruction in discrete trial training. The program was first developed to train autism support workers and clinical supervisors for the preschool autism intervention treatment centers, established in New Brunswick several years ago, in response to intense parent pressure. It was adopted for use in training teacher assistants and resource teachers in our neighborhood schools, again after some determined parent advocacy. As parents supporting our children with autism, we were successful because we were focused, persistent, and well informed about autism and effective interventions. We also succeeded because we had the tools (the Lovaas studies) with which to convince political and civil service leaders that ABA was an effective evidence-based intervention that would help children with autism to learn.

Dr. Lovaas provided our family and our government with evidence that ABA is a powerful intervention for children with autism. He said that “if a child cannot learn in the way we teach, we must teach in a way the child can learn.” He also proved to us that it could be done, and showed us how to do it.

Harold Doherty is the former President of the Autism Society of New Brunswick, involved with advocacy for establishment of UNB-CEL Autism Intervention Training program, provision of ABA early intervention up to 20 hours per week provided by the Province of New Brunswick for children with autism between 2 and 5 years old. He currently advocates for autism youth and adult residential care systems in New Brunswick.
CONSUMER CORNER:

Review of Life as an Autism Sibling

By Alice Bravo, MEd

Having a sibling comes with rewards and challenges. The Organization for Autism Research recently published Life as an Autism Sibling: A Guide for Teens, a booklet created by young adults with siblings with autism spectrum disorder (ASD), for teenagers with siblings with ASD. It is meant to provide support and guidance for the unique experiences that come alongside growing up with a sibling that is on the spectrum.

Alice Bravo, MEd
Consumer Corner Contributor

The booklet addresses six difficulties that siblings often experience, with each page of the booklet addressing a different topic:

- “Explaining autism”: This page contains suggestions for how teenagers may explain what autism spectrum disorder (ASD) is to their friends, classmates and strangers in a way that others will understand.

- “Dealing with a different ‘normal’” - Many adolescents experience a sense of loss as they witness their peers experiencing “normal” sibling relationships that appear very different from their own. This is addressed by working to identify activities that both siblings enjoy doing together.

- “Parents, time and expectations” - To a teenager, it may seem like his or her sibling with ASD takes up a large portion of their parents’ attention. This section of the booklet acknowledges the hurt that the teen may feel as a result, and makes recommendations as to how to discuss this feeling with parents. Four succinct steps are provided:
  1. “Know what you’re going to say,
  2. Think about the outcomes,
  3. Remain calm and
  4. Be honest.”

(Continued on page 13)
“When you need some space” - Strategies are provided for instances when a teenager is stressed out by his or her sibling, and how he or she may create their own personal space for unwinding and relaxation.

“Meltdowns” - Meltdowns by one’s sibling with ASD in public can lead to feelings of embarrassment. This page provides five strategies for dealing with those feelings:

1. “Remember that everyone gets embarrassed,
2. Surround yourself with good people,
3. Take a different perspective,
4. Make it a funny story and
5. Let it go.”

“Looking ahead” - The teenage years are a common time for individuals to start thinking more about their future: their life after high school. This section addresses moving away from home, thoughts regarding one’s future role in a sibling’s life, and having an open conversation with one’s parents if he or she is feeling worried about the future. Resources are also provided for additional support beyond the scope of the booklet – SibTeen, Sibshops, and the Organization for Autism Research website.

Life as an Autism Sibling: A Guide for Teens targets an under-supported population – teenage siblings of children with ASD. One of the biggest messages presented in the booklet is that these individuals are not alone, and that there are strategies and resources available to them.

Know a teenager with a sibling with ASD who might benefit from this resource? Download it for free on the Organization for Autism Research website, or by clicking here!
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A Clinical Treatment Guide to 10 Common Behavioral Pediatric Problems
By Ennio Cipani, Ph.D.

Our colleague, Dr. Ennio Cipani, has made this wonderful resource available for free!
- Daniela Fazzio, SIAT Co-Editor

This free e-book addresses 10 common behavioral pediatric problems with behaviorally-based solutions such as: bedtime problems, night awakenings, sibling rivalry, problems during car trips and other similar types of areas of family life that can be challenging. The book includes data sheets for progress monitoring. Many of the tips contained within each problem area are suggestions already advocated by professional groups, including pediatricians. However, you will also find additional tips that have a basis from my extensive clinical behavioral practice working in vivo (i.e., in the actual homes of parents who have children with disabilities, often coaching the parents during times when such problems occur) since 1983. If you are a professional who serves families, this resource can be used as handouts to share with parents.

If you are so inclined, a small ❤️ donation to ASAT would be appreciated (but not required, obviously).

If any SIAT subscriber desires to disseminate this free e-book to listserves of people who serve children with disabilities or other parents, you may post any information or link to Facebook or listserv - the below hot link leads right to the book table of contents and download link. While it is intended for professionals, some parents may be able to use the information with possibly some consultation from a person who provides behavioral parent training.

To get your free copy: ❤️ http://goo.gl/BUCF7r
To donate to ASAT: ❤️ www.asatonline.org/donate/
For more than three decades, countless families and professionals connect to learn, network, and be inspired at the Autism New Jersey Conference. This two-day event offers 72 workshops and an expected 100 exhibits on evidence-based intervention, accessing services, legal and financial issues, and more—all presented by leading experts.

- Begin with the keynote by Mark Mautone, M.A., the 2015 New Jersey State Teacher of the Year. He is a Lead Teacher for the Hoboken Public School District ABA/Autism Program who has been nationally recognized for his work teaching children with autism and integrating technology into the classroom.
- Hear frequently requested speakers including Drs. Andy Bondy, Sean Casey, Peter Gerhardt, Bob LaRue, Michael Selbst, Christina Vorndran, Mary Jane Weiss, and Thomas Zane.
- Learn about science-based practices to address challenging behavior, social skills, communication, and more as well as behavioral consultation, supporting families, and ethical concerns.
- Share your research with our Call for Posters available online through August 15.
- Promote your organization through exhibiting, advertising, and sponsorship options.

**BACB Type 2 CEUs and ASHA CEUs will be available for the majority of workshops. Call 800.4.AUTISM for information about social work credits.**
Targeting Sexuality With Teenagers With Autism
By Frank Cicero, PhD, BCBA

As individuals with autism grow into adolescence and adulthood, addressing sexuality education is of critical importance to ensure personal safety and knowledge of appropriate behavior. In this issue of Clinical Corner, Dr. Frank Cicero provides helpful guidelines for parents and educators to consider when determining how and what to teach when it comes to sexuality instruction in individuals with autism.

We have a teenage son with autism, and as he continues into adulthood we are concerned about being prepared to address specific issues related to sexuality and safety. What are the most important issues for us to consider and what skills should we target to maximize his safety and healthy development?

Answered by Frank Cicero, PhD, BCBA
Director of Psychological Services, Eden II Programs

This is a particularly difficult question to answer without being familiar with your son. As we all know, the autism spectrum is extremely varied with how it manifests in different individuals. Interests and abilities within sexuality, regardless of ASD, also differ widely across individuals. Put the two together and you have a content area that needs to be assessed and taught with the utmost of individuality and precision. One guiding principle to keep in mind is to make sure your son knows enough to ensure he is socially appropriate and physically safe. From there, decisions on what to teach and how to teach it, however, are not as difficult as you may be thinking. A good place to start is to assess what your son appears interested in doing and identify ways that he can go about it safely. An important point to keep in mind is that there are appropriate and inappropriate sexual behaviors. Think of sexual behavior as a behavior that needs to be shaped into being more appropriate. For example, if your son is exposing himself in public places in an attempt to masturbate, the issue is not that his desire to masturbate is wrong, but rather that he needs to be taught the boundaries and rules of when and where it is appropriate to do so. Similarly, if your son is very awkward in asking a girl out on a date and shows increases in stereotypic behavior in situations that make him anxious, we would need to teach him the social skills necessary to be successful. It may also be helpful to teach him strategies to overcome his anxiety, thereby diminishing his stereotypic behavior.

(Continued on page 18)
As stated earlier, you can see that the “sexuality curriculum” necessary for individuals on the autism spectrum will be very broad. What you teach and how you teach it will need to be highly individualized. So, the first thing to do is to assess what your son seems to be interested in doing and how you can best shape his behavior in order for him to be most socially appropriate, physically safe and personally satisfied. The next step would be to decide on a teaching method that will best shape his behavior. Rely on the teaching methods, techniques and materials that have been successful in the past to teach your son other skills such as how to brush his teeth, how to play a board game with peers or how to sit appropriately in a chair while in school. Use the teaching methods that you know work best with your son and simply change the target behavior. For example, if your son learned many self-care skills through a visual schedule and task analysis, you can use that same technique to teach the appropriate steps and behaviors associated with masturbation. If your son learned his colors, letters and numbers through traditional discrete trial instruction using expressive and receptive identification of picture cards, you can use that technique to teach private vs. public spaces. While these are just a few examples, the point is to match up the skill to be taught with the teaching methods that have been most successful in teaching your son new skills. Some examples of useful teaching techniques within the applied behavior analytic literature include social stories, social scripts, video modeling, discrete trial instruction, task analysis, picture schedules, written schedules, verbal and physical prompting and prompt fading, practice with verbal feedback, and role playing. Do not let the sexual nature of what needs to be taught prevent you from using a teaching method that you know would work.

Unlike programs which target academic, self-management or general social skills, those related to sexuality require a greater level of discretion as to when, where, and by whom these skills should be taught. For example, teaching masturbation skills such as understanding where it is acceptable to do it, defining and setting up private time, and ensuring privacy (e.g., door closed, curtains closed) are more appropriate to be taught at home, not in a classroom. Similarly, practicing a dating script should probably be done one-on-one versus with a group of peers at school. However, ensuring that your son practices personal safety behaviors in a bathroom (e.g., locking a stall door, appropriate behavior for using a urinal) involves skills that can be generalized across all environments.

Although the details of the way ASD presents across individuals vary, social awareness and social skills deficits are core deficits. Difficulties in social knowledge can lead to problems with appropriate sexual expression. We need to teach and practice social skills that are necessary for the individual to engage in appropriate sexual behavior. For some individuals on the spectrum, that might mean teaching such skills as: when and where it is appropriate to remove your clothing, how to appropriately express affection, and when and where it is appropriate to watch adult media. For others, we might focus on teaching the appropriate social skills necessary to navigate a first date, to deal with rejection or to move a romantic relationship to the next level.

Due to possible cognitive deficits, issues with abstract problem solving and attention, and/or a lack of opportunity to practice behaviors related to dating and sexuality, individuals on the spectrum often show deficits in knowledge when
it comes to sexual behavior. If your son portrays knowledge deficits that are leading to safety concerns, sexual frustration, or inappropriate sexual behaviors, design a teaching program to fill in the knowledge gap. For example, repeated touching and rubbing of the genital areas in public is often related to a lack of knowledge of how to actually masturbate to climax. Repeated touching in public is not only a social concern, but can lead to soreness of the genitals over time. Frustration associated with a lack of climax or from being continuously interrupted by others can also lead to problem behavior. As with other tasks, masturbation as a complex skill might need to be broken down into component steps and taught as a task analysis through a picture schedule, written schedule, verbal prompting, video modeling, etc. This would be done simultaneously with a program designed to teach the difference between private and public spaces, redirection to a private space when sexually aroused and response interruption when masturbation is observed in public. If your son is interested in engaging in sexual behavior with a partner, and if it is deemed appropriate for him to be doing so, you might need to teach him the basics of sexual education, such as the mechanics of sexual intercourse and other sexual acts, reproduction and pregnancy, sexually transmitted diseases and illegal sexual behaviors that should be avoided. Often if the learner is at the level of requiring these subjects, they can be introduced through didactic lessons using visual aids (pictures and videos) where needed and an open and honest question and answer session with a nonjudgmental person they trust.

Another important area to focus on is self-protection and personal safety. There are several aspects to consider within this domain and a good place to start is in helping your son identify different types of relationships (e.g., friends, family, acquaintances, strangers) and the types of behaviors that are appropriate within each. Of course there are many complex social rules that come into play here, but again, teaching the basics can go a long way to ensuring personal safety. Targets you would want to teach and practice are:

- body part identification,
- saying “no” to others,
- identifying appropriate and inappropriate touch,
- expressing affection,
- public versus private behaviors and places
- leaving the area when needed,
- accurate reporting to others,
- identifying and avoiding unsafe social-sexual situations and behaviors.

So, in summary, you would want to identify what your son seems to desire as well as what seems to be impeding his success and/or leading to inappropriate expression. You would want to teach him the appropriate social skills and necessary information for him to be socially appropriate, sexually satisfied and physically and emotionally safe. You can always introduce additional skills as he matures and new desires and needs arise. Choose your teaching methods based on the methods that have been successful with your son in the past across other skill areas. Teaching methods should be empirically supported. A Board Certified Behavior Analyst with experience and knowledge in teaching sexuality skills to individuals on the autism spectrum would likely prove beneficial in assisting you in your program development in this area.
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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.

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Thank You!
For many, summertime brings with it happy childhood memories many of which involve ice cream! Thus, it seems very fitting to take this opportunity to express our ongoing and heartfelt appreciation to Kathy and Larry Hannon, owner of Dairy Queen locations in Maine. Through their generous support and the patronage of Dairy Queen customers over the last several years, the Hannons have raised well over $10,000 dollars from donation jars placed on their counters and at their drive-thru window! Pennies DO make dollars!

We believe our readers would be interested in the events that have led up to these tremendous acts of benevolence. Nine years ago, the Hannon’s daughter was diagnosed with autism. The psychologist informed the Hannons that her prognosis was quite poor, and that she may not learn to talk. Fortunately, their daughter was already enrolled in an inclusive preschool with a team of people well versed in Applied Behavior Analysis. Almost immediately, the Hannons observed that their daughter was acquiring important skills and was responding quite well to intervention. In this setting, children with autism received:

- A broad spectrum of effective, behavior analytic teaching techniques;
- Intensive one-on-one instruction;
- Related services by providers committed to collaboration;
- Reverse mainstreaming to provide meaningful and structured opportunities for skills to generalize within interactions with typically developing peers; and
- Carefully planned and delivered shadowing in the classroom.

Discovering www.asatonline.org through their internet research, the Hannons learned more about the science (and lack of science) underlying various intervention options. Against the backdrop of hundreds of treatments with many boasting huge promises, the Hannons were comforted to know that the decisions made for their daughter were not only scientifically sound, but demonstrated best practice.

“I’m a realist- I believe in facts -but sometimes parents don’t know if the information they find online is fact or fiction. This is why ASAT is such an important organization for the autism community.”
- Larry Hannon – 2009
As the years continue to pile on, Larry and Kathy’s commitment to giving back to ASAT has persisted and the Hannons have shared hundreds of business cards, brochures and flyers showcasing ASAT’s resources, such as our newsletter and website.

On a bright note, their daughter has just completed sixth grade and participates in a general education classroom for much of the day. In fact, she received high honors for the last trimester of the school year. She is a good hearted, inquisitive young lady with many gifts including an incredible singing voice. Stay tuned for further updates from this wonderfully supportive and dedicated team from Maine.

In the meantime, for those of you in Maine or traveling to Maine, please stop by the Bangor Mall, Old Town, or Freeport Dairy Queen and let Kathy and Larry Hannon know that you join us in our heartfelt appreciation of all they do to support families, to raise awareness, and to help every person with autism have a greater chance of accessing science-based treatment.

"Hope this article helps at least one family make a good, sound decision on the best proven treatment known. It's a lot of hard work no doubt, but the reward has definitely been all worthwhile and gratifying for sure! Time is of the essence, there is NO time to waste on unproven treatments based on hype, lies, and greed!"

- Larry Hannon 2015

And while you are there, buy yourself a Blizzard. Just because you can!
We’re excited to announce that ASAT is connected with AmazonSmile! AmazonSmile is a simple and automatic way for ASAT readers to support our important work every time you shop, at no cost to you! When you shop at smile.amazon.com, you’ll find the same low prices, great variety and convenient shopping experience you’ve come to know and love on Amazon.com with the added bonus that Amazon will donate 0.5% of every purchase to ASAT.

No sign up is required. Simply go to smile.amazon.com and when asked to “Choose your charity” select, “Association for Science in Autism Treatment Inc.” Bookmark smile.amazon.com on your phone or computer so that each time you shop, Amazon gives!
This section provides family members and professionals who care deeply about those with autism an opportunity to share their perspective about any topic they choose. Whether sharing innovative ideas about the future for people afflicted with autism or presenting challenges that need to be conquered, this section is a platform for members in the autism community to communicate their ideas. Please contact us if you would like to contribute. In this first installment, we focus on employment, and feature Pam Browne from Langley, Canada, who carved out a meaningful and viable job opportunity for her son.

Sabrina Freeman, PhD
Board Member

Franca Pastro, BA
Perspectives Coordinator

Franca: With great excitement, I have the opportunity to interview you, Pam, for the first of a series of interviews in our Lifespan section. One of our goals is to provide encouragement to families and professionals by showcasing passionate, dedicated parents like you who are making employment for their children with autism a reality. To start off, please tell us a little bit about your son, Joseph.

Pam: Joseph is fifteen years old, having been diagnosed with severe autism at the age of three. At that time, we set up a home ABA program for him, and ran it as intensively as we could with the money and resources we had available—when Joe was diagnosed we had four children under the age of five. I think we averaged about 30 hours per week for the first few years. As Joe was getting older, we thought it was time to start considering ideas for some kind of employment for him. We felt that being able to make money of his own would provide him with greater opportunities for independence.

Franca: I know that concerns about the future weigh heavily on the minds of parents who are so actively involved in their children’s intervention. How did Joe, you and your family come to choose self-employment as opposed to “traditional” employment—and why T-shirts?

Pam: We had considered different traditional types of employment, and had listened to other parents speak about what their children had done as adults, but trying to think of a particular job that would work for Joseph was difficult. As he is now, I can’t see Joseph being happy in a typical occupation. I considered ideas that other people talk about, such as brick laying, because he is so orderly. He likes to organize things, but for the most part only when it fits his personal wishes. It is not always easy for him to understand when it is a task set by someone else—especially if the task changes regularly.

When parents have had success with employment situations, they certainly are worth listening to—we don’t have to reinvent the wheel! On one occasion, a mother shared something that stuck with me—she said, in essence, to find something that works for your child, that he is good at and enjoys doing, and then find a way for him to make money at it.

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Because Joseph loves and is able to draw pictures that people find interesting, we thought: “How about a business with his designs featured on T-shirts?” So we decided to try the self-employment option and see how that worked out for him.

Franca: What a great idea! Now, can you share with us how this initial idea evolved into “BroJoe,” the business?

Pam: Around June 2014, we decided to go for it! Joe drew a picture, I found a print shop that would work with us, and away we went. The shirt was of a good quality, and the print very colourful and eye-catching - the whole thing turned out great! We didn’t make a large quantity, as we wanted to see how the whole system worked without spending too much money.

One of the many things we learned through the process of making the shirts is that if the picture is in a Vector based file—and not just drawn on paper —it would save time and money during the set up. We hired an amazing Behavior Interventionist (BI), Amanda, to teach Joe how to draw in a Vector file. This is not an easy concept to learn, however because Amanda has a very strong background in ABA, she conducted her sessions in a systematic way, providing Joe lots of reinforcement as Joe was learning new skills. The beginning was a little challenging, but once Joe figured out what he could do with the end result, he loved it! This was a real eye-opening experience for us. I have to say, I don’t think I have ever seen Joe so interested and engaged in anything.

The next step was to register Joe’s business. The registering part was easy; the hard part was trying to figure out what umbrella to put the business under—sole proprietorship, partnership or limited company—and the implications for Joe as well as tax considerations were all very confusing. We made our decision, did a name search, chose a name and moved forward.

In December 2014, I received an email from Autism Support Network (ASN), a non-profit parent-run organization active in our area, stating that they were going to have a Christmas party and would be selling some goods with proceeds going to ASN. I contacted Dione Costanzo, ASN Director, to ask if they would consider selling Joe’s T-shirts at the party, with the commitment to donate some of the profits to their group. Dione agreed to it, and the sale was very successful.

A few weeks later, Dione contacted me with the news she had been approached by three university students who wanted to support autism in some way for their final business project, T2Unlock. The students thought it would be a great idea to sell Joe’s T-shirts and she said they would welcome Joe’s involvement. We were delighted about the opportunity: Joe took the students’ ideas, turned them into creative drawings, and we ended up with a very saleable product. The students then successfully sold the T-shirts, bringing awareness to autism, ASN and also of course to Joe’s fledgling T-shirt business!

We then decided that we needed a way to promote Joe’s business ourselves, so we created a Facebook page called “BroJoeCo” with Amanda’s help. Amanda is teaching me how to monitor and post things to the site - this is a new experience for me! As well, she is showing me how to read the data to see what people are interested in or not. Our next step will be to set up a format so that people can view and purchase the T-shirts directly through the Facebook site. Now, Joe has many Facebook followers, and people talking about him and his designs. This, in turn, could lead to a significant increase in social interaction for him and possibly opportunities to develop new friendships. We have also cre-

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Franca: This is truly an exciting story. How would you describe Joe’s take on his BroJoe T-shirt business?

Pam: Joe has not had a lot of input into the “business” side itself, in a traditional way, as comprehension and ability to express his thoughts are at times challenging for him. I do know that he likes creating T-shirts because he tells me he wants to make more. When he draws things now, it is with the intention of putting it on a T-shirt. Joe enjoys seeing people wearing his shirts and is eager to come up with additional designs. I told him that we would have to sell all of the shirts before we could produce new ones. So one day I found the remainder of the shirts in the garbage can! I laughed as I thought this was very clever; if the shirts were gone, Joe obviously figured out, he could make more. Seeing how happy Joseph is in the creation process is what motivates all of us to want to build his business. Like many of us, Joe has found a job that not only pays him, but also one he greatly enjoys.

Franca: What resources have you used and are you currently using for Joe’s business? Have you heard of job training/coaching or supported employment programs in your community?

Pam: I found very few, if any, resources to help us set up the business, and I have not heard of employment programs for persons with special needs in our area. I don’t feel I have access to tools to help Joe with his employment skills. Resources are scarce for teenagers and adults with autism, and even scarcer for creating entrepreneurial employment opportunities. Equally frustrating is the lack of information sharing and difficulty in accessing the few programs available out there.

What I think would have made it easier would have been a better system of pre-vocational and vocational education and training for children, teens and young adults: a system that recognizes the benefits of ABA for individuals of all ages, maintains adequate financial support past the age of six, and provides a place where a family can know that all of the staff were qualified under the same ABA training, held to the same standards, and professionally supervised. In other words, parents should not have to weed through all the garbage out there to obtain what should be readily available and effective. Families should be able to have access to quality trained providers - and lots of them!

Franca: Looking back, did you ever expect your son to be able to consider such an enterprise?

Pam: I knew he could do something. Even as challenged as Joe is, he is still very smart in many ways; he just thinks differently. Things important to him are not necessarily important to typically developing individuals. Once you can really understand that concept, you can see the potential in all people with autism. It doesn’t mean that it’s not still frustrating, as we do live in a typical world and need to find a way to participate and adapt to it, whether we want to or not.

My thoughts are that, with the direction we have gone, a possibility in the future for Joe could be the field of animation. I think he would find it fascinating if he could make his characters move about—I have discussed this

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with Amanda, and she is looking into ideas. I have a daughter who is interested in animation as well, so it would be great if they could work together.

Regardless, we have learned so much and Joe has really enjoyed seeing people wear his designs. It shows us that he has the ability to do something really great and different.

Franca: Do you have any advice for other parents of young adults with autism who are thinking about their future?

Pam: I have been very blessed to meet some amazing people on this journey: our Lovaas replica site trained ABA Consultant, Michele Shilvock, our many BIs and all the many wonderful other parents who were willing to share their stories, experiences and friendship. ABA has been huge in Joe’s ability “to be Joe” and to develop to his full potential.

I would like to offer one bit of advice—something from Shelley Davis, guest speaker at the very first FEAT of BC conference I attended. At that time, Joe had not yet been diagnosed, but I wanted to know what ABA was all about. What Shelley said that was impactful was, “Get them out there!” — meaning, get your kid out into society; they can’t learn to be a part of it if they are not in it. Much of what we have done for our children may have begun at a therapy table, but the ultimate goal is generalization of important skills to real world settings - otherwise, what’s the point?

Franca: Can you describe specific skills that Joe has learned through his ABA training that have helped “Joe’s ability to be Joe” as you mentioned earlier?

Pam: We were fortunate to have found an evidence-based method of teaching for Joe at a young age and have seen how it has benefited his quality of life at school, with peers, in his home, with his family, his community and now with his employment. He has learned to read at a basic level and develop some math skills. He is able to go places with friends, share and participate—he has a great personality. Communication is still challenging for him, but because of behavioral therapy, it has improved significantly. ABA has taught him the skills to participate in his community and school, such as the ability to take turns, wait and transition. He is learning to control his verbal self-stimulatory behaviors, so he is less distracted and can pay attention. All of these skills that he has acquired through behavioral programming have been crucial in his path towards employment potential.

What is frustrating, though, is that I have had to direct Joe’s instruction on my own, rather than being able to access a centre-based program with trained individuals already in place. I had to create the team much like I did when Joe was first diagnosed at three, except this time his team is focused on employment.

With much work on my part as a coordinator, along with a team of individuals skilled in the principles of behavior analysis, Joseph has been able to turn an interest into a form of employment. His is a success story which I hope will encourage other families with individuals on the autism spectrum.

Franca: Thank you, Pam, for sharing your experiences regarding Joe’s business.

Pamela Browne is the mother of four children ranging from 13 to 16 - two are identical twins and her middle son, Joseph, has the diagnosis of autism spectrum disorder. Pam has been coordinating an Applied Behavior Analysis (ABA) program for the last 12 years. Pam, the kids, and her husband live in Langley, British Columbia, Canada.

To learn more about BroJoe:
www.facebook.com/Brojoeeco

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What I think would have made it easier would have been a better system of pre-vocational and vocational education and training for children, teens and young adults: a system that recognizes the benefits of ABA for individuals of all ages, maintains adequate financial support past the age of six, and provides a place where a family can know that all of the staff were qualified under the same ABA training, held to the same standards, and professionally supervised.”
In this letter Dr. Brown certainly makes some salient points showing that if advocacy is consistent, persistent and in sufficient numbers, politicians will listen and changes can be made for the better. We should never waiver in our commitment to make ABA universally available.

Franca Pastro, BA
Perspectives Coordinator

Dear Neighbours to the South,

First, an admission. We often walk around up here, north of the 49th parallel, with puffed out chests when comparing our universal and publicly funded health care system to your system. We may even sneer a little, “Can you imagine having to live in the US. where a private health insurance company dictates decisions about your health? Your child’s health?” When I began my postdoctoral fellowship in 2012 in San Francisco I certainly arrived at the airport full of this brand of arrogance. This was before my child’s autism diagnosis. This was before I realized how having a child with a disability could change everything you thought you once knew.

Indeed, when we became increasingly concerned about our son’s development my first instinct was to race back home to the supposedly safe haven of Canadian healthcare. My arrogance and ignorance would end up costing us all dearly. Because much to my surprise health insurance in Canada does not cover ABA treatment for children with autism. Despite decades of research that have demonstrated ABA as a highly effective treatment intervention in reducing or eliminating symptoms of autism and yielding improvements in behaviour, communication, and social skills, Canadian governments do not see it as “medically necessary”. Some provinces provide partial coverage, but it varies widely and treatment waitlists can be as long as four years.

Now, I know you have serious challenges with HMOs and private health insurance- I do not wish to dispute or minimize this. However, from one neighbour to another, I want you to take a moment to congratulate yourselves for your hard won successes of having 41 of 50 states who have enacted insurance reform laws to mandate coverage for applied behavior analysis (ABA) treatment for children with autism spectrum disorders. By mandating coverage for ABA, state legislators have recognized and enshrined your children’s rights to medically necessary treatment.

These state legislators, however, have largely come to this conclusion through sustained advocacy of parents like yourselves, and in particular through the efforts of Autism Votes. With 1 in 68 children in the US now diagnosed (we suspect autism prevalence is similar in Canada, but we have NO national autism surveillance program so we’re basically guessing), Autism Votes harnesses the power in numbers of voters in states (and Federally) to lobby and advo-
catalyst for insurance reform, new legislation (the ABLE Act, for example) and other state and federal initiatives benefitting families and individuals with autism.

You should be very proud of this, of Autism Votes, and of your state legislators who took seriously the very real threat of a large cohort of voters who presented them with a reform agenda. They listened this time. You have 8 states remaining (as of May 6, Hawaii is poised to become the 42nd state to pass insurance reform), but even when these states sign on, and I hope they will, the one thing I have learned in the short two years since my son’s diagnosis is that advocacy is chronic. None of us live in the kind of society yet that treats our children with the respect, support, and justice to which they are all entitled.

A group of parents in Canada took their complaint regarding the absence of insurance coverage for ABA to the Supreme Court of Canada in 2004, and the Court ruled that while ABA was a "medically necessary" treatment, the Court was not in a position to compel the Government to pay for it. So, Canadian parents are now left to learn from and emulate your successful advocacy efforts; we must compel legislators to change the law (the Canada Health Act) to include ABA treatment for individuals with autism.

I am a proud Canadian, but this pride will never override my love and concern for my disabled child. I wish we had stayed in California. I wish I didn’t have to fight this fight. I wish I could simply parent my child with the knowledge that his disability is well supported with effective treatment interventions. Raising a disabled child is difficult enough without having to assume another full-time job of chronic advocacy. But you, dear neighbours to the south, have shown me change is possible, and for that I thank you from the bottom of my heart. Thank you for renewing and sustaining my hopes for a better future for our children.

Love,
One Canadian Autism Mom

Quinn, Dr. Brown’s 5-year-old son

(Continued from page 28)

Dr. Brown is a lecturer at Simon Fraser University with research interests and experience in the politics of access to health care and treatment. She is the mom to five year old Quinn, a nonverbal 5 year old boy with autism spectrum disorder.
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**Autism New Jersey**

Well known for its commitment to evidence-based practices, Autism New Jersey leads the way to lifelong individualized services provided with skill and compassion. They recognize the autism community’s many contributions to society and work to enhance their resilience, abilities, and quality of life. In 1965, a group of concerned parents, frustrated by a lack of programs and support from their local school districts, met to discuss ways to support their children and each other. This nonprofit membership organization underwent a few name changes over the years and was most recently known as COSAC (Center for Outreach and Services for the Autism Community). For 50 years, the agency has supported the expanding needs of individuals with autism, the professionals who work with them, and the families who love them. Autism New Jersey continues to serve as a collective and influential voice for the community. As the agency’s vision statement makes clear, “We are GROUNDED in science, STRENGTHENED by knowledge and DEVOTED to creating a society of compassion and inclusion for all those touched by autism.”

Autism New Jersey is committed to four service pillars. Individuals outside of New Jersey are welcome to access any of these services as well.

**Information Services**: New Jersey’s most valued and reliable resource for referrals, services, and the latest information about autism includes the toll-free Helpline, **800.4.AUTISM** and informative website, [autismnj.org](http://autismnj.org). Individuals, families, and professionals from other states are also welcome to these free resources, including specialized publications. Whether seeking information on early intervention, special education, state-funded services, adult issues, insurance coverage, treatment options, and so much more, compassionate and knowledgeable staff are ready to provide specific, research-based information.

**Education & Training**: Autism New Jersey provides evidence-based information to families and professionals on several levels, including the well-respected Annual Autism Conference in October and unique Transition Conference in April. Trainings are also provided for families, partners in the state service delivery systems, schools, agencies, and other community professionals. Both advocacy and clinical topics are offered.
(Continued from page 30)

**Awareness:** Autism New Jersey strives to enhance public understanding of individuals with autism through the popular Autism Awareness Ambassador Program during the month of April. This year, more than 1,200 Ambassadors received a kit of tips and tools for building awareness of not just autism but evidence-based practices and available resources. An active social media presence maintains this focus year-round.

**Public Policy:** Autism New Jersey serves as a strong voice in Trenton, working to advance initiatives addressing topics across the lifespan such as increasing access to and funding for high-quality educational, behavioral, and residential services. Legislators and their staff often turn to Autism New Jersey and recommend its services to their constituents throughout the state. Regular communication and collaboration takes place with the Departments of Children and Families, Human Services, Health, Education, Banking and Insurance, and more. Along with adult services, the current focus is on recognition for the BACB credentials across all departments to address provider qualifications and thereby increase access to high-quality services for individuals with autism.

For further information, please visit [autismnj.org](http://autismnj.org) or contact 800.4.AUTISM.

### Little Star Center

**Mission:** The mission of Little Star Center, Inc. is to provide a structured, child-friendly facility where children with autism receive individualized therapeutic intervention. Based on the fundamental principles of applied behavior analysis (ABA), Little Star provides an atmosphere where children, therapists, and families can interact, support each other and receive ongoing training so that each child can reach his or her full potential at home and in a variety of settings outside of therapy.

**History:** Started in Carmel, Indiana, Little Star Center is a non-profit organization founded in 2002 to serve the needs of children and families affected by autism. A pioneer in the state of Indiana, our state-of-the-art facility offers an environment where children receive individual intervention based on the fundamental principles of Applied Behavior Analysis (ABA) and Verbal Behavior. Families are provided the support they need to face the challenges of autism and become integral partners in their child’s success.

Little Star Center’s commitment to science-based treatment was evident from the very beginning. Steele and Amy Gudal faced many challenges with their daughter, Gentry, who was diagnosed with autism in 2001. They had done everything they were told to do – First Steps, private speech, and occupational therapy, the school district’s developmental pre-school program, but still found that Gentry struggled and made limited progress. After much research, the Gudals found the treatment their daughter needed – Applied Behavior Analysis. ABA was (and still is) the only treatment for autism endorsed by the American Surgeon General and considered to be the best researched treatment by the American Academy of Pediatrics. However, the closest treatment facility was five states away – there were none in Indiana. Undaunted, the Gudals (Continued on page 32)
founded Little Star Center for their Gentry and for other families who needed the same intensive, medically necessary treatment for their children. The Gudals created a center model so unique that families from Florida, Ohio, Sri Lanka, Massachusetts and California have come to obtain services at Little Star.

Tragically, in the spring of 2006, Steele Gudal was killed in a small plane crash. Jim DeVoe, Steele’s father-in-law (and Amy’s dad), was also killed. The contributions these two men made to all Hoosier families affected by autism will never be forgotten and remain a significant inspiration for those committed to continuing their important work Little Star Center opened its second location in Lafayette, Indiana in March of 2011. Today, Little Star has over 100 employees working toward the success of its clients and is continuing to grow to meet the needs of even more children. Through this growth, however, Little Star has kept its core mission as its top priority. Little Star Center provides year round therapeutic intervention and various other programs for children with autism based on the science of ABA.

Since its inception, Little Star has become a shining example of a grass-roots effort. Each year Little Star serves more children and families and offers support to the Indiana autism community. Little Star Center celebrated its 11th anniversary in September, 2013 as well as hit the million-dollar mark in services that were provided to families at no charge. In August of 2011, Little Star Center was named the 2011 Excellence in Direct Care award winner by the Autism Society of Indiana. Little Star is the first and only center to win this title. LSC is currently in the process of opening a center in Bloomington, Indiana, expected to open in 2014.

**LSC Programs:** LSC is comprised of three distinct programs each targeting a specific age range. The Early Learner Program (ELP) serves individuals <5, LSC ages 5-12, Middle Star Center (MSC) ages > 12.

- Full day, part day or braided school/center/home programs (i.e., components remain distinct)
- 12 month program
- Center, Community and Home-Based, tailored to meet the needs of each learner
- 1:1 intensive therapy provided by trained ABA therapists
- Group-based instruction
- Baseline assessment of skills
- Individualized programming developed and monitored by a BCBA
- Fully staffed training department to develop and maintain skills for both BCBAs and ABA therapists
- Natural environment, incidental teaching, and discrete trial instruction
- Verbal behavior

(Continued from page 31)

(Continued on page 33)
Monarch House

Within Canada, understanding the dramatic gaps in treatment delivery to children and youth with ASD and developmental delays was the catalyst that led to opening the first Monarch House centre in Vancouver, BC in 2009. Since that time the integrated treatment service model has been expanded to seven sites in British Columbia and a new state-of-the-art facility near Toronto, Ontario.

CBI Health Group, the parent company of Monarch House, recognized that families needed help identifying and assembling the array of clinical specialists their child might require, navigating daunting funding and logistical challenges, and, importantly, finding a connection with other families. Thus, Monarch House was developed to be a network of interdisciplinary clinical experts, a place for coordinated treatment, an access point for parents to obtain critical information, and an innovative healthcare organization engaged in applied research and dedicated to the advancement of best practices. Monarch House offers effective treatment for individuals requiring services in the areas of challenging behaviour, communication, motor skills, and learning. These services may be provided in the community, the home, or in one of our state-of-the-art facilities in British Columbia and Ontario.

Monarch House provides the following services and programs:

- Assessment and Diagnosis: Individual assessments and group screenings are offered by experienced clinicians for communication, learning, motor skills, and behavior concerns. Diagnostic services are provided by qualified professionals (e.g., Paediatrician, Psychologist) to identify medical or psychological conditions or disorders and to recommend appropriate treatment avenues.
· Speech-Language Pathology: Assessment and treatment of speech, language, communication, and social skills concerns are provided by a qualified SLP or a Communications Disorders Assistant (where appropriate). Our speech and language team follows best practice guidelines where intervention goals are individually developed, progress against goals is consistently measured, and outcomes are shared with parents on a regular basis.

· Occupational Therapy: Occupational therapists assist children to develop their independence in activities that are important and meaningful to their daily lives. Our OTs provide assessments and specialized programming in the areas of self-care, sensory-based issues, gross and fine motor skills, and play skills.

· Intensive Behaviour Intervention (IBI): We offer intensive (10 or more hours per week) Applied Behaviour Analysis (ABA) within an interdisciplinary approach. The ABA services are overseen by a Board Certified Behavior Analyst (BCBA) with additional consultation from a Speech-Language Pathologist (SLP) and Occupational Therapist (OT). BCBAs are educated and experienced in the scientific study of learning and behaviour. They develop and monitor intensive ABA programs carried out by frontline therapists/Registered Behavior Technicians (RBT). They may also consult to family members or other professionals to address behaviour challenges that may range from toileting and parenting skills to extreme problem behaviour.

· Afterschool and Recreational Programs: We offer a wide range of individual and group programs for clients and their family members to provide social opportunities, new skill building activities (e.g., karate), or give family members a chance to reconnect with each other (e.g., child drop off for parents to have a night out).

· Summer Camp Programs

· Research Studies

· Student Practicum/Placement site

For more information, please visit www.cbi.ca/web/monarchhouse

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

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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 2015 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 2015 Sponsor Now!

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

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

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

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It was pleasure to talk with Dr. Eitan Eldar, PhD, BCBA-D, Chairperson of the Israeli Applied Behavior Analysis Association and Director of the Applied Behavior Analysis Certification Program at Kibbutzim College, Israel. He has done so much for the field not only in Israel, but internationally too.

Daniela Fazzio, PhD, BCBA-D
SIAT Co-Editor

Daniela: Dr. Eldar, please tell us about your background and how you became a behavior analyst.

Dr. Eldar: I came from the sports world. While working with physical education, I realized that through sport and movement I could do clinical and pedagogical work. I then looked for a psychological model or approach that would fit my interests and goals, and found behavior analysis. I then received my PhD at Ohio State where I came in contact with Cooper, Heron, and Heward, and connected physical education with applied behavior analysis. In the late 1980s, I returned to Israel and started the first academic training program in behavior analysis in 1990, at the Physical Education College at the Wing Institute.

Daniela: What is autism diagnosis and treatment like in Israel?

Dr. Eldar: We have leading experts advanced in diagnostics, and well acquainted with assessment tools; the Israeli system is very sensitive. Staff in our hospitals who see children for routine check-ups are trained to spot any red flags; consequently, children are diagnosed early. Parents and clinicians are aware of signs and symptoms, and the experts are familiar with ABA and recommend behavioral intervention as the first choice of treatment.

Daniela Fazzio: How are diagnosis and treatment funded?

Dr. Eldar: There is governmental support offered by several offices such as the Ministries of Education, Health and Social Affairs and Social Services. Support should be available through health care coverage, yet most families still find themselves supporting the home/school programs substantially. There is a pending law proposed which deals with services and support to autistic populations.

Daniela: How has autism treatment changed in your country during the course of your career?

Dr. Eldar: It has changed dramatically as a result of the hard work of professionals who recognize and promote behavior analysis as first choice of intervention. The first steps were done by parents who were exposed to ABA effectiveness and spread the word to parent groups, and to the educational and clinical systems. Twenty five years ago, there were only a few behavior analysts in Israel and, as of June 7, there are 88 of them

(Continued on page 38)
listed in the Behavior Analyst Certification Board’s registry. These articles, Eldar, Talmor, and Dayan – Romem, 2009; Eldar, Talmor, and Wolf-Zukerman, 2010, identify some important steps I believe have contributed, and will contribute further, to the practice of applied behavior analysis. Examples include: specific training for support staff, educators, parents, peers and other decision makers, and an evidenced based model for inclusion.

Daniela: In the US there is a gap between available services for young children and support to adults on the autism spectrum once they no longer qualify for special education. How is Israel responding to the demands for continuation of services into adulthood?

Dr. Eldar: The Ministry of Social Affairs and Social Services supports a wide variety of activities such as individual support, social and vocational activities and more for adults on the autism spectrum living either at home or in a group home.

Daniela: Are there organizations that promote applied behavior analysis? How about organizations like ASAT?

Dr. Eldar: Parents are the greatest supporters and they organize to recruit public funding to operate behavioral programs for children with autism. They also work actively to propose laws. One such organization is The Israeli Society for Autistic Children, ALUT (www.alutfriends.org). They worked to implement a special education law, which was approved in 1998.

Daniela: Is there an ABAI Chapter in your region?

Dr. Eldar: Yes, in 2003, the Israeli Association for Behavior Analysis, IABA was established. We have 180 members and hold conferences and workshops every year. Our association strongly supports the dissemination of ABA in Israel, connected to government offices as well as to educational institutions. We publish a newsletter in Hebrew, allowing professionals to be updated in their native language. We also offer a few academic conventions every year, inviting leading experts from Israel and other countries to share their knowledge. Continuing Education credit is offered at all of these events. This is a great time for behavior analysis in Israel! The dissemination strategy we have implemented has been based on broadening the clinical foundation and adoption of behavior analysis in the education and health arena. At this point, there are hundreds of behavior analysts providing services to institutions and families while disseminating ABA among decision makers.

Daniela: You are also the Head of the Applied Behavior Analysis Certification Program at Kibbutzim College. Could you tell us about the program?

Dr. Eldar: The program has prepared hundreds of behavior analysts since 1990. It has been approved by the BACB for BCaBAs and BCbBAs, including practicum courses. Besides the practicum, the two-year program includes 16 courses which present Applied Behavior Analysis in different contexts. Currently, there are 140 students enrolled in the programs with over 10 staff members.
Daniela: You were involved in establishing a behavioral treatment center in China. How did that come about and how was your experience?

Dr. Eldar: My involvement with the Wucaiulu center in Beijing started following the 2005 ABAI conference held in that city. For six years, I served as their clinical director, developing a comprehensive clinical and data collection program, based on Applied Behavior Analysis principles and procedures. During this time period (there were 16 students at the beginning), the center expanded to three other locations in Beijing serving over 200 students.

Dr. Eldar, representing ASAT, I thank you sincerely for taking the time to share information about your professional career and ABA treatment for autism in Israel. I was delighted to hear about your experience and the support for science in autism treatment you describe exists in Israel.

For more information about Dr. Eldar:

★ www.eitaneldar.com
★ http://www.iaba.co.il/
★ http://www.smkb.ac.il/continuing-edu-program/applied-behavior-analysis

References:


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PLAY Project Home Consultation Intervention Program for Young Children with Autism Spectrum Disorders: A Randomized Control Trial


Reviewed by Antonia R. Giannakakos, Caldwell University

Why this topic?

Many children with ASD have difficulty in the area of social communication. Previous research has shown that early intensive intervention is effective in improving outcomes and decreasing skill deficits in this area. Intensive intervention can be very costly and there may be a shortage of trained personal to administer treatment. The authors suggest that a parent-mediated intervention may provide a more affordable alternative.

What did the researchers do?

The present study was a randomized clinical trial (RCT) that evaluated the effects of the Play and Language for Autistic Youngsters (PLAY) Project Home Consultation program in combination with usual community services (CS) as compared to CS services only. PLAY is based on Greenspan and Wieder’s developmental, individual-difference, relationship (DIR) model, commonly called Floortime. One hundred and twenty-eight families with children ages 3-5 participated in the study. The children were randomly placed in either a group that received CS only or a group that received PLAY+ CS. In the PLAY + CS group, consultants trained in the PLAY program provided each parent with training on how to play one-on-one with their child and provide appropriate developmental challenges. In the CS group children received special education public school services. Assessments were conducted before and after treatment, on parent stress and depression, parent-child interactions, and each child’s social and communication behaviors. The results of these assessments were used to evaluate if changes occurred in the communication and social skills of the children in each group.

What did the researchers find?

Overall 54.3% of children in the PLAY + CS group and 32.6 % of children in the CS only group showed improvement in social and communication skills according to the ADOS-G (Autism Diagnostic Observation Schedule – Generic; Lord, Rutter, & LeCouteur, 1995). The ADOS-G is a standardized test that assesses social and communication (Continued on page 42)
skills. The remaining children in each group showed either no change in social and communication skills or a decline (CS-5%, PLAY-4%). The PLAY + CS group also showed larger improvements than the CS group on behavior observations of parent-child interaction, but not on standardized tests of cognitive or language skills. The parent measures indicated that parental stress and depression reduced over time regardless of what treatment their child received.

What were the strengths and limitations of the study?

One strength of this research was the use of a standardized assessment for measuring the effects of the PLAY + CS or CS alone on the social and communication skills of the children in the study. The use of these measurements administered by outside practitioners provides a more objective measure of the children’s skills. A significant limitation is that children in the PLAY+ CS group received an average of 732 hours of intervention during the course of the study as opposed to children in the CS group who received only 101.87 hours. This biases the results toward the intervention with most hours, preventing a conclusion that PLAY + CS is really more effective than CS only. Another limitation is that the authors did not provide enough detail on the components of the PLAY program to allow full evaluation of its procedures, and a written manual of the program has not been developed.

What do the results mean?

This is the third RCT to show benefits from parent training in DIR. The first two studies were pilot studies (see http://www.asatonline.org/for-parents/learn-more-about-specific-treatments/developmentally-based-individual-difference-relationship-based-intervention-dirfloor-time/). The current study is a larger, more definitive test and indicates that more children in the PLAY + CS group showed improvement in their social and communication skills than in the CS only group. However, the study is limited by the absence of detail about the intervention and the much larger number of treatment hours given to the PLAY + CS than to the CS group. Based on the available research, parent training in DIR may be considered possibly efficacious, but additional research is still needed to draw clear conclusions about this intervention.

Reference

News articles abound about autism and individuals who claim a given therapy has “cured,” or otherwise improved deficits of children diagnosed with autism. Our Media Watch initiative provides guidelines to help journalists think about their stories from a science-minded perspective, as well as written feedback to journalists and editors about their presentation of autism and autism treatment in the media. You can access over 100 letters written by ASAT board members and collaborators on our website. Below, we summarized the latest ones.

Barbara Jamison, BA, Parent Board Member
Media Watch Coordinator

ASAT responds to:

- **Abc.net.au’s “Horses, scientists and the search for effective autism treatment”** (February 4, 2015): The research tells us that discovering a child’s interests and aligning learning opportunities with activities that a child enjoys can have robust outcomes, but does this establish riding a horse as a scientifically validated, effective intervention? [http://www.asatonline.org/media-watch/asat-responds-to-abc-net-aus-horses-scientists-and-the-search-for-effective-autism-treatment/](http://www.asatonline.org/media-watch/asat-responds-to-abc-net-aus-horses-scientists-and-the-search-for-effective-autism-treatment/)


- **ConsumerAffairs.com’s “Psychologists say discredited autism therapies still being practiced”** (April 2, 2015): As a result of the difficulties involved in treating ASD, pseudoscientific methods such as FC have been too quickly adopted by professionals, too sensationalized by the media, and too quickly embraced by consumers. [http://www.asatonline.org/media-watch/asat-responds-to-consumeraffairs-coms-psychologists-say-discredited-autism-therapies-still-being-practiced/](http://www.asatonline.org/media-watch/asat-responds-to-consumeraffairs-coms-psychologists-say-discredited-autism-therapies-still-being-practiced/)

- **Psychologytoday.com’s “NJ’s I/DD community strongly opposes the state’s transition plan: now what?”** (April 15, 2015): It is critically important to recognize that all developmental disabilities, including autism, exist on a wide continuum of severity, and unfortunately, individuals with more severe impairments and behavioral challenges have a strong likelihood of falling through the cracks of this new plan. [http://www.asatonline.org/media-watch/asat-responds-to-psychologytoday-coms-njs-idd-community-strongly-opposes-the-states-transition-plan-now-what/](http://www.asatonline.org/media-watch/asat-responds-to-psychologytoday-coms-njs-idd-community-strongly-opposes-the-states-transition-plan-now-what/)


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**SCIENCE IN AUTISM TREATMENT TEAM**

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**Clinical Corner**

Nicole Pearson, PsyD, BCBA-D
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