



Science in Autism Treatment

Newsletter of the Association for Science in Autism Treatment

Volume 13, Issue 2 | Spring 2016

Welcome to the Spring 2016 issue of Science in Autism Treatment. SIAT is the Association for Science in Autism Treatment's quarterly newsletter, now reaching 12,500 subscribers worldwide with each issue. Autism Awareness Month is behind us, but we are here 24/7 working toward our goal to *promote safe, effective, science-based treatments for people with autism by disseminating accurate, timely, and scientifically sound information, advocating for the use of scientific methods to guide treatment, and combating unsubstantiated, inaccurate and false information about autism and its treatment.* The blue puzzle pieces will disappear from Facebook pages and billboards, the media will focus their attention on other topics of interest, and we will return to business as usual. As our Executive Director says in his blog post, [<http://blog.difflearn.com/2016/04/01/10-things-autism-awareness-should-be-about-by-david-celiberti-phd-bcba-d/>], "business as usual is not OK." Pseudoscience is still pervasive and a serious obstacle ahead of those seeking effective treatment. We are committed to helping individuals, families and professionals arrive at scientific information as quickly as possible, and avoid wasting time and resources with unproven, and sadly often dangerous *therapies*, and SIAT is an effective way to do that! Will you help us by sending an invite to your friends, family, and colleagues? With a simple click you can share our subscription page on [Facebook](#), [LinkedIn](#), [Twitter](#), or [Pinterest](#). Below is the Table of Contents of another wonderful issue. As always, we look forward to your comments; please write to us at newsletter@asatonline.org.

Warmest regards,

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

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PERSPECTIVES

Interviews with:

Barbara McLeod, Mom of Alex, from The Canine Kitchen Co.

&

Alexandra Penzi, Sibling of Christopher and Advocate of Autism Awareness

In this issue we present two interviews. The first is with Barbara McLeod. She shares the successes of her son, Alex, in both employment and community inclusion, and tells us about his business, The Canine Kitchen Co.

The second is with Alexandra Penzi. She gives us a wonderful example of how the sister of a young man with autism has immersed herself into his world to create positive outcomes.

Franca Pastro, BA
Perspectives Coordinator

INTERVIEW

Barbara McLeod, Mom of Alex, from The Canine Kitchen Co.

Franca Pastro, BA

Franca: Tell us a bit about your youngest son, Alex.

Barbara: Alex is an active, happy 22-year-old young man whose life is severely impacted by his autism, which includes significant communication deficit, an intellectual disability, and seizure disorder. He was diagnosed with autism on his 2nd birthday and started receiving intensive Applied Behaviour Analysis (ABA) therapy at three years four months. Alex is a gentle, easy-going soul. He wants to please and is happy when he knows you are happy. Positive comments or cheers for a song well played or a lap well swum will always get a smile from him. He loves to play Happy Birthday on the piano for friends or family. He relies on order and schedules to understand what is happening in his day and to complete many tasks. He always makes his bed, quickly grabs a dishcloth if someone is washing

the dishes, and always puts things back in their place. He has been known to take a product out of a customer's buggy or hands at Home Hardware to put it back on the shelf (oops!).

Franca: Sounds like a great young man! When did you start thinking about employment for him?

Barbara: Pre-employment skill-development has been part of Alex's Three Year Goals and IEPs since he was 10 years old. He began participating in work experience opportunities in his grade 10 year. In 2010, we participated in an exercise called "A Day in the Life of Alex 2016." We used this exercise to start transition planning for Alex and employment was an important part of that exercise. We asked each of our team members to write up their ideas/hopes of what an ideal day in

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his adult life might look like. My husband, David, and I did the same. Our consultant and we used the ideas to identify skills he would need to learn in order to lead a positive, productive life. It was a brilliant activity. I remember one of our team members, when we were looking at the results, saying, "We have a lot of work to do!"

Franca: You have certainly dedicated years of preparation for employment for Alex and I understand that he is engaged in various types of employment. Can you share how this came about?

Barbara: In looking at employment options for Alex, we looked for jobs that he would do well - that had a specific list of tasks we could teach him with a check list and then fade ourselves from the process. He had work experience opportunities while at school as part of a work experience program. After he left school, two of them resulted in post graduation employment positions - one paid and one as a volunteer. He is currently a paid employee at our local Home Hardware stocking liquids one day and one evening a week. Also, he volunteers at Community Lunches one morning a week where he sets up the hall for the lunches.

After graduation, our family started a micro-business for him, The Canine Kitchen Co. This employment opportunity generates some income to help offset support costs.

Franca: Does Alex enjoy his work?

Barbara: Alex has very little language; he doesn't articulate whether he likes or doesn't like



Alex preparing Canine Kitchen dog treats

his work. He does all three jobs very successfully and cooperatively. He knows exactly what is expected of him and works consistently at each of them until the jobs are complete. He is happy that others are pleased with the job he does. He is always content and ready to go to work. We believe working

allows others to see Alex's abilities, not just his disabilities. It contributes to a life of dignity, purpose and options.

Franca: Can you share with us how the initial idea of The Canine Kitchen Co. evolved?

Barbara: Our team brainstormed a number of different micro-business options. The idea of the pet treat business came from one of Alex's ABA therapists, Carla. She had a new puppy and talked about how much people spend on their dogs and how important pure, local and healthy food is to pet owners. We started with dehydrated beef liver, chicken and yam chips. Carla was committed to making the project work; she and Alex's dad, David, approached local stores, decided on the products, researched packaging ideas, generated name ideas and chose our logo. David took the lead on packaging and labels, buying equipment, working on sample product and interacting with businesses. Alex's uncle put together the website www.thecaninekitchen.net. At this point, we are purposefully keeping his business manageable by supplying three local stores only, but that could change over time.

Franca: How involved is Alex in his pet treats business?

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Barbara: Because of his intellectual disability and limited communication skills, Alex has little involvement in decisions about his micro-business. For safety reasons, he requires substituted judgment with some of the tasks. What I love about the business, however, is that Alex is able to complete 75-80% of the tasks independently. He doesn't operate the meat slicer or make the final decision about doneness. Interacting with the businesses about ordering, preparing the invoices (yet) or managing the accounts, is done by others. He does, however, load the dehydrator trays, load the dehydrator, turn on the machine,



Alex working at Home Hardware

put the labels on the packages, package the products, seal them and make the deliveries with his dad or with me. When asked about it, he says he is taking Pet Treats to Bosley's. When asked why, he tells me "Business." :)

Franca: What resources have you used or are currently using for Alex's business? Were you able to access any job training/coaching or supported employment programs in your community?

Barbara: Alex requires specific and full-time job coaching / support. That isn't automatically available to him. I did meet with the Career Centre folks in our area and Alex was put on a wait

list for services. We were offered the possibility of half-salary for a three-month training contract if we found a place of employment that would take him on. We haven't pursued that option as yet. Finding employment options has been our responsibility.

Franca: Can you describe specific skills that Alex has learned through his ABA therapy that have aided in his preparation for employment?

Barbara: We feel everything Alex is able to do is the result of his ABA program. This is true for his regular and volunteer employment as well as his micro-business. Some examples would be:

- Demonstrating compliance / instructional control
- Referencing skills
- Following a checklist
- Learning routines
- Completing tasks
- Responding to reinforcement
- Following a schedule

One thing we have learned on this ABA journey is that Alex is able to learn almost anything that we are able and willing to teach him. Our challenge is finding the folks to support him at whatever he undertakes.

Franca: How much do you feel Alex's employment has contributed to his community inclusion?

Barbara: Very much so. Much of our focus, in all of the activities Alex is involved in, revolves around Alex being out in the community. David has a saying everyone quotes, "It takes a village to raise a child, but the village needs to know the child." Home Hardware is in the centre of our little town. Folks in town know Alex from working in the store. His fellow employees like him and watch out for him in town. One of the employees

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was on our team for a while taking Alex to Community Events on Friday evenings - street dance for the Father's Day Show 'n Shine, Sandcastle Contest in a neighbouring town, Thursday night market, Coombs Fair. When Alex delivers the pet treats to the three stores, all the people there know him and make a fuss of him when he does the deliveries. Lots of people now request "Alex's treats" specifically when they go to Bosley's.

Community Lunches is a well-known program in our community; 20 plus people work there preparing lunches, helping with set up, etc. All of those people know Alex and talk to him when they see him in town. Also, one of the volunteers picks Alex up in the morning and takes him to Quality Foods to pick up breads and pastries for the program. All of the people who work in the bakery know him and say hello when he is in the store. So, yes, all of his employment opportunities have been crucial in helping Alex be included in the community.

Franca: How has all this impacted your lives personally and as a family?

Barbara: Such a huge question! Having a child, even an adult child, with autism defines

your life and that of your family. It has demonstrated that our kids, in spite of their significant impairment, can learn and be productive members of society. It doesn't, however, make worrying about his future any less, knowing that he is completely reliant on others - and we won't always be here!

Franca: Do you have any “gems of wisdom” for other parents of young adults with autism who are thinking about their son’s or daughter’s future?

Barbara: I think that planning, using something like our “Three Year Goals” plans or the “A Day in the Life of Alex 2016,” will help to keep you focused on the future and working on the skills your son or daughter needs to lead a full, rich life. Planning with set measurable goals and objectives, for us, has been incredibly valuable.

Franca: Thank you so much for sharing, Barbara.

To learn more about Alex’s pet treats, go to www.thecaninekitchen.net

Barbara McLeod and family live in Qualicum Beach on Vancouver Island, BC, Canada.

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INTERVIEW

With Alexandra Penzi, Sibling of Christopher and Advocate of Autism Awareness

May Chriseline Beaubrun, MEd, BCBA

Springtime for high school students is a very busy time. There are college visits, proms, and making plans for the summer. For one extraordinary teen, spring is also the time for Autism Awareness in April. Alexandra Penzi, age 17, has a special interest in autism awareness because her brother Christopher, age 13, is diagnosed with autism spectrum disorder. To Alexandra, autism is “a condition that can be a heartache to the family, who simply wants to see their child flourish in society and hopes for their ability to someday be independent and take care of themselves.”



Alexandra and her brother, Christopher

Alexandra gets involved with Autism Awareness by selling blue bracelets for her school's Key Club (division of Kiwanis). Alexandra also tries to get her friends involved. As co-president of the National Art Honor Society at Manhasset High School, she collected art piece donations for raffling at the EdenII/Genesis Outreach Program, the school her brother attends.

Alexandra says growing up she “wasn’t quite sure” when she was formally told that her brother had autism, but it seems as if it was always a part of their lives. She remembers being around 8 or 9 and thinking that Christopher “was going to get better, because multiple therapists would tell me that he's going to be *cured* in a few years, and other people told me that he would outgrow it.” Because of this, on every birthday Alexandra would blow out the candles on her birthday cake and make a wish “that Christopher would be cured of autism.”

Alexandra was kind enough to take time out of her busy schedule to be interviewed about her experience having a brother with autism.

May: What was one thing that changed after learning that your brother had autism?

Alexandra: I just loved him even more, and I kept hoping and praying that he would be cured miraculously one day. I was scared for him, and the way people would treat him, and if he would ever have a normal life. I wondered if I would ever be the fun aunt I had always planned on being, and I wondered if he was ever going to get married and have a family of his own, or if he would be able to have a job, or if he would ever have any friends, or if I would ever be able to joke and interact and

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talk and play games and quarrel and do other things with him that all my other friends were able to do with their siblings and took for granted. I felt guilty that I wasn't spending all my time with him, and I felt guilty when I was with friends because I knew that he didn't have any. Whenever we would try to include him on playdates, he wouldn't interact, and my friends would get really bored - I even lost some friends because they didn't want to come over to play with him.

May: What remained the same after learning that your brother had autism?

Alexandra: I still loved him, more than anyone else. I loved him even more fiercely. Our lives continued going on the way that it had for the most part - new therapists would come and go in my home; there was never any continuity or long term commitment from any of them-to the point where seeing strangers in my home was commonplace, but other than that, as a child I didn't really pick up on major changes in our daily life.

May: How did you find out about the Association for Science in Autism Treatment (ASAT)?

Alexandra: My brother's consultant, Dr. Mary McDonald, told us about ASAT and how I might be able to promote it to individuals and families that needed information on autism to better educate themselves. I wanted to provide people with an accurate and honest organization - ASAT-that was knowledgeable about autism, providing sound and science-based information and strategies for families. When I was making bookmarks for April's Autism Awareness Month, I thought it would be the perfect opportunity to get the word out in my school and community.

May: When did you start to get more involved in autism awareness?

Alexandra: After a few ugly scenes where people didn't seem to understand that Christopher had a disability, and would say horrible things about him, such as how they "would punish him if he was their child," and about my parents' "poor job raising him," I was really upset. Many of those instances will never be forgotten. I remember when one time at Walmart, Christopher was having a meltdown and a woman walked by and said that if he was her kid she would "slap the s#*% out of him." Another time, when Christopher was having a scene outside of a pet store, a man walked inside and said that the kid outside was a "%\$#@_ animal and should be locked up" and "if he was my kid I would beat the %\$# out of him," as well as a few comments that were even worse. One day I was singing in the church choir, and the director's assistant asked my parents to take my brother out of the church after he had clapped his hands in excitement after I finished singing a song. This was on Christmas Day, a day I will never forget. These were just a few instances, out of a myriad, and I was getting really fed up with the way people would discriminate and treat my brother. It sickened me, and I became really disgusted with people. I wanted to spread more awareness so that other families, as well as my own brother, would not have to suffer mistreatment from ignorance any longer.

May: Tell me about the fundraiser where you will be selling blue bracelets for your school's Key Club.

Alexandra: Every year since ninth grade I have participated in selling bracelets for autism

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awareness at my school. The money raised goes to support a job agency that has employed many autistic children from my school and surrounding areas. This year, when I heard that the bracelets were being sold once more, my friends and I immediately signed up to sell the bracelets during our lunch period. We quickly sold out, and decided to throw our own bracelets in for resale, to raise more money! It was so heartwarming to see people genuinely excited to support our cause, including some people that came as a surprise. Very encouraging!

May: Besides the National Art Honor Society, what else are you involved with at school?

Alexandra: Besides being the co-president of National Art Honor Society, I'm the vice president of International Club, and an active member of both Phoenix (The school's art and literary magazine) and Key Club. I'm also part of National Honor Society, Spanish Honor Society, English Honor Society, Social Studies Honor Society, and Math Honor Society. I really enjoy the activities that we all do. Two of the honor societies in particular, English and Math, require peer tutoring for its members. I really enjoy peer tutoring, because it's really fulfilling to be able to explain a certain concept to a younger child and have their eyes light up when they finally understand it.

May: What do you like to do after school and on the weekends?

Alexandra: After school, normally I'm doing homework and studying (it seems like it never ends!!). In spare moments of leisure time, I love drawing, writing, reading, going on Pinterest to find new craft ideas and recipes, cleaning my room (bet you weren't expecting that one, mom!), and hanging out with my friends. I also volunteer at a local hospital and spend time with my brother. Other activities that I enjoy doing (but don't seem to get much time to do them) are scuba diving, fly fishing, and ballroom dancing.

May: What would you like to do after high school and why?

Alexandra: I'm not quite sure what I want to do after high school yet. I want to go to a good college to continue my education, but I don't know what I want to major in yet. I just know that whatever I do, I want it to be fulfilling, and I want to be able to reach out and help people. And I want to be able to protect disabled individuals, like my brother, from crippling discrimination and scrutinizing due to ignorance.

May: What other events have you participated in or ran for Autism Awareness?

Alexandra: Besides the bracelet fundraiser at school, I have made and collected artwork from

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members of the National Art Honor Society to donate for fundraising at the Genesis/Eden II program for autistic individuals in East Meadow, NY. As previously mentioned, I have also designed bookmarks for April's Autism Awareness Month for distribution in my Middle School and High School libraries as well as our community Public Library.

May: Is there anything else you would like us to know?

Alexandra: There are many students interested in this cause at my school, and we would glad-

ly welcome any guest speakers or other information from your organization on autism at any time. Also, I would be more than willing to help out with anything you might need in my area to help spread awareness and more importantly education on autism.

May: Thank you immensely for sharing your experiences with Science in Autism Treatment and our subscribers!

Calling All Supporters: Donate Items for Our Silent Auction

This is ASAT's 4th year launching an online auction through Bidding for Good which means that bidding can be opened up to anyone! We have created a list that details donations that may serve as successful silent auctions bid items. Much of this is based on data collected by Bidding for Good pulled from hundreds of live online auctions. These types of items typically draw the greatest number of bidders, and the greatest revenues among charities. Please check out the list below:



1. Travel packages and hotel stays;
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5. Collectibles; and
6. Gift certificates (restaurants, stores, businesses in which merchandise can be offered online).

If you are in a position to donate an item for our auction, please write to us at auction@asatonline.org.

We deeply appreciate your support! In the meantime, please check out our [auction](#) and bid....and bid again! We will showcase our donors in the Summer Issue of *Science in Autism Treatment*.



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RESEARCH REVIEW

Comparison of Behavioral Intervention and Sensory-Integration Therapy in the Treatment of Challenging Behavior

&

The Role of Treatment Fidelity on Outcomes During a Randomized Field Trial of an Autism Intervention

In this issue of SIAT, we summarize two studies. The first compares two interventions meant to decrease challenging behavior in children with autism. The second looks at whether students with autism can improve in behaviorally-based teaching programs in the general public school setting. We hope you this information is helpful.

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



Comparison of Behavioral Intervention and Sensory-Integration Therapy in the Treatment of Challenging Behavior

Devlin, S., Healy, O., Leader, G., & Hughes, B. (2011). Comparison of behavioral intervention and sensory-integration therapy in the treatment of challenging behavior. *Journal of Autism and Developmental Disorders*, 41, 1303-1320.

Reviewed by: Jennifer Cote, BS, ASAT Extern, and Karen Fried, PsyD, BCBA-D, ASAT Board Member.

Why research this topic?

For individuals with autism spectrum disorder, challenging behaviors can affect their ability to function at home, in school and in the community. Challenging behaviors can also be dangerous, in the case of aggression and self-injury for example. Given the importance of reducing challenging behaviors, it is essential for parents and professionals to select the most effective intervention. The current study builds upon previous research by comparing the use of a behavioral intervention (BI) to the use of sensory-integration therapy (SIT) to decrease challenging behavior in children with autism spectrum disorder (ASD). BI and SIT are commonplace interventions in school and community settings. Just because two interventions are commonly used does not mean they are equivalent for a particular purpose. Previous research shows that BI is effective in reducing challenging behavior in children with ASD and that SIT shows questionable efficacy for this purpose. It is important to build on previ-

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ous research to compare and contrast BI and SIT so that children with ASD have the best possible outcomes. BI is commonly delivered by behavior analysts. SIT is commonly delivered by occupational therapists. The second part of this study measured the stress levels of the same children in the BI and SIT conditions by examining saliva samples for cortisol. Cortisol is a component of saliva and is associated with the human stress response. Some researchers have suggested that measurement of cortisol might help assess stress levels in children with ASD.

What did the researchers do?

Researchers studied four males, ages 6½ to 11 years, with diagnoses of ASD. All participants had a history of challenging behavior, in the form of aggression and self-injury. The study took place in a school setting. Functional assessments were conducted for each participant to determine the function of the challenging behaviors prior to the intervention phase of the study. For each participant, a behavioral intervention was designed by a behavior analyst based on the results of the functional assessment. Also for each participant, an SIT intervention was designed by an occupational therapist (OT) trained in designing and implementing SIT procedures. The SIT intervention was not based on the results of the functional assessment but rather on the OT completing direct observation of each participant over a period of one month. Before the intervention phase, researchers measured the challenging behaviors of each participant. Once intervention began, each participant received intervention that alternated randomly between BI and SIT over the course of 10 days. Challenging behaviors were measured throughout. After the 10-day period, the intervention that showed the best results for each participant was repeated alone for another 8 days, during which the challenging behaviors were measured. Before and throughout the alternating intervention phase, researchers also collected several daily samples of each participant's saliva. Those samples were then analyzed for cortisol according to whether the participant was engaged in BI or SIT.

What did the research find?

During BI, challenging behaviors decreased for all four participants. Conversely, for SIT, challenging behaviors increased for one participant, showed no change for one participant, and decreased for two participants, though to a much lesser degree than the decrease produced by BI. Since BI produced the greatest effect for all four participants, it was continued alone for another 8 days. Over the course of that 8-day period, challenging behaviors decreased further, to zero occurrences for one participant. An analysis of cortisol levels revealed no overall difference between the BI and SIT conditions. Cortisol levels were relatively low compared to normal resting data for children without any special needs.

What are the strengths and limitations of the study?

The design of the study was strong in terms of alternating randomly between BI and SIT across participants. Another strength was that the BI strategies were tailored specifically to each individual based on results of the functional assessment or analysis. Challenging behaviors were clearly defined in ways that were observable and measurable. Yet another strength is that challenging behaviors were

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measured by more than one observer (i.e., interobserver agreement or IOA) for a large portion of the sessions to make sure measurements were accurate. To improve the study, the researchers could increase the total number of intervention sessions to extend the trends they saw; the current data included possible regression after weekends and unexpected absences in a few participants. The researchers might consider repeating the alternating treatment study with additional participants. Finally, the researchers might improve the study by spending more time describing how they made sure each session of BI and SIT was carried out as intended (i.e., treatment integrity or fidelity).

What do the results mean?

This study builds on previous research supporting the use of BI strategies to effectively reduce challenging behaviors in children with ASD, including aggression and self-injury. Effective use of BI includes basing treatment decisions on the results of a functional assessment or analysis. SIT remains a popular treatment among various consumers despite lack of evidence for its efficacy, especially compared to BI.

The Role of Treatment Fidelity on Outcomes During a Randomized Field Trial of an Autism Intervention

Mandell, D. S., Stahmer, A. C., Shin, S., Xie, M., Reisinger, E., & Marcus, S. C. (2013). The role of treatment fidelity on outcomes during a randomized field trial of an autism intervention. *Autism, 17*(3), 281-295.

Reviewed by: Ethan Eisdorfer, Rutgers University Graduate School of Applied and Professional Psychology.

Why Research This Topic?

In general, intervention research that is conducted in highly controlled settings, such as university-based laboratories and clinics, shows stronger results than research in community settings, such as schools or clinics. This “implementation cliff” is the focus of a growing body of scientific study (Weisz, Ng & Bearman, 2014; Weisz et al., 2005). One contributor to this difference in outcomes may be how well the interventions are conducted (“treatment fidelity”). The current study sought to answer the question, “If previous research shows that a program is effective when it is conducted very well (by its designers), how effective is that program when it is not executed as well as the designers intended (as it might be in many community settings)?”

What Did The Researchers Do?

Thirty-three teachers and their classrooms, containing 119 students with autism, were randomly assigned to be trained in either Strategies for Teaching based on Autism Research (STAR) or Struc-

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tured Teaching (ST). STAR is an ABA approach that incorporates three empirically supported teaching strategies: discrete trial instruction, pivotal-response training, and functional routines. ST is based upon the Treatment and Education of Autistic and Communication Handicapped Children (TEACCH) program, which aims to maximize student independence by using visual cues alongside verbal teaching and clearly signaling transitions.

What Did The Researchers Find?

Overall, STAR and ST appeared to be about equally effective. Students in both programs improved from pre- to post-intervention. These findings could indicate either that both programs were beneficial or that students would have gotten better regardless of intervention. Interestingly, treatment fidelity was low (57% for STAR and 48% for ST, compared to 80% or more, which would be expected in research settings). Also of interest, STAR appeared most effective at either high or low levels of fidelity, while ST performed best at moderate levels of fidelity.

What Are The Strengths And Limitations Of The Study?

This study appears to have been conducted rigorously, but nevertheless had some limitations. First, although ST was intended as a contrast to STAR, the researchers found that these programs had considerable overlapping content, which might account for the similarity in outcomes. Second, although the randomization of students to interventions produced groups that were comparable on most pre-intervention variables, the ST group contained a disproportionate number of Latino students. Finally, fidelity was measured via monthly videos, which may have been too infrequent to accurately capture teachers' implementation of STAR and ST.

What Do The Results Mean?

This study provides evidence that students with autism can improve in behaviorally-based teaching programs, such as STAR and ST, in general public school settings, even when treatment fidelity is imperfect. However, it is unclear whether students improved more than they would have without specialized instruction or whether higher fidelity would have produced more favorable outcomes.

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Caitlin Reilly, MA, BCBA
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This installment of *From the Archives* outlines the essential components of play dates for children with autism spectrum disorder. There are several essential things to consider when setting up play dates such as selecting peers, setting and monitoring goals, as well as how to plan an effective play date in order to maximize benefits. In this piece, Caitlin Reilly and Carole Deitchman share some valuable strategies on how parents can set up the most effective play dates for their child.

Caroline Simard, MS, BCBA
Newsletter Content Coordinator

My child with autism is doing well in his academic programming, but I'd like to help him develop social skills with peers. He participates in play dates, but I often worry that we are not making the most of these opportunities. How can I help him learn to play with a friend?

Answered by Caitlin Reilly, MA, BCBA & Carole Deitchman, MA, BCBA

The importance of play dates

Fostering the development of play and social skills should be an essential component of any educational or home program for children with autism. Possessing these skills not only improves a child's overall quality of life and ability to sustain relationships, but also enhances his or her ability to learn from others. Many children with autism often need direct and systematic instruction to learn these skills.

Parent-guided play dates can provide the structure and practice needed to help a child improve peer social skills and make friends (Koegel, Werner, Vismara, & Koegel, 2005). Play dates may be a more effective and rewarding social activity for your child if the following foundation skills are already in the child's repertoire or are being currently targeted:

- knowing how to tolerate, attend to, and imitate other children;
- being able to communicate his or her wants and needs;

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- understanding simple directions;
- taking turns; and
- playing with a few age-appropriate toys and one or two simple games (Smith, 2001).

As you think about the types of activities that may occur during the play dates, make a list of the skills that your child will need to successfully play with a friend. It is often very helpful to teach these important skills with adults first (Leaf & McEachin, 1999), as an adult is more likely to reliably and favorably respond to your child than a peer might be. Many of the above listed skills are likely ones that your child is also working on in school, and your addition of practice opportunities at home will help your child generalize learning to other people and situations.

Planning an effective play date

In addition to empowering your child with an array of foundational skills, it is important to guide his play dates using evidence-based methods. These methods incorporate techniques that have been repeatedly shown to be effective through controlled, scientific research. For your child's play dates, such methods include the use of motivational systems, the strategic use of reinforcement, and the use of systematically faded prompts. While the first few play dates may require a close adult shadow and contrived reinforcement for desired behavior (e.g., chips or candy), the goal is to systematically fade the adult's proximity and prompts and foster the child's contact with naturally occurring reinforcement (e.g., the enjoyment of playing a game or talking to a peer). Evidence-based methods also call for the collection of objective data to monitor progress.



In order to increase motivation during the play date, use toys and activities that are especially enjoyable for your child and his friend (Koegel et al., 2005). Motivation is essential for keeping both children engaged, and for maximizing your child's learning. Your child will be more likely to ask his friend to play a game if he enjoys that game. Similarly, the peer may be less likely to engage with your child if he does not enjoy the play date activity. Taking turns in selecting activities or using a choice schedule of activities may help in this regard.

It is also important to identify specific skills that you want to teach your child during his play dates. These may include such skills as greeting friends, initiating an activity, or asking questions. For

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example, the first several play dates may focus on saying “Hi” and “Bye” to the peer and playing catch. As with other types of skill instruction, consider pre-teaching these play and social skills with adults or at home with a sibling. Your child may require significant prompting initially, so think about how you can fade those prompts as your child’s skills improve and how to provide plenty of practice opportunities across settings, activities and individuals. Once your child greets his friend with ease and independence, focus on teaching him more complex play skills such as asking questions (e.g., “How are you?” and “Do you want to play?”) and making comments while interacting with the peer (e.g., “This is fun!” or “This is my favorite game.”). Start with teaching simpler skills, and then build on those your child has already accomplished.

If your child has difficult behavior, make a plan for how to manage it and follow through during play dates. Your plan may include “preventative” strategies, such as limiting the duration of the play date, using visual supports (e.g., activity board), providing a break, or minimizing activities that are a source of obsession or possible angst. Do not be concerned so much about embarrassing your child as giving him the support and repeated practice opportunities that he needs to be successful (e.g., repeating an interaction in which eye contact was not exhibited). Consistent consequences are essential in order to decrease disruptive behaviors and to help your child successfully relate to his peers (Maurice, Green, & Luce, 1996).

Selecting peers

Potential play date peers should include boys and girls of different ages (Smith, 2001). The best peers for play dates are often open and responsive. That is, they provide ample opportunity for your child to learn; they ask questions, they respond with enthusiasm, and they exhibit patience as your child practices socializing. From a behavior analytic standpoint, we might view a peer’s response as reinforcement for your child’s response. So, if his peer is unresponsive, your child may be less likely to initiate with that peer again during future opportunities. Ask your child’s teacher or other school staff for peer suggestions, or ask the parents of neighborhood children whom you know. Peers that your child naturally comes into contact with on a regular basis, such as family members, are ideal for practicing social skills (Oppenheim-Leaf et al., 2012). It is important that your child’s peer and his or her parents know about your child’s unique behaviors and needs (Baker, 2003). Prepare them for what to expect, and ask the other parent for permission to give rewards during or after the play date. For example, the peer might be rewarded for asking your child a question or waiting patiently while your child responds. Reinforcing the peer for interacting with your child will motivate him to interact with your child more in the future.

Data collection

Taking data on your child’s progress is essential to ensuring effective teaching strategies. This process will help you set goals, monitor changes objectively, and alter your teaching methods if progress has stalled or declined. For example, if your child is not learning to say, “Hi” to his or her

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peer, you may need to increase motivation to learn, increase your level of assistance (such as providing a verbal model of the greeting), or consult with a qualified therapist for other suggestions.

The following is an example of a basic data sheet that can be created to track your child's progress during each play date. The skills that you teach and the data you collect will vary depending upon your child's individual needs and abilities.

Tommy's Play Date Data Sheet	Tommy's Play Date Data Sheet
Date: 10/25/12	Date: 11/2/12
Peer: Kyle	Peer: Kyle
1. Says "Hi" to peer when prompted –	1. Says "Hi" to peer when prompted +
2. Initiates activity with peer using photo prompt in activity schedule.	2. Initiates activity with peer using photo prompt in activity schedule.
- / - / - / + / +	- / + / + / + / +
3. Instances of problem behavior (tally): 1	3. Instances of problem behavior (tally): 0

Conducting an effective play date

Set aside favorite snacks to use as rewards for your child during his play dates (Leaf & McEachin, 1999). It is best to save these special snacks for play dates only, as this will make your child more eager to earn them. During the play date, "shadow" your child by positioning yourself behind him in order to prompt initiations with and responses to his peer (Krantz & McClannahan, 1993). When your child demonstrates target behaviors (e.g., making eye contact with his peer) or is successful in relating to his peer (e.g., making eye contact and saying "Hi, Kyle."), praise him (e.g., "Great job saying 'Hi' to Kyle!"), and give him a small piece of his favorite snack. As your child's learning progresses and he demonstrates these skills independently, you should fade use of this shadowing technique, including use of your prompts and instruction, as well as reducing the delivery of snacks and social praise as rewards. Ultimately, your child's behavior will be rewarded by playing and talking with his friend, rather than your delivery of verbal and edible praise. It may also be necessary to reinforce the efforts of the peer, particularly if your child is not cooperating.

Many children with autism learn new things by using activity schedules (Krantz & McClannahan, 1998). Therefore, it may be worthwhile to make a "play date schedule" that your child and his friend can follow. This might include pictures of the activities and/or peer. As your child learns, you can gradually fade out the schedule so that the play date becomes more natural. You might also arrange materials so that the children must work together to complete an activity (Koegel et al., 2005). For example, if making cookies, have one child hold the measuring cup while the other pours the ingredients.

When starting out, keep the play dates short rather than stretching them out as long as the child seems comfortable or until something goes awry (Smith, 2001). A five-minute-long successful peer

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interaction is better than a 30-minute one that ends in a disruptive outburst. It may take several play dates for your child to become comfortable with his peer, and it will take time for him to learn new skills. It may be helpful for your child to have play dates with one particular child until he demonstrates mastery (i.e., independence) of specific skills; then try teaching those play skills with another child.

Since the pioneering work of Dr. Ivar Lovaas (1981), who demonstrated how parents could teach important skills to their children with autism, we have learned many effective ways to teach social and play skills (Leaf & McEachin, 1999; Lydon, Healy, & Leader, 2011; Koegel, Werner, Vismara, & Koegel, 2005; Smith, 2001; Krantz & McClannahan, 1993; Krantz & McClannahan, 1998; Maurice, Green, & Luce, 1996). Consulting with a qualified specialist may be helpful for planning and implementing effective play dates, but remember, you are your child's first teacher. By using these techniques during guided play dates you are not only teaching your child essential social and play skills, you are teaching him how to have more fun!

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Thank You!

CLINICAL CORNER

How to Manage the Impact of a Child With a Disability on Siblings

Mary Jane Weiss, PhD., BCBA-D
Nicole Pearson, PsyD, BCBA-D

Parents of children with autism face a myriad of unique challenges. If the child with autism has siblings, the parent(s) must also address the unique needs of the siblings to ensure a positive family environment. In this installment of clinical corner, Mary Jane Weiss and Nicole Pearson discuss some of the unique needs of siblings of children with autism, offer suggestions for creating supportive experiences, and suggest resources for parents.

Amanda Guld Fisher, PhD, BCBA-D
Clinical Corner Co-Coordinator

I am a mother of three children, one of whom has autism and requires a tremendous amount of time and care. I worry about how this is impacting my other children, both of whom are a few years older and are very aware of how our family has changed as a result of their sibling's diagnosis. Do you have any advice on how to best address this with them?

Answered by: Mary Jane Weiss, PhD., BCBA-D, Professor of Education and Director of Autism and Applied Behavior Analysis Program and Nicole Pearson, Director of Education, NYC Autism Charter School.

Having a child with autism spectrum disorder inevitably impacts the entire family. From the stress and anxiety that accompanies the initial diagnosis to the time-intensive nature of navigating treatment options and providers, raising a child with autism presents unique challenges for parents. It can also present challenges for siblings as the sibling relationship is inevitably different from that of typical siblings. And while many of these differences can be positive and rewarding, it's important for parents to be aware of the needs of siblings so that they can provide meaningful guidance and support.

While children of younger ages may not be fully aware of their sibling's disability, they likely detect parental stress, perceive inequities in the amount of time and attention given and struggle with a sense of disruption in overall family life (Feiges & Weiss, 2004; Smith & Elder, 2010). As children age and their awareness grows, siblings may experience adjustment difficulties. These difficulties are influenced by such factors as sibling age and gender as well as family size. Siblings closer in age to the child with autism, and those who are younger and have not yet developed effective coping strategies can be more affected. However, as a parent, there are many strategies you can take to support sibling coping and adjustment.

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Foster a supportive environment at home: Siblings are often aware of how different their experiences are from that of others, especially their friends. As a result, they may feel many emotions, including fear, anger, embarrassment, resentment and guilt, among others. Encouraging an environment of open communication allows the sibling to safely express negative emotions and frustrations. Listen to and reassure your child that it's okay to have these feelings, and offer suggestions on how to work through them together. Doing so also helps with positive coping and establishes a foundation for good familial communication and problem solving.

Further, as siblings become aware of such differences, they will likely look to their parents and family members for guidance. Thus, parent coping and adjustment play an important role in sibling adjustment. As such, it is important for parents to be cognizant of the impact their actions, behaviors and decisions will have on all of their children.

Ensure your child understands what autism is: Parents sometimes overestimate their typical child's understanding of autism as the child may be able to explain what it is without fully comprehending it. They may also pick up on information they overhear but likely have more questions than answers. Making sure that siblings have developmentally-appropriate information will help reduce their fears and misconceptions (Glasberg, 2000; Harris & Glasberg, 2003). These explanations can go a long way in influencing how siblings view and interact with their sibling with autism and how well they are able to explain autism to their peers.

When speaking with children under age nine, parents should keep explanations brief and frame the sibling with autism's deficits in the context of having not yet learned or mastered particular skills, such as playing with others or communicating in ways that other children do. For example, saying, "Your sister learns a bit differently than you and me, so she needs extra help." or "Your brother may not be able to talk but we are teaching him other ways to show us what he wants to say."

As children age, explanations can be more involved, such as sharing that autism is a problem in the brain and that it presents differently in each child. Depending on the extent of the child with autism's behavioral problems, it may be necessary to help the sibling understand why they're occurring and their role in behavioral escalations. Such escalations can be scary, embarrassing and disruptive for typical siblings so providing them with clear explanations can help alleviate some of these feelings. Regardless of the children's age, parents should offer reassurance (especially of safety) to typical siblings, and convey love and acceptance of everyone in the family.

From a timing perspective, starting to discuss autism with siblings at an early age can be helpful, especially before they begin school or start having friends over. That way, they can be prepared with information about how to explain what may appear to be usual or different behavior in their sibling with autism. There are several free online resource guides available:

- Autism Speaks offers a "Siblings Guide to Autism" toolkit designed for siblings ages 6-12 that parents and siblings can read together to learn more about autism and facilitate conversation about it

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- Organization for Autism Research's "Kit for Kids" offers an illustrated booklet for elementary and middle school students, called "What's up with Nick?" and "Autism, my sibling, and me"

Promote meaningful relationships between siblings: While every sibling relationship is special, the communication and socialization deficits inherent in autism diagnoses can make sibling bonding more difficult. Creating opportunities for younger children to play together or helping older siblings to find common interests, even if its as simple as doing a puzzle together or playing a video game, can go a long way in increasing the quality and quantity of interactions and ultimately building sibling bonds.

Another way to foster meaningful relationships between siblings is to teach your typical children how to be mentors to their younger sibling with autism. Doing so can be very fulfilling for siblings and promote feelings of self-efficacy and nurturing. It also creates opportunities for siblings to engage with one another socially and have positive interactions with their sibling with autism. Prior to starting, make sure that your typical children understand their sibling with autism's skills, preferences and interests and start with easy tasks to ensure success. Such tasks might include modeling how your typical siblings can engage in simple toy play or teach their sibling with autism a basic daily living skill like putting on a coat or how to wash hands. Other skills that can be useful to teach include:

- how to get your sibling with autism's attention,
- how to provide praise and reinforcement when he does well,
- how to assist him when he cannot do something,
- how to help him stop playing and clean up.

Build in one-on-one time for each sibling and foster individuality: Siblings are inevitably affected by the inordinate amount of time, energy and resources that are spent caring for their sibling with autism. Further, activities common in typical family life such as all spending time together, going to a movie or on vacation may be more limited. While inequities exist in all families, they are intensified in a family who has a child with autism. And if typical siblings feel dissatisfied with these inequities, their relationship with their sibling with autism is negatively impacted (Rivers & Stoneman, 2008). To help minimize the impact of these inequities, it's important to make time for one-on-one interaction with each sibling. While this can seem difficult in the throes of managing busy schedules and the demands of therapies, carving out even a small amount of time where you're giving your child your undivided attention can go a long way. So whether its running errands together or going for pizza, make time to check-in with your other children and let them know that even though they may not always get as much attention as their sibling, they're loved and cared for equally.

And while having a child with autism is a 24/7 commitment, helping to foster distinct roles and interests in each child can further reduce the stress that siblings may feel. Encourage siblings to get involved in sports, clubs or other community activities where they can develop relationships with peers and just have fun. Doing so allows them the time and space to be their own person and establish a

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sense of individuality not defined by their sibling with autism (OAR, 2014). Ultimately, it may also make siblings more available to enjoy spending time with their sibling with autism.

Consider additional sources of support: Finally, sibling groups can be a helpful source of support. They provide siblings the chance to meet and speak with others who are going through similar experiences and can give them accurate and age-appropriate information about autism. Often these groups can help reduce fear and misconceptions among siblings as well as the feelings of isolation many experience. If a support group isn't readily available within your children's school or your community, consider looking at some of the following resources for more information:

– **Sibling Support Project** – offers more than 475 community support programs, called *SibShops*, for younger siblings of children with special needs.

– **Online resources:** There are several online communities for siblings, both teens and adults:

– SibTeen, an online Facebook group for teen siblings: https://www.siblingsupport.org/connect-with-others-sibs/meeting_other_sibs_online/sibteen

– SibNet online forum for adults: https://www.siblingsupport.org/connect-with-others-sibs/meeting_other_sibs_online/sibnet

The *Organization for Autism Research (OAR)* has also developed the “Autism Sibling Support Initiative” offering helpful resource guides for young children, teens and parents.

While much is often said about the challenges faced by siblings of people with autism, there are also substantial positive outcomes. Most siblings who reflect on the experience in adulthood attribute their high levels of compassion, tolerance, patience, and concern for others to having had a sibling with special needs. Furthermore, many of them develop a sense of mission and enter helping professions.

There is no universal description of the ways in which this role changes the lives of siblings of children with autism. And every sibling pair is on their own unique journey. But while this is a role that is not chosen by the sibling, it is a role that most siblings truly embrace. Parents can help their typically developing children by creating an environment of transparency and openness about autism and about issues arising in the family associated with it. They can help siblings find effective ways to interact with their brother or sister with autism, and can foster mentorship roles for them with their sibling. Parents can also ensure that every child in the family gets needed attention and permission to pursue their own dreams. Finally, they can remember that most siblings of children with autism end up being compassionate human beings who treasure their sibling and who note both the struggles and the strength that the family experienced as a result of being touched by autism.

Note: This submission was adapted from Drs. Weiss and Pearson's book chapter, “Working effectively with families of children with autism spectrum disorders: understanding family experience and teaching skills that make a difference” which appeared in “School success for kids with autism.”

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CONSUMER CORNER

Some Resources for Parents, by Peggy Halliday, MEd, BCBA & Health Insurance Coverage in New Jersey, by Jodi F. Bouer, Esq.

For this installment of Consumer Corner, Peggy Halliday has created a valuable resource list designed to help parents navigate the field of autism treatment and advocacy. Each professional or parent-led organization is briefly discussed and the tools offered are summarized. In addition, for those lucky parents and providers who live in New Jersey, Jodi Bouer has provided an *in-depth* analysis on the steps required to obtain health insurance coverage for Autism Spectrum Disorders. Although this article relates to the New Jersey law specifically, it may be of value for those advocates with autism mandates in their states or for those who are advocating for the adoption of such a law in jurisdictions where children are still denied access to health insurance. Keep in mind that these worthwhile resources will also be archived on the ASAT website for future reference. In a future installment of Consumer Corner we will be showcasing websites that offer content related to adolescents and adults with autism. Stay tuned!

Sabrina Freeman, PhD
Consumer Corner Coordinator

Some Resources for Parents

Peggy Halliday, MEd, BCBA

The following websites include milestones' checklists, booklets, and a wealth of other helpful information. The contributions have been offered by parent groups as well as professional, medical, scientific, and legal and/or advocacy organizations which are available to meet the needs of families.

American Academy of Pediatrics (AAP)

The AAP is an organization of 64,000 pediatricians committed to the well-being of all infants, children, adolescents, and young adults. The AAP website contains recent information about autism prevalence, links to many external resources and training websites, information about pediatrician surveillance and screening, and early intervention. This site offers great tools and resources for both pediatricians and families. <https://www.aap.org/en-us/about-the-aap/Committees-Councils-Sections/Council-on-Children-with-Disabilities/Pages/Autism.aspx>

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Association for Behavior Analysis International (ABAI)

The ABAI is a nonprofit professional membership organization whose objective for education is to develop, improve, and disseminate best practices in the recruitment, training, and professional development of behavior analysts. ABAI offers membership to professionals and consumers, which entitles them to the newsletter and other benefits. www.abainternational.org

Association of Professional Behavior Analysts (APBA)

The APBA is a nonprofit organization that is focused on serving professional practitioners of behavior analysis by promoting and advancing the science and practice of applied behavior analysis. The APBA is a nonprofit professional membership organization. Membership is open to professional behavior analysts and others who are interested in the practice of ABA, including professionals from various disciplines, consumers, and students. www.apbahome.net

Autism New Jersey (Autism NJ)

Established in 1965, Autism NJ is now the largest statewide network of parents and professionals dedicated to improving the lives of individuals with autism and their families. Autism New Jersey is a nonprofit agency committed to ensuring safe and fulfilling lives for individuals with autism, their families and the professionals who support them through awareness, credible information grounded in science, education, and public policy initiatives. www.autismnj.org

The Autism Science Foundation (ASF)

As well as supporting autism research, the ASF provides information about autism to the general public and serves to increase awareness of autism spectrum disorders and the needs of individuals and families affected by autism. www.autismsciencefoundation.org/

Autism Speaks

Autism Speaks supports global research into the causes, prevention, treatments, and cure for autism and raises public awareness. The website contains information on resources by state, resources for families, advocacy news, and suggested apps for learners with autism. The Autism Speaks 100 Day Kit for Newly Diagnosed Families of Young Children was created specifically for families of children ages 4 and younger to make the best possible use of the 100 days following their child's diagnosis of autism. <http://www.autismspeaks.org>

Behavior Analyst Certification Board (BACB)

The BACB is a nonprofit corporation established as a result of credentialing needs identified by behavior analysts, state governments, and consumers of behavior analysis services. Their mission is to

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develop, promote and implement an international certification program for behavior analysis practitioners. The BACB website contains information for consumers (including a description of behavior analysis), conduct guidelines, requirements for becoming certified and maintaining certification, and a registry of certificants that can be searched by name or state. www.bacb.com

Cambridge Center for Behavioral Studies

The Cambridge Center for Behavioral Studies website contains behavior analysis resources, a glossary of behavioral terms, online tutorials and suggestions for effective parenting. A continuing education course series is offered through collaboration with the University of West Florida and is designed to provide instruction in a variety of areas of behavior analysis. To utilize all of the features of the website, you must register. www.behavior.org

Centers for Disease Control and Prevention (CDC)

The *Act Early* website from the CDC contains an interactive and easy-to-use milestones' checklist you can use to track how your child plays, learns, speaks, acts, and moves ages 3 months through 5 years. There are tips on how to share your concerns with your child's doctor and free materials that you can order, including fact sheets, resource kits, and growth charts. www.cdc.gov/ncbddd/actearly/index.html

Council of Parent Attorneys and Advocates, Inc. (COPAA)

The Council of Parent Attorneys and Advocates is a national American advocacy association of parents of children with disabilities, their attorneys, advocates, and others who support the educational and civil rights of children with disabilities. The website provides important information about entitlements under federal law. www.copaa.org

Council for Exceptional Children (CEC)

The CEC is an international professional organization dedicated to improving the educational outcomes and quality of life for individuals with exceptionalities. The focus is on helping educators obtain the resources necessary for effective professional practice. Autism is one of many disabilities discussed. www.cec.sped.org

Education Resources Information Center (ERIC)

Sponsored by the Institute of Education Services (IES) of the U.S. Dept. of Education, ERIC provides ready access to education literature to support the use of educational research and information to improve practice in learning, teaching, educational decision-making, and research. <http://eric.ed.gov/>

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First Signs

The First Signs website contains a variety of helpful resources related to identifying and recognizing the first signs of autism spectrum disorder, and the screening and referral process. A video glossary is useful in demonstrating how you can spot the early red flags for autism by viewing side-by-side video clips of children with typical behaviors in comparison with children with autism.

www.firstsigns.org

Individuals with Disabilities Act (IDEA)

IDEA is a law that ensures services to children with disabilities throughout the nation. IDEA governs how states and public agencies provide early intervention, special education, and related services to more than 6.5 million eligible infants, toddlers, children, and youth with disabilities. The IDEA website contains information on early intervention services, local and state funding, and Individualized Educational Plan (IEP) issues including evaluation, reevaluation, and procedural safeguards. <http://idea.ed.gov><http://idea.ed.gov>

National Autism Center (NAC)

The NAC is a nonprofit organization dedicated to disseminating evidence-based information about the treatment of autism spectrum disorder and promoting best practices. Through the multi-year National Standards Project, the NAC established a set of standards for effective, research-validated educational and behavioral interventions. The resulting National Standards Report offers comprehensive and reliable resources for families and practitioners. www.nationalautismcenter.org

National Professional Development Center on Autism Spectrum Disorders (NPDC)

In 2014 the NPDC, using rigorous criteria, classified 27 focused interventions as evidence based practices for teaching individuals with autism. This website allows you to access online modules for many of these practices as well as an overview and general description, step-by-step instructions, and an implementation checklist for each of the practices. <http://autismpdc.fpg.unc.edu/evidence-based-practices>

NIH National Institutes of Health (NIH)

The NIH, a part of the U.S. Department of Health and Human Services, is the primary federal agency for conducting and supporting medical research. Helping to lead the way toward important medical discoveries that improve people's health and save lives, NIH scientists investigate ways to prevent disease as well as researching the causes, treatments, and even cures for common and rare diseases.

www.nih.gov

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Organization for Autism Research (OAR)

OAR is a nonprofit organization dedicated to applying research to the daily challenges of those living with autism. OAR funds new research and disseminates evidence-based information in a form clearly understandable to the non-scientific consumer. The OAR website contains downloadable autism information for families and professionals, as well as information on studies, research and grants. OAR offers recommendations and worksheets for educators and service providers to assist in classroom planning, and a newsletter, "The OARacle." www.researchautism.org

Parents of Autistic Children (POAC)

POAC is a nonprofit organization that is an educational leader for the New Jersey autism community. The group provides more free training than any other organization. Additionally, POAC provides recreational and support services to children with autism and their families. www.poac.net

Rethink

The mission of Rethink is to offer parents and professionals immediate access to effective and affordable applied behavior analysis-based treatment tools for the growing population affected by autism spectrum disorders. Their web-based platform includes a comprehensive curriculum, hundreds of dynamic instructional videos of teaching interactions, step-by-step training modules, and progress tracking features. www.rethinkfirst.com/Default.aspx

Virginia Commonwealth University Autism Center for Excellence

VCU-ACE is a university-based technical assistance, professional development, and educational research center for autism spectrum disorder in the state of Virginia. VCU-ACE offers a wide variety of online training opportunities for professionals, families, individuals with ASD, and the community at large. The website contains many useful resources, including a series of short how-to videos demonstrating particular evidence-based strategies. www.vcuautismcenter.org/index.cfm

Wrights Law

Wrights Law is an organization which provides helpful information about special education law, education law, and advocacy for children with disabilities in the USA. The Wrights Law website contains an advocacy and law library including articles, cases, FAQs and success stories, and information on IDEA. www.wrightslaw.com

Zero to Three: National Center for Infants, Toddlers, and Families

This is a national, nonprofit organization which seeks to inform, educate, and support professionals who influence the lives of infants and toddlers. The mission of the organization is to support the healthy development and well-being of infants, toddlers, and their families. The website shares information about the Military Families Project, which supplies trainings, information, and resources for military families with young children. www.zerotothree.org.

How to Obtain Health Insurance Coverage for Therapies for Autism Spectrum Disorder Under New Jersey Law

Jodi F. Bouer, Esq.

As a New Jersey law firm that specializes in representing providers and policyholders seeking health insurance reimbursements, we at Bouer Law have been asked to draft the following updated and practical guide on how to use New Jersey law to obtain health insurance coverage for children in this state who need therapies for Autism Spectrum Disorder (ASD). This guide also contains many tips which can be used to compel coverage by providers for families with children with ASD that do not enjoy the right to coverage under New Jersey law.



A. The New Jersey Autism Insurance Mandate

Many families in New Jersey who have children with ASD have been tapping into the health insurance coverage compelled by the Autism Insurance Mandate (the “Mandate”) that was signed into law in the summer of 2009. According to Autism Speaks, some form of this bill has been passed in most states throughout the country.

To determine if the Mandate will apply to your insurance plan, you first need to call your insurer and/or employer to determine whether your policy is state-regulated or is a self-funded insurance plan. Generally speaking, if your employer has less than 50 employees and is based in New Jersey, the Mandate will apply to your insurance plan. If your employer has more than 50 employees and is based in New Jersey, you can tell if the plan is state regulated if the appeals section allows you to make a third level external appeal to the New Jersey Department of Banking and Insurance (“DOBI”). If the plan documents indicate that they are self-funded, appoint an insurer

as claims administrator, or do not allow for an external review to DOBI, the plan is likely self-funded. New Jersey regulations also require your insurance card to state if your plan is self-insured/self-funded, so you can review your card for such a reference.

Determining whether your insurance plan is state regulated is important because the Mandate only applies to state-regulated insurance plans and the New Jersey insurance plans that cover state workers (and most New Jersey teachers). If you have a state-regulated plan, the Mandate:

- Prohibits the denial of coverage on the basis that therapy is not restorative;
- Requires screening and diagnosis of autism and other developmental disabilities;
- Requires coverage for expenses incurred for medically necessary occupational, physical and speech therapy; and

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- Requires coverage for medically necessary ABA therapy as prescribed through a treatment plan to treat a primary diagnosis of ASD.

The Mandate was originally written so that it allowed insurers to impose a \$36,000 limit on Applied Behavior Analysis (ABA) therapy provided to children with a primary diagnosis of ASD, but only up to the age of 21.

GOOD NEWS! Since the enactment of the Affordable Care Act, which imposes federal mental health parity requirements on almost all insurance plans, the DOBI has interpreted the Mandate to have no monetary or age limits.

MORE GOOD NEWS! Additionally, based on federal mental health parity law, DOBI has also determined that insurers in New Jersey can no longer place visit limits on speech, occupational therapy and physical therapy when prescribed to treat ASD.

Please keep in mind that in New Jersey, the Mandate has been interpreted to require a diagnosis of ASD by a physician. Services compelled under the Mandate must be provided only when ASD is the child's primary diagnosis and a physician indicates that the services are "medically necessary" to treat the child's ASD diagnosis.

The Mandate also specifies that therapy must be prescribed through a "treatment plan." Although the Mandate references a physician creating the treatment plan, many insurers in New Jersey currently allow and even require BCBA's and other therapy providers to create a child's treatment plan. That being said, you should check the insurer's guidelines to determine whether a physician needs to either prepare the treatment plan or approve and sign off on a child's treatment plan.

The Mandate is also very specific in regards to the elements that must be included in a treatment

plan. Whether a treatment plan is for ABA therapy or other specifically mandated therapies (speech, occupational and physical therapy), it is required to include "all elements necessary for the insurer to appropriately provide benefits, including, but not limited to: a diagnosis; proposed treatment by type, frequency, and duration; the anticipated outcomes stated as goals; the frequency by which the treatment plan will be updated; and the treating physician's signature."

Finally, the Mandate also specifies that an insurer "may only request an updated treatment plan once every six months ... [to] review medical necessity, unless the insurer and the treating physician agree that a more frequent review is necessary due to emerging clinical circumstances." As such, unless it is to a child's advantage, if an insurer tries to issue an authorization that is less than 6 months or requests treatment planning in less than 6 month increments, you should object based on the requirements of the Mandate and report the insurer to DOBI if it insists on proceeding in this direction.

New Jersey still has no regulations issued in relationship to the Mandate, so providers and parents should rely on Bulletin (No. 10-02) issued by DOBI, if they have any questions about what types of services are covered or compelled by the Mandate. DOBI Bulletin 10-2 describes ABA therapy services in detail and indicates that even though Board Certified Behavior Analysts (BCBAs) are not licensed healthcare providers in New Jersey, insurers should still consider BCBAs healthcare providers for the purposes of insurance reimbursements for ABA services. The Bulletin states:

Under Bulletin 10-2, DOBI believes carriers should consider behavioral interventions based on ABA and related structured behavior program services eligible for benefits if administered directly by or under the direct supervision of an in-

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dividual who is credentialed by the national Behavior Analyst Certification Board as either:

- A Board Certified Behavior Analyst – Doctoral (BCBA-D); or
- A Board Certified Behavior Analyst (BCBA).

Some insurers that are not subject to the Mandate will try to argue that they will not cover services provided or supervised by BCBA's as they are not licensed healthcare providers. Significantly, if your plan is self-funded and your insurer attempts to argue that your BCBA is not a licensed provider and therefore it has no coverage obligation, you can refer the insurer to Bulletin 10-2 and respond that no license is required in New Jersey for ABA therapy, and the DOBI recognizes BCBA's as healthcare providers for insurance reimbursement purposes. Moreover, this issue was squarely addressed by the New Jersey Supreme Court in *Micheletti v. State Healthcare Benefits Commission*, 192 N.J. 588 (2007) (ordering payment of speech, physical, occupational and behavioral therapy), which predates the Mandate by two years. In the oral argument before the New Jersey Supreme Court, the insurer attempted to overcome an Appellate Court ruling that it pay for the insured's ABA therapy by asserting that the therapist was an unlicensed BCBA. The Supreme Court would have none of this argument and, in fact, ordered the insurer to pay the plaintiffs' claims regardless of his BCBA's lack of a license.

If New Jersey law does not apply to your insurance plan, review the plan language carefully so you can poke holes in your insurer's assertion that only licensed practitioners may provide ABA therapy. This firm has reviewed many insurance policies that do not clearly require the provision of all services by licensed practitioners. Make sure that your insurance plan states in clear and concise terms that the policy only covers services

provided by licensed practitioners and if not, you can also assert that the plan should not be interpreted in such a restrictive manner, especially in light of the fact that New Jersey does not require a license for BCBA's to be reimbursed by insurance under Bulletin 10-2.

In order to get around a licensing requirement, you should see if it is possible for your ABA provider to associate with a licensed provider such as a medical doctor or a licensed psychologist, psychiatrist or social worker. He or she can also apply for a behavior analyst license in New York. Once your ABA provider associates with a licensed practitioner or obtains a New York license, the basis for your insurer's denial on lack of licensing will no longer exist.

B. The New Jersey Mental Health Parity Act

In New Jersey, children with ASD are also protected by the New Jersey Mental Health Parity Act (the "NJ Parity Act"). The Parity Act is a mighty weapon, unique to New Jersey, that can be used by insureds to obtain coverage for the therapies needed by children with ASD. Like the Mandate, the NJ Parity Act also only applies to state-regulated insurance policies. It requires insurers to provide "coverage for biologically-based mental illness under the same terms and condition provided for any other sickness under the contract." N.J.S.A. 17:48-6v. The NJ Parity Act defines biologically-based mental illness to mean: a mental or nervous condition that is caused by a biological disorder of the brain and results in a clinically-significant or psychological syndrome or pattern that substantially limits the functioning of the person with the illness, including but not limited to pervasive development disorder.

Under the NJ Parity Act, insurers cannot deny coverage because:

- The illness is chronic

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- Medically necessary therapy is long-term
- Medically necessary therapy is not restorative
- The illness involves behavioral problems
- The illness is otherwise defined as a developmental or learning disability/delay
- A defined period of time has elapsed from date of injury or onset of illness

For more information, see N.J.A.C. 11:4-57.3

Even more promising for insureds in New Jersey is the fact that case law interpreting the NJ Parity Act bars insurers from denying coverage on the basis of the:

- Non-Restorative Exclusion
- Developmental Disability Exclusion and
- Educational Exclusion

See *Micheletti v. State Healthcare Benefits Commission*, 389 N.J. Super. 510 (App. Div. 2007) (barring reliance on non-restorative exclusion); *Markiewicz v. State Healthcare Benefits Commission*, 390 N.J. Super. 289-99 (App. Div. 2007) (barring reliance on developmental disability and educational exclusions).

Further, the courts in New Jersey bar insurers from denying coverage for the medically necessary therapies used to treat ASD, such as speech, occupational and physical therapy, and have extended that coverage obligation to ABA therapy. The Appellate Division has reasoned that to “allow carriers to exclude the primary mode of treatment for autism and pervasive development disorder ... would render the statutory directive” in the Parity Act meaningless.

Although the New Jersey Parity Act may not apply to your insurance plan because it is self-funded, you can certainly still use the New Jersey

court rulings in *Micheletti* and *Markiewicz* as a sword to respond to any insurer arguments that ABA therapy is experimental or not medically necessary to treat an ASD diagnosis. Although we can make you no promises in your specific case, when self-funded plans issued to large New Jersey employers have attempted to raise a medical necessity/experimental defense to coverage in relationship to our clients’ coverage demands/appeals, we have used this argument successfully to overturn denials in the course of settlement negotiations and/or appeals.



C. Insurance Plans Regulated By Federal Law

Do not despair if your insurance plan is governed by federal and not state law. The Employee Retirement Income Security Act (“ERISA”) is a federal law that allows employers to step outside of state insurance law to draft, fund, and administer insurance plans for their employees and such insurance plans do not have to comply with state insurance law. Generally speaking, ERISA allows employers to make coverage determinations, which are only overturned, if arbitrary and capricious. Insurers like to assert that this standard is almost insurmountable – rest assured, IT IS NOT.

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The arbitrary and capricious standard can be overcome, especially when there are procedural anomalies, a conflict of interest or vague and ambiguous language in plan documents which do not adequately inform employees of their right to coverage and the obligations of the parties.

Under ERISA, insurers cannot read exclusionary language into insurance plan documents. As such, if your plan has any ambiguities or does not actually state a basis to deny coverage that the insurer is relying on, coverage may be interpreted in your favor. The Affordable Care Act restricts almost all insurers from imposing annual and lifetime limits or denying coverage on the basis of pre-existing conditions. Moreover, almost all insurance plans (group and individual) must comply with the Mental Health Parity and Addition Equity Act (the “Federal Parity Act”). The Federal Parity Act broadly prohibits insurers from imposing more restrictive limitations on mental health treatments than are applied to substantially all medical and surgical benefits. This means that if your plan has visit limits, age limits or uses more restrictive utilization review criteria that are applied only to ASD-related therapies (or to ASD-related and a few other therapies), these types of limitations are in violation of the Federal Parity Act. For instance, if an insurer is making it harder for you to obtain an authorization, claim reimbursements or is using a more restrictive utilization criteria (like requiring parent participation or denying coverage) than is used for medical services, the insurer is violating the Federal Parity Act. You should appeal on this basis and immediately bring a complaint directly to DOBI at www.state.nj.us/dobi/consumer.htm#insurance.

We are also always glad to answer any emails on whether an insurer’s criteria are in violation of the Mandate, the NJ Parity Act, the ACA or the Federal Parity Act.

D. How to Argue for Coverage and Win Regardless of Whether State or Federal Law Applies to Your Insurance Policy

Whether you have a state-regulated or a self-funded insurance plan, the following analysis applies to combat any denials of ASD-related coverage.

First, you should call your insurer and check your referral requirements as well as your time limit to make claims/appeals, and get your ABA therapy claims and appeals filed with your insurer within that time frame. Advise your insurer of your child’s diagnosis and treatment plan and inquire about whether the relevant therapy is covered, any monetary or visit limits, exclusions, etc.

Second, you should obtain a copy of your insurance plan and confirm what you were advised. Review the plan to determine:

- Annual and aggregate limits
- Deductibles
- Cost share
- Exclusionary language
- Out-of-network coverage
- Number of visits allowed
- Maximum days of coverage

If your policy has a maximum visit limit, look at the policy to see if it has any similar limitation in the outpatient services section which applies to substantially all other outpatient medical services. If not, you should argue that the limitation is in violation of the Federal Parity Act.

Third, when your insurer inevitably attempts to deny or limit coverage, scrutinize the language in your insurance plan and utilization review criteria/denial letter carefully. Whenever possible, argue that:

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- Your insuring agreement should be construed broadly in favor of covering ABA and any other medically-necessary treatment for ASD;
- Ambiguities in the policy should be construed in favor of coverage;
- Utilization review criteria is more limiting or restrictive than applied to other medical conditions/services;
- Exclusionary language is not clear and the insurer cannot read exclusionary terms into a plan document – the fact that exclusions are reflected in an insurance guideline/criteria is not sufficient to allow the insurer to deny coverage;
- Procedural anomalies occurred which indicate your insurer is singling your child out to deny coverage not because the therapy is not covered, but rather because the insurer simply doesn't want to pay for the therapy;
- The insurer failed to comply with state or federal law and related regulations;
- The insurer failed to comply with policy terms, limitations and deadlines;
- ABA therapy is a medical necessity and appropriate, not experimental – insurers can no longer argue in New Jersey that ABA therapy is experimental because both the New Jersey Supreme Court and the state legislature has deemed the therapy medically necessary and appropriate to treat ASD;
- Medical documentation shows past and expected progress and continuing need; and
- Proper coding was used by your therapist.

Finally, don't give up hope! Make your claims and appeals timely or they will be forever barred! And please, unless you are certain that no coverage exists, appeal all denials of coverage in a timely manner. When in need, reach out to an insurance advocate or an attorney for support.

In our practice, we are continually confronted by insurance companies who count on the fact that providers and parents are so overwhelmed that they will likely not appeal a denial of coverage, however erroneous, ill-conceived or contrary to law. Federal law requires that most insurers allow for an external appeal by a disinterested third-party. If you have a good case, make an external review request, but please figure out first whether the determination will be binding and if so, see an attorney to obtain opinion on whether it makes sense to bring an external appeal or instead, refrain from external appeal and pursue litigation. Remember that often times, a call to your insurer to clarify issues, resubmitting the claims or providing supporting information is sufficient to overcome a denial of a claim or a preauthorization request. Appeals are time-consuming to prepare but worth the effort when you consider that a child's progress and a family's financial well-being are at stake.

Disclaimer: The above is a general summary of the law. It does not address the provisions and exclusions in your insurance plan including, but not limited to the timing in which your claims must be made or will otherwise be barred, preauthorization requirements which may limit or otherwise bar your coverage, or medical necessity, which is required to invoke insurance coverage under most insurance plans. To determine your obligations and the obligations of your insurer, you should review your plan, consult your insurance agent or broker, consult counsel and make your claims accordingly. Please also be advised that an attorney-client relationship is not created by this summary.

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- ★ All providers will be guided by science when selecting and implementing interventions and use data to demonstrate effectiveness.

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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.

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www.asatonline.org/direct-financial-support/

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