



Science in Autism Treatment

Newsletter of the Association for Science in Autism Treatment

Volume 13, Issue 4 | Fall 2016

Letter from Dr. David Celiberti, ASAT Executive Director and SIAT Co-Editor

Dear Subscribers,

I hope you will enjoy the Fall issue of *Science in Autism Treatment* (SIAT). **ASAT strives to improve access to** effective, science-based treatments for all people with autism. Our newsletter exemplifies ASAT's mission to disseminate accurate, scientifically sound information about autism and autism intervention. I am very pleased to share that we are launching a new column *Is There Science Behind That?* coordinated by Dr. Thomas Zane. The first installment, authored by Kelley Harrison and Dr. Thomas Zane from the University of Kansas ([page 28](#)), addresses the scientific underpinnings of hyperbaric oxygen chamber therapy (HBOT).

As we approach the closing of 2016, we have the opportunity to reflect on the accomplishments of this year (I know, I know...2016 is not over yet). I would like to highlight some of them here and will report on next year's goals in the Winter 2017 issue. Some of our many 2016 accomplishments include:

- ★ Added new members Julie Azuma, Sarah Treadaway, and Dr. Renee Wozniak to our Board of Directors, and Drs. Bridget Taylor and Robert LaRue to our Professional Advisory Board. Furthermore, former Board Member Barbara Wells will be rejoining the board as our Treasurer.
- ★ Created posters reflecting ASAT's mission and commitment to science-based treatment.
- ★ Published four issues of *Science in Autism Treatment* covering a myriad of topics of interest to families and professionals, and launched a new column called *Is There Science Behind That?*
- ★ Garnered subscribers from over 100 countries.
- ★ Further developed our website with special pages for parents of older children and adults, medical professionals, and members of the media.
- ★ Published numerous *Media Watch* letters and *Media Alert* Facebook posts in response to accurate and inaccurate news articles and broadcasts related to autism treatment.
- ★ Developed a resource booklet for parents of newly diagnosed children with autism available free online and to be distributed in print in 2017.

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- ★ Expanded our Externship program, now including Externs from other countries such as Canada, Australia, United Arab Emirates, and India. We graduated several Externs, many of whom assumed Coordinator level or Board Member roles within the organization.
- ★ Increased social media activity to reach families and professionals, with almost 11,000 followers on [Facebook](#) and over 1,300 on [Twitter](#).
- ★ Published monthly blog posts in collaboration with [Different Roads to Learning](#) (DRL).
- ★ Rolled out the 6th Annual Rock'n 4 Autism Awareness campaign ([page 21](#)) with more than 50 business donors and over \$8,000 raised to promote autism awareness on global, national and local levels. We also hosted of our first “[Cut-a-thon](#)” fundraiser in Canada.

Our accomplishments to date and goals for the future would not be possible without the tireless efforts of a cadre of parents and professionals, our Board of Directors ([page 15](#)), Advisory Board members ([page 15](#)), Committee members ([page 49](#)), and SIAT team ([page 7](#)). It is wonderful to have so many individuals committed to ASAT's success.

In keeping with our mission, we are committed to continue to update our [website](#), distribute this quarterly newsletter free of charge, and engage in initiatives such as Media Watch. During tough economic times, we would not want consumers to be unable to access our information due to financial constraints. Having said that, I would like to end this letter with an appeal.

The ongoing success of ASAT is predicated on the financial support of generous donors. We strive to keep our expenditures very low, relying heavily on volunteers, and donations enable us to carry out our mission and initiatives. The abundance of pseudoscientific treatments and the rampant proliferation of misinformation about autism treatment make our place within the autism community as important now as ever.

In a related vein, we are just wrapping up our 2016 Sponsorship Campaign and would like to thank the many sponsors who share our dedication to science in autism treatment and support ASAT's mission. If you are interested in sponsoring ASAT in 2017, please visit the Sponsorship Page at www.asatonline.org/professional-sponsors/. Some of our Champion level sponsors are featured on page 44. The rest will be showcased in the next issue of *Science in Autism Treatment*.

In the next few weeks we will be soliciting donations from our subscribers. If you support our mission and the promotion of science and the need for the education that we continue to do, and we hope you do, [please give ASAT full consideration](#). These are tough times, but as you know the number of children being diagnosed on the autism spectrum has risen dramatically and we believe there is a greater need now than ever for ASAT to make a positive impact. Simply put, there is too much nonsense out there and ASAT will do all it can to help parents and providers make the most informed decisions.

In the spirit of this past Thanksgiving, I would like to take this moment to thank you, our readers, for all your support. It truly takes a village to promote the relevance of science in autism treatment.

Warmly,
David Celiberti, PhD, BCBA-D
ASAT Executive Director

Interview With Preeti Chojar, MCA, ASAT Board Member and Mom to Ravi

Conducted by David Celiberti, PhD, BCBA-D

I am pleased to have this opportunity to interview Preeti Chojar, a longstanding and invaluable member of ASAT's Board of Directors. Preeti is also the author of a Clinical Corner response that can be found [here](#).

As many of you know, we have been in the process of assessing and improving upon our website offerings, and Preeti has been integral to that effort.

David Celiberti, PhD, BCBA-D
Executive Director, ASAT



Preeti and baby Ravi

David: Prior to responding to questions specific to contributions and involvement with the website, I was hoping you could share a bit about your background. Can you tell our readers a bit about your family?

Preeti: I grew up in India, where I completed my Bachelors in Computer Science and Masters in Computer Applications. In 1994, I married my wonderful husband and we first moved to the United Kingdom and then ultimately to the United States in 1996. Our son, Ravi, was born in Lancaster, Pennsylvania in 1997. We moved from Pennsylvania to Texas to Maine following my husband's work assignments. Ravi was diagnosed with autism in Maine which is where he started to receive services. After searching for the best public schools for him all over the USA, we finally settled in Maryland. My husband and I are both software consultants. Ravi is now 19 years old.

David: Sounds like you and your family have traveled quite a bit over the last 25 years. Let's back up for a moment. Please describe the journey to diagnosis and ultimately to early intervention?

Preeti: I still remember the doctor's words, "That concerns me." It was at the 2-year check up with my son's pediatrician. We were living in Houston at that time. I had just told the doctor that instead of saying "1, 2, 3, 4, 5" Ravi was saying "Wa, Ooo, Eee, O, I."

The doctor's words stunned me and my face went white. I said to the doctor that he had been calling Cheerios "Coco," too. The doctor said that "Some word substitutions are okay but when every word is being substituted..." He stopped mid-sentence and said "We need to get a hearing test." That night I slept in a fetal position. The next day, I went to the library and started looking for books

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about children who cannot hear.

Ravi passed the hearing test with flying colors. Before we could return for a follow-up, we moved to Maine. But my fears had been allayed - his hearing was fine. He was fine. Or so I thought. He still wasn't talking though. My friends and family, living in various countries, but always my first line of defense, advised me to put him in daycare and maybe exposure to other kids would help him to start talking. While looking for a daycare I stumbled upon an ad for Child Development Services. I did not know at that time that it was a government agency. I called them for a list of daycares in the area, but also happened to mention that he wasn't talking. They offered to do a screening for him.

At the screening he was unable to follow any directions and couldn't perform even basic tasks, some of which I knew he was able to do at home. The screener finally said that he needed to have an evaluation by a team of doctors; "We need to find out what is going on with him." She did not mention the word "autism."

During the long 3-month wait for the evaluation, I did my research. One of the questions brought up during the screening was about his eye contact. At the time, I had reflexively answered, "Yes" but at home I started to notice that he did not make eye contact. At the daycare, I saw that other kids initiated and sustained eye contact, but Ravi's eye contact was rare and fleeting.

When I googled "lack of eye contact" the word

autism came up. That was my first exposure to the word. I then googled the word autism and then autism diagnosis. Everything seemed to match: the lack of language development and the lack of interest in other people. Most kids were diagnosed with autism around 3 years of age; he would be exactly three when his evaluation was scheduled.

I emailed my husband at work about what I had found, but he asked me to not jump to conclusions and to wait for the evaluation. I called my sister and she told me that maybe he just had ADHD and he would grow out of it as he grows older.



Ravi's first day at home

I also considered at the time that in most homes, parents point to pictures and the kid labels them. In our home, Ravi would point to pictures but I would have to label them. I noticed that if I mislabeled an animal, like calling a chicken a duck, Ravi would not move his finger to the next picture until I corrected myself. "He

does understand language," I thought to myself, he cannot have autism. It was only later I would learn that there is a huge difference between receptive and expressive language.

When, finally, the day of his evaluation came up, Ravi refused to participate in the evaluation. Instead, he kept running around and around the room. The only thing he did well was to find the letters of the alphabet by visually scanning the board, skills not expected from a 3-year-old. It was only later, again, that I learned that those were splinter skills, not uncommon for kids with autism. I was a few hours away from the diagnosis but still kept thinking he couldn't possibly have autism.

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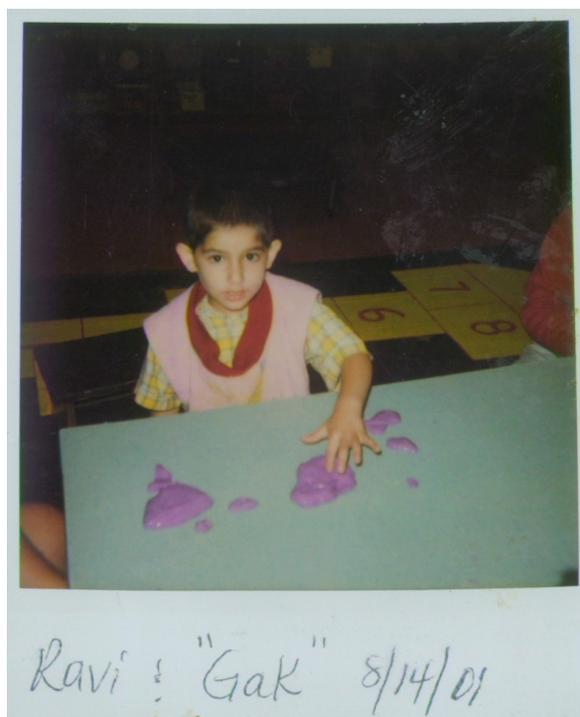
When my husband and I returned for the evaluation results, the lead doctor drew a Venn diagram on the board. The first circle was lack of language development, the second was lack of social interaction and the third was unique behaviors. A child can have any of these by themselves and it wouldn't be autism, but when a child has all three: it is autism. She never said to me, “Your child has autism.” But when the person taking notes asked the doctor, “Should I write suspected autism or definite autism?”, the doctor said, “He definitely has autism. He is hardly making eye contact.” So that is how I learned: from a side conversation.

The next few months were a blur. I forgot how to smile. Child Development Services took my husband and me to visit various programs for kids with autism. We chose the Green House Nursery School because we liked their school model. It was a regular preschool with a special inclusive program for kids with autism. The team at Green House was incredible, each person seemed to be energized and engaged. Lynn, the principal at Greenhouse, was our family trainer. She came to our house and worked with Ravi. Looking back, I think when she was working with Ravi, she was actually showing me how to work with Ravi. Betsy was Ravi's speech therapist. She would later become a dear friend and also a fellow board member. A clinical psychologist/Board Certified Behavior Analyst (BCBA), the consultant on the team, was extremely knowledgeable, detail-oriented and responsive. When I was going through the biggest crisis of my life, I found the most sincere and adept team in a tiny town in Maine.

David: I am so glad you were able to find an early intervention program that appealed to you and your husband and found confidence in those working with your son. What role did you play in your son's intervention?

Preeti: I initially thought that I would just drop Ravi off at school and they would “fix” his autism. I quickly realized that I had to be an active participant. I started by watching the therapists work with him. I wasn't just looking for what they were doing but also trying to understand the principles behind the methods. I asked lots of questions. I attended many seminars. I read a lot of books.

Maya Angelou has said, “When you know better, you do better.” Armed with a theoretical foundation in applied behavior analysis (ABA) and practical observations, I naturally started working with him during our daily routines. I involved language in everything we did together: emptying the dishwasher, doing the laundry, making breakfast, etc. We counted steps every time we went up and down the stairs. We played language games in the bathtub (e.g., “pour water



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“ From being powerless I started to feel powerful. Watching gains, however small, however slow, made me smile again.

with the right hand on the rubber ducky’s left eye”). We read books every night. When Ravi wasn’t able to answer questions, I would give him written choices on the Magnadoodle and he would circle his choice. Very slowly, but surely, Ravi’s expressive language improved and so did his eye contact and social interaction. Having something to do was actually a relief for me. From being powerless, I started to feel powerful. Watching gains, however small, however slow, made me smile again.

David: Thank you so much for sharing those words of encouragement, particularly for our readers who are parents of newly diagnosed children. It sounds as if you were very involved and worked hard at expanding upon his spontaneous language. What specific strategies did you find the most useful?

Preeti: We tried everything we could. We practiced manding and intraverbal skills whenever we could and I relied heavily on incidental teaching to expand his language.

To help me better understand the concept, the consulting psychologist said that intraverbal skills were critically important and could actually be practiced in a pitch dark room as no materials are needed. Say the first part of a phrase, and have Ravi complete the phrase. You say “Mickey” he says “Mouse”. You say “Donald” he says “Duck.” So at night, after lights were out, we practiced intraverbals. We went on for a long time but when I did eventually run out of phrases and started to practice fill-ins, I went on to animal sounds: I would say “Dog says” and Ravi would say “Woof.” Then names of books: I

would say “Green Eggs and,” Ravi would say “Ham.”

My first exposure to incidental teaching was when I told the consulting psychologist that Ravi was saying “Pickaaa” instead of “Pick me up.” He suggested that I model “Pick me up” every time he said “Pickaaa.” He explained that in general, if Ravi was using gestures for anything, I should require language. If he was already using some form of language; I should shape it to be more understandable. And once I got some understandable language, to expand it to fuller sentences. Always use every opportunity to induce language. If there is no opportunity to capture naturally, then sabotage the environment to create an opportunity. Keep things in sight but out of reach (e.g., spoon for eating, pencil for writing). Play naive: if he gestures, pretend not to understand.

It made so much sense to me. I followed the advice and though it took a painfully long time, he did start saying “Pick me aaa” and then “Pick me up.”

Another opportunity came up when Betsy brought the Cheerios book to our house. It had small holes, which Ravi would fill with Cheerios and then go on to eat them. Betsy showed me an



Ravi with his dad Atul in 2008

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opportunity for inducing language there. I would hold the Cheerios box and hand him the Cheerios only when I got some language. We loved the book and we would go through it several times a day. I looked for and bought other Cheerios books and even a Froot Loops book. We worked with the book intensively for more than a year. His expressive language improved. We went from a gesture to sound to word to phrase to sentence to expanded sentence. Grabbing the Cheerios box morphed to saying “CoCo” to “Cheerios”. And then to:

- “Want Cheerios.”
- “I want Cheerios.”
- “I want Cheerios please.”
- “I want 4 Cheerios please.”
- “Mummy, I want 4 Cheerios please.”
- “Papa, I want 4 Cheerios please.”

Another very important skill we worked on was saying “No.” There was a book that Ravi didn’t like and every time I brought it out, he would scream. I wanted him to say “No” instead of screaming. I brought that book out every night without fail. I would only put it away when he

would say something close to a “No.” When that worked, I used the same technique to get a “No” for other unwanted items.

And sure enough, we also had to teach him to say “Yes.” When we were moving from Maine to Maryland, we travelled by car. I happened to have a big bag of chips. When asked, “Do you want chips?” Ravi would respond by saying “Chips” instead of “Yes.” I wouldn’t give it to him until he said “Yes.” Sometimes when he couldn’t remember what to say, I would offer the same chip to his Dad; Dad was happy to provide a model for him.

David: I really appreciate how generous you are with sharing the details underlying your efforts with your son. Please describe the next chapter of your journey from early intervention to public school.

Preeti: I had watched an effective and well-oiled machine at Green House in Maine and when we moved to Maryland, I tried to implement all the ideas with our own team at home. Ravi was attending school in the day time and in the evenings we had therapists working with him every day in our home. The therapists

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were sponsored by the Autism Waiver, a program of the Maryland State Department of Education. We had monthly meetings at our home with our therapists and our new family trainer, the consultant to the team, Stacy Whipp. She has been our family trainer since Ravi was in first grade. She is naturally resourceful, very knowledgeable and genuinely cares about me and Ravi. She always lauds our team on our successes but right away pushes us further to work harder with Ravi. She never lets us rest on our laurels. She is rational when I am emotional. She is both my reality-check and my shoulder to lean on. She has proven to be a worthy successor to Lynn. I have been blessed with the amazing people, both at home and in the community. I have received their help to overcome many problems. For example:

Ravi's occupational therapist from school called me one night, when I was in the kitchen making chapatis, all covered with flour. She had discovered an alternate way of tying shoelaces and was going to work with Ravi at school and wanted me to follow-up at home with him.

Ravi's elementary school teachers took it upon themselves to take him grocery shopping on community trips when I told them that he had a habit of running around the store.

Once, Stacy came to our house at 7AM to help me with a task analysis when Ravi was missing his school bus as many as three times a week.

We did a reading contest with our team to see who could read the most books with him.

Being a data analyst by profession, I collected data on Ravi's talking and even created "Grand Mander Awards", given to the team member who could make him mand (request) the most.

When Ravi was 12, I was called to a meeting at his school and was happily surprised to learn that he was ready to be moved to a less restrictive environment.

Fast forward to now, his new school has a great program for kids with special needs. They have a very well-defined upper school program. We've had our ups and downs but he has been doing well: He is making good progress in Math, being able to do addition, subtraction, multiplication and division. His reading comprehension has gone up several grades and we continue to work on it. He was in his school's choir, not only playing musical instruments on stage, but even singing the song Yellow Submarine. He came second in the spelling bee, which gave us some bragging rights.

David: Preeti, this is wonderful and inspiring. We are fortunate that you shared your experience with the spelling bee. Readers can find it [here](#). How you are planning for his future?

Preeti: I have the same dreams for Ravi as most mothers, I want him to have a happy and purposeful life. I hope that one day he can live independently. I hope that one day he is able to hold a job. I also hope that one day he can get married. But having high hopes does not preclude me from making backup plans for him. If unable to live independently, I am thinking that we could buy a two-story house where he



Ravi and his parents on prom night (2014)

could live above us. We would give him as much independence as possible, but we would be always there when he needs us. We keep

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working so that someone can replace us when the time comes. If, for some reason, that doesn't work, we will also look into group homes. We have put into place services he will be needing like Metro access for transportation, DDA, State ID, Guardianship, Special Needs trust and SSI.

David: I appreciate the many layers to how you are approaching the future and your generosity in sharing your experiences with our readers, many of whom are parents and caregivers of young people with autism. In many ways this speaks directly to the work you have been doing over the last ten years with ASAT. What is your current role in ASAT?

Preeti: I am leading the website committee and have assumed a wide array of duties. I would like the ASAT website to be the bridge between parents and scientists. For parents and providers, I want it to be the site to turn to when seeking to separate the anecdotes from the scientifically accurate information. For scientists, I want it to be the site where their important work can be shared more broadly.

As part of my role, I maintain a comprehensive list of all articles published in our newsletter and upload new content to our website. I recently took a course in WordPress to formally learn what I have been learning in bits and pieces and now I take care of the majority of the changes to the website. Our webmaster is fantastic in helping me whenever the task is too big or too complicated for me. I also act as a liaison between our webmaster and other members of the board.

David: I want to take this opportunity to acknowledge all of your important work in helping to improve both the content offerings and overall layout of our website. On a more personal level, what suggestions do you offer parents of newly diagnosed children?

Preeti: However strong someone might appear to be on the outside, there is no one who isn't heartbroken about their child's diagnosis. I

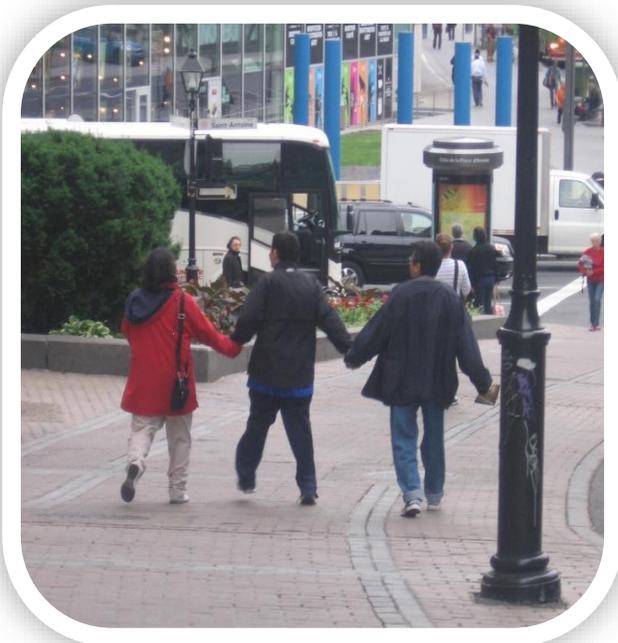
found a path to healing when I found that there was something that I could do to help my child. Each person's journey will be different but I do want to share some thoughts that I wish I had known at the beginning:

Focus on the small picture: Take it step by step, bit by bit, little by little. Sometimes the big picture is so scary that it might scare you into inaction. Just solve one problem and then the next and then the next. Focus on the small picture.

Talk: Even if you don't think your child understands, keep talking to your child. In our case it took us years to realize that he had been listening to us the whole time.

Listen: Listen to all the people who give advice, whether a consultant, a therapist or a neighbor. That doesn't mean follow every piece of advice blindly. But do listen, process and thoughtfully accept or reject.

Learn: Learn as much as you can. Learn from books, learn from people and also learn from



Family trip to Montreal

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your child.

Ask: If you don't know something, ask. In my experience, people are more than willing to explain.

Make time for yourself and be joyous in doing that: Make sure you make time for yourself. And also for your spouse, your family, and your friends. When you do spend time, do it guilt-free. Do it with joy, not with a cloud hanging over you. It is a long journey and it cannot be done without steady support.

You are the determining factor: A parent's involvement will make the biggest difference in your child's life because a parent is the common thread throughout their life. A parent's dedication towards the child inspires everyone to work harder with the child. A long steady path to work with your child is better than a burst of energy followed by burnout.

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

Preeti: I do have a few thoughts about this. 1) Be positive when talking about a child's response to intervention. During a particularly frustrating day, I said to Lynn: "Ravi cannot do anything right." Without missing a beat, Lynn started reciting all the things that Ravi does do right. She also pointed out the gains Ravi had made since we started. My advice to professionals is to think of a reply to this question while driving to the child's home or waiting for an appointment: "What does the child do right?" We, parents, sometimes need reminders. 2) Encourage parent participation, to whatever level possible. One hour of therapy a week can multiply by a huge factor if parents reinforce whatever is taught by therapists. 3) Some parents have many questions, please take the time to answer them and check in often.

David: Wonderful words of wisdom. Any final thoughts?

Preeti: I sometimes imagine a day when

“I sometimes imagine a day when autism has disappeared from our family and from every family affected by it. I imagine that Ravi is able to talk to me. I hope he says that he now understands why I made him use his words for everything instead of just giving him things. And he now understands why we had therapists working with him daily. And why we were always in his face pushing him further rather than just letting him be. I also hope he says that, “I turned out okay. Now you can rest, Mummy.”

autism has disappeared from our family and from every family affected by it. I imagine that Ravi is able to talk to me. I hope he says that he now understands why I made him use his words for everything instead of just giving him things. And he now understands why we had therapists working with him daily. And why we were always in his face pushing him further rather than just letting him be. I also hope he says that, “I turned out okay. Now you can rest, Mummy.” Until then...

Message to anyone who has ever worked with Ravi: It truly takes a village. I thank each and every one of you from the bottom of my heart for the role you have played in helping Ravi and, in turn, helping me out. Each step matters, each gain is important. Each one's role is like a piece of a jigsaw puzzle, which we are still putting together. Big or small, the puzzle wouldn't be complete without each piece.

Message to my wonderful husband: I know this is not what we signed up for when we got married. But if adversity reveals character, what a beautiful revelation it has been. You have attended every IEP meeting with me. No matter

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how challenging it may have been when we took him out in the community, you still always wanted to take him. It is a testament to your patience and love for him that we can now take him with us, everywhere we go. Throughout the journey your love for Ravi hasn't dimmed even one bit.

On behalf of ASAT, we are forever grateful for the contribution of your time and talent so that parents and other family members can garner reliable, scientifically validated information. Preeti, we are lucky to have you!

“Message to my Ravi: My face still lights up when you enter the room I am in. My heart still dances when I hear your voice. I still get filled with inspiration to work harder when you say a new phrase or when you learn a new skill. Even though the journey isn't over, there's a lot still to learn and do. There is just one thing I know for sure. I might not have every answer but I don't need to. As long as I have the village around me: we will find an answer.

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David: Thank you so much for participating in this interview! I have no doubt that our readers will be touched by your heartfelt words and inspired by your positivity and “can do” approach to raising a child with autism.

CONSUMER CORNER

Review of CDC's "Learn the Signs. Act Early." - Resources For Early Identification of Developmental Disabilities Including Autism Spectrum Disorder

Sunita Chhatwani, MSc, MEd
Maithri Sivaraman, MSc, BCBA

We at ASAT are delighted to showcase a comprehensive list of resources created by the Centers for Disease Control (CDC) to promote the early identification of autism spectrum disorder. This toolbox is not only valuable for families and early childhood caregivers and educators; medical professionals will also benefit from the many resources provided by the CDC. Due to the value of the CDC's contribution to early identification, the list we compiled for this issue of our newsletter will also be archived on the ASAT website. We encourage everyone to generously share these resources since early identification is the first step to effective treatment and a promising future to those touched by autism spectrum disorder.



Sabrina Freeman, PhD
Consumer Corner Coordinator

Although signs of autism spectrum disorder (ASD) may be present by the child's first birthday, clinical diagnoses are not typically made until age 4. According to a [CDC report](#), 20% of children identified with ASD had records of showing symptoms of autism; however, neither a school nor a clinic classified those children as having autism. Early identification of ASD is crucial, as it means intervention services can begin early and thereby increase potential to make a significant impact on a child's functioning and future well-being. To achieve this goal, the Centers for Disease Control and Prevention (CDC)

developed the campaign "Learn the Signs. Act Early." which aims to improve early identification of children with autism and other developmental disabilities so that children and families can gain access to treatment as early as possible. The "[Learn the Signs. Act Early.](#)" webpage provides a comprehensive list of resources that ASAT has summarized for our readers. A brief discussion of, and link to each resource, is provided below.

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Resources and Tools for Parents & Families

Families play an essential role in the identification of developmental concerns because, as parents, they know their child best. The following CDC tools will equip parents and families with a better understanding of typical development and possible developmental delays and disorders.

- 1) [Milestones](#)¹: An entire section is devoted to milestones that children should reach from 2 months to 5 years of age, including interactive tools and a [Parent Resource Kit](#) to help keep track of the milestones. A free library of photos and videos of developmental milestones are also provided.
- 2) What to do if a parent is concerned: A comprehensive list of [tips on what a parent should do](#) is provided (if there is concern about their child's development). These tips serve to reiterate the perils of waiting and the benefits of early identification and intervention.
- 3) [Developmental monitoring and screening](#): This section lists recommendations and discusses the importance of these practices and the link to early intervention.
- 4) [Positive parenting](#): Tips to promote healthy development, safety, and health at every stage of development are provided.
- 5) The children's book, *Amazing Me- "It's Busy Being 3!"* is a free children's book that teaches parents and teachers about developmental milestones and can serve as a fun activity to do with young children.
- 6) "[Create My Child's Story](#)" is a printed form for parents (a type of child's resume), that parents can leave with their doctor to explain who the child is within the family and outlines his or her medical history.
- 7) In addition, the CDC provides a number of links to other websites with information on developmental milestones.

Training for Early Childcare Providers and Educators

The '[Watch Me!](#)' online training is designed for

early childcare providers and educators with resources to help one learn about [developmental monitoring](#). Developmental monitoring includes the observation and recording of ways in which a child plays, acts, speaks and moves everyday. This ongoing process can be done by parents and teachers using the milestones checklists and other free resources provided on the CDC webpage. As important as it is for early educators to be aware of the various milestones that a child must attain by a certain age, it is equally important to know what needs to be done when typical development does not seem to occur. This is exactly what the 'Watch Me' training addresses.

The course is divided into 4 modules:

- 1) [Module 1](#) brings out the importance of educators in the developmental monitoring of a child. A video of a mother recounting her experience during her son's autism diagnosis highlights the role played by the preschool teacher who identifies delayed milestones and refers them to a pediatrician. The video serves to emphasize the unique role that an educator plays in monitoring the development of a child by being one of the first people to observe potential delays and the first person that parents would approach with their concerns.
- 2) [Module 2](#) is entirely about understanding children's developmental milestones. Four different categories (socio-emotional, communication, cognition and physical) are introduced and the module includes sample milestones in all domains from birth until 3 years of age. A case study illustrating how to look for milestones and possible warning signs helps put the theory in perspective.
- 3) [Module 3](#) is where the trainee learns to 'Act Early.' A simple task analysis walks us through the role of the educator in the entire process of diagnosis starting from developmental monitoring until providing referrals to special education services.
- 4) [Module 4](#) is all about communication. It aids the educator in planning for conversations with

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¹ Disclaimer from the CDC: "Learn the signs. Act early." materials are not a substitute for standardized, validated [developmental screening tools](#).

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the family regarding concerns about a child's development. The list of "try" and "avoid" statements and the video model of a [teacher discussing her concerns](#) for a child in class are concrete examples of how an educator can suggest a possible developmental delay to a parent.

Training and Information for Health Care Providers

A health practitioner's role in monitoring a child's development and identifying and referring for special services is significant as parents usually consult their doctor when they have questions about their child's development. The CDC estimates that 1 in every 6 children has a developmental delay; this makes it crucial for health practitioners to be sufficiently prepared to conduct screening or make referrals when necessary.

[AUTISM CASE TRAINING \(ACT\)](#)

The Autism Case Training (ACT) courses focus on developmental **screening** as opposed to the 'Watch Me' training that educates the reader about developmental **monitoring**. Developmental screening is a formal process conducted by doctors, licensed psychologists or teachers with special training and a specific tool is always used. The course has two versions aimed at different groups:

1. For future health care providers: The [pediatrics curriculum](#) is designed to educate future health care providers on the fundamental components of identifying, diagnosing and managing autism spectrum disorders. The classroom-based training has 7 modules.

- **Module 1** focuses entirely on the early signs of autism and case studies involving informal consultations at weddings or parties are discussed.
- **Module 2** is all about the [diagnosis](#) including information on developmental screening tools, diagnostic tools, screening in the practice setting, recommendations, and myths. The [M-CHAT-R](#) is discussed in detail, scoring criteria are mentioned and specific information is provided on what needs to be done if the

results indicate a low/medium/high risk for autism. The ASAT website already contains a part of this information under [Parents and Educators- Screen your Child](#).

- **Module 3** deals with communicating the results of the screening to the family. Specific steps are listed suggesting a method to deliver difficult information and recommendations are provided on discussing the results with parents who disagree with the screening conclusions and refuse evaluation.
- **Modules 4 and 5** address evaluation and early intervention. These two modules include a glimpse of the various available evidence-based treatments and then describe the structure and contents of an [Individualized Education Plan](#) (IEP).
- **Module 6** includes a section on maladaptive behaviors, their treatment and the evidence-based indications on pharmacotherapy as a treatment. With more than 400 treatments being used for autism, it is likely that families consult doctors before deciding on a particular intervention. There is an entire section devoted to handling questions about the use of [Complementary and Alternative Medicine](#) such as chelation therapy or hyperbaric oxygen therapy.
- **Module 7** provides anticipatory guidance for 3 common challenges observed in children with autism: sleep, feeding, and toilet training.

2. For primary health care providers: The [Web-Based curriculum](#) (CE) is a continuing education course which helps primary health care providers to earn educational credits while gaining knowledge and skills to improve early identification of children with autism spectrum disorder and ensure timely and appropriate care. There are 3 modules covering the identification, diagnosis and management of ASD; each module contains two or three case studies based on real-life situations.

There is also an extensive [video library](#) consisting of videos of children exhibiting echolalia, difficulty with transitions, reduced eye contact and other ritualistic behavior patterns

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often observed in children with ASD. Health practitioners can find relevant data and statistics related to ASD, CDC's latest research on the topic and recent articles published in scientific journals on the site. They can [download all the material for free](#).

All the materials are in English and Spanish and certain materials are available in other languages as well (i.e., Arabic, Korean, Portuguese, and Somali). The CDC has offered the flexibility to translate and customize the materials according to one's needs upon request and allows sharing material if appropriately cited.

Summing It Up

Overall, the online program is an excellent comprehensive tool for families and other service providers involved in the screening and diagnosis of children with autism. Although the resources are voluminous and can be overwhelming at first glance, the format of the training makes the program easy to follow and accessible to all. If paired with other training such as practice and feedback, CDC's "Learn the Signs. Act Early." can be an extremely efficient program to prepare families, educators and health practitioners in the early identification and treatment of autism spectrum disorders.

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CLINICAL CORNER

Improving Food Selectivity of Children With Autism

Laura Seiverling, PhD, BCBA-D
Keith Williams, PhD, BCBA-D

Food selectivity can take many forms in individuals with autism, from eating a limited variety of foods to significant food refusal. In this issue of Clinical Corner, Dr. Laura Seiverling provides readers with recommendations for how to address many of the most common food selectivity challenges and shares helpful resources to support the implementation of a feeding program.

Nicole Pearson, PsyD, BCBA-D
Clinical Corner Co-Coordinator



I am the parent of a 10 year-old boy with autism who has a very limited diet, not due to any food restrictions or allergies; he just refuses to try different types of foods. This makes for really challenging meal times and I worry about the lack of nutrition in his diet. I heard this is common in autism spectrum disorder. What can I do to address it?

Answered by: Laura Seiverling, PhD, BCBA-D, Clinical Supervisor of St Mary’s Hospital for Children’s Center for Pediatric Feeding Disorders in Bayside, NY and Keith Williams, PhD, BCBA, Director of Penn State Hershey Medical Center’s Pediatric Feeding Program. Drs. Seiverling and Williams are the co-authors of *Broccoli Boot Camp: A Guide For Improving Your Child’s Selective Eating*.

Please know your concerns are commonly reported by parents of children with autism spectrum disorder (ASD). Below are just a few examples of the statements we frequently hear from parents of children with ASD when describing their children’s eating habits.

- ★“My child only eats foods that are room temperature”
- ★“My child only eats foods that are crunchy”

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★“My child eats chicken nuggets, but only those from fast food outlets”

While the prevalence of selective eating among children with neurotypical development ranges from 10% to 35% (Reau, Senturia, Lebailly, & Christoffel, 1996; Wright, Parkinson, Shipton, & Drewett, 2007), among children with ASD, prevalence estimates range from 46% to 89% (Ledford & Gast, 2006). Parents of school-aged children with ASD reported their children ate, on average, about half as many dairy products, fruits, vegetables, and proteins as the parents of children without ASD (Schreck, Williams, & Smith, 2004). These parents also reported the children with ASD were more selective by texture, required foods be presented in specific ways, and required particular utensils and dishes at meals. In another study, less than half of parents reported their children with ASD ate the family meal (Collins, Kyle, Smith, Laverly, Roberts, & Eaton-Evans, 2003).

Selective eating and ASD

Selective eating has long been described as a feature of autism. In his initial description of children with autism, Leo Kanner mentioned restrictive diets as being common (Kanner, 1943). In the latest diagnostic manual used by mental health providers, the DSM-5, one of the criteria for autism spectrum disorder includes restricted, repetitive patterns of behavior, interests, or activities. Under this criterion, eating the same food is provided as an example of restrictive or repetitive behavior (American Psychiatric Association, 2013). Restrictive mealtime behavior extends from eating only a few foods to specific mealtime routines, such as only eating foods out of the original containers or eating preferred foods or beverages in ritualistic ways (e.g., touching a food to the mouth several times before eating it or tilting one’s head to the side when drinking out of a cup). Unfortunately, the insistence on eating the same foods reduces children’s opportunities to taste new foods, increasing the difficulty of expanding diet variety, as you have mentioned, is the case with your son. Problems with social communication may further complicate the expansion of diet variety, as children with ASD may not imitate when other family members are modeling eating a range of foods.

Consumption of a wide variety of foods, especially fruits and vegetables, has a range of health benefits, including the prevention of chronic diseases such as diabetes, heart disease, and even cancer. There are also social benefits to increasing diet variety. When children with ASD learn to eat new foods, they are learning how to tolerate change, which may help reduce their insistence on sameness and open them up to new experiences. Further, efforts to increase diet variety involve teaching the child to follow directions and just as importantly, it allows parents to practice giving instructions, providing praise, and ignoring inappropriate behaviors.

Improving food preference through taste exposure

At the most basic level, the development of a preference for a new food requires only one thing: repeated tasting of that particular food over time. For many children with ASD, this step is neither simple nor easy. There are, however, a number of interventions which provide this repeated taste exposure and have been shown to be effective at increasing diet variety (for review see Williams & Seiverling, 2014). These interventions often include one or more of the following components:

- 1) Repeated presentation of small tastes (e.g., crumb-size to pea-sized bites) of each new food across the course of several days or weeks. It is best to start with foods that are similar in taste and texture to the foods already in your child’s diet as well as foods that your child has previously

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eaten well, but no longer eats. Further, it is sometimes easier to start with foods that do not require chewing (e.g., yogurt or pudding) in order to reduce the likelihood that your child will hold the food in his mouth or spit the food out. It may also be helpful to allow your child to take a sip of a preferred beverage immediately after eating the food on the first several exposures.

- 2) Stimulus fading, which often involves making gradual increases in the bite size of new foods being introduced (e.g., from crumb or pea-sized to half-spoonful and finally full-spoonful). We recommend increasing bite sizes when your child has accepted at least three consecutive bites of the food within 30 seconds without gagging and disruptive behavior such as crying or screaming.
- 3) Positive reinforcement for acceptance of new foods and appropriate mealtime behavior in the form of verbal praise as well as access to preferred foods, toys, or activities (i.e., reinforcers) reserved only for when the child accepts new foods. It is helpful to restrict access to these reinforcers in order to keep them motivating to your child.
- 4) Planned ignoring of child inappropriate mealtime behavior, which involves providing as little attention as possible to the child's disruptive or unwanted behavior during mealtimes. Planned ignoring can be hard to do after you have spent time and effort preparing a meal or a new food and your child yells, tantrums, and refuses to eat what is presented; however, you do not need to respond in kind. Planned ignoring allows you, not your child, to set the tone of the meal. Ignoring your child's inappropriate behaviors will result in those behaviors eventually decreasing, but it requires a lot of patience on your part. It is likely that your child has been practicing these behaviors for some time so helping to change them through planned ignoring will also take time. Also, it's important to know that your child's inappropriate behavior may also *increase* initially in frequency and intensity before improving because you are no longer responding to those behaviors. And remember that while you should be ignoring your son's unwanted mealtime behaviors, be sure to provide positive attention to his appropriate behaviors during the meal.
- 5) Escape prevention by not removing a new food if the child exhibits mealtime problem behavior (e.g., pushing the food away or screaming) and often involves having a child accept at least a single bite of the food presented before leaving the eating area.
- 6) Establishment of a meal schedule in order to eliminate the child's grazing between meals to increase your child's appetite and motivation to eat during meals.

In order to track your son's progress when implementing an intervention to expand his diet variety, it may be helpful to use a data sheet to indicate which foods you have introduced, the size of the bites presented (e.g., pea-sized, half-spoonful, or full-spoonful) and if your child accepted the food presented without a problem or if he exhibited behaviors such as gagging or crying. Tracking your child's mealtime behavior can help guide your decisions regarding when to increase bite sizes of new foods introduced or when to change the intervention you have in place (if progress is not being made).

Several examples of these types of data sheets can be found and downloaded for free at www.broccolibootcamp.com/downloads.html.

Using Visual Supports

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Many parents of children with ASD express concerns about intervention success due to their child's limited understanding (and/or use) of language. Visual supports are an excellent way to address these concerns and have been shown to promote independence and decrease problem behavior associated with schedule changes (Carnahan, Musti-Rao, & Bailey, 2009; Dettmer, Simpson, Myles, & Ganz, 2000). Visual supports may include:

- ★ A chart specifying when meals or snacks will be offered across the day;
- ★ A chart or token system (e.g., a sticker chart) indicating how many bites of a food need to be eaten before earning a child's preferred activity, toy or food; and
- ★ A detailed list or set of pictures showing which foods will be presented and in which order within a meal.

Establishing a new mealtime routine

When working with children with ASD who have food selectivity, an important goal is to establish a new mealtime routine. This can be done by having parents consistently implement a structured meal plan which will replace the child's current mealtime routine of eating a limited variety. This plan may include providing reinforcement (e.g., access to a preferred food or toy) consistently for tasting new foods, presenting very small bites of the new food initially, and requiring that the child sit at the table for an established amount of time before being allowed to leave. Once a new routine is established, many children with ASD become comfortable eating new foods as long as the routine is in place. Over time, as your child begins eating a variety of new foods you've introduced and is no longer exhibiting inappropriate mealtime behavior, you will be able to fade out the various components of the structured meal plan. In order to maintain the gains made by your child in expanding his diet variety, it may be helpful to put a weekly schedule in place to use as a guide to continue presenting foods that have been successfully introduced to the child. If several weeks or months pass between presentations of a food that has been introduced, a child may start to show resistance to eating that food because it has not been offered regularly.

While food selectivity is common among many children with ASD, the good news is that it can be addressed successfully through targeted, individualized interventions that are implemented consistently. Although we have seen many children progress from eating a few foods to dozens of foods through various behavioral interventions, it is important to understand that one child's success with a particular feeding intervention does not predict success for another. Further, interventions utilized by some families may not be feasible for others due to such factors as mealtime schedules and parent availability to be present at mealtimes. Identifying which interventions will work best within the context of your family's mealtime schedule and routines is an important first step in planning. In more severe cases, it is recommended to seek the assistance of a Board Certified Behavior Analyst (BCBA) or Pediatric Psychologist who can help identify your child's specific feeding issues and develop an appropriate intervention plan. Additionally, you can access many free resources including meal plans, various types of data sheets to track your child's progress, and visual supports on our website, www.broccolibootcamp.com.

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6th Annual Rock'n 4 Autism Awareness Campaign

Catherine Rooney, BCaBA

The 6th annual Rock'n 4 Autism campaign recently completed a two-phase auction which started in April to coincide with Autism Awareness month. Thank you to each and every one of you who visited our auction site on [Bidding For Good](#) and to those who bid - you have helped to promote further public awareness of science in autism intervention. We had many items up for bid this year including: autism-related tools, software, signed books, conference tickets, sports and entertainment memorabilia, hotel stays, amusement park tickets, recreational and sports tickets, and so much more!

The purpose of the auction is to raise funds to support several important initiatives and efforts, including distribution of our free quarterly newsletter [Science in Autism Treatment](#), and expanding our outreach to various communities regionally, nationally, and globally. Some of the specific projects include:



Regional initiatives:

- Provision of resources about our comprehensive website and newsletter to public and private schools in the region.
- Distribution of posters to promote autism awareness and best practices.
- Pursuit of local collaborations that culminate in dissemination of information about our offerings and resources.

National initiatives:

- Distribution of a resource book for parents of newly diagnosed individuals with autism, [Becoming a Savvy Consumer: A Resource Booklet for Family Members of Newly Diagnosed Children with Autism](#).
- Creation of materials to support our growing externship program.
- Expansion of our website offerings for parents of newly diagnosed children as well as older children and adults.

Global initiatives:

- Translation of printed material about our resources into Spanish, French, Italian, Hebrew, and German.
- Purchase of key words to steer parents towards science-based information during their online searches.
- Resource development for the international journalism community.
- Provision of information regarding ASAT and autism treatment to university programs nationally and abroad.

We would like to extend an enormous thank you to the organizations and individuals who donated items for this auction (See page 23).

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Thank you to h-MAG and Little Town Social for the opportunity to be showcased during this year's mixer held on Thursday April 21, 2016. This hMIXER event featured drink specials, appetizers, LIVE MUSIC from Tommy Strazza and a RAFFLE to benefit Rock'n 4 Autism Awareness. The music was phenomenal and we raised almost \$500 to support families of children with autism.

"As more and more Hobokenites wisely choose to raise their families in our community, hMAG is proud to stand with those who are striving to make our city a better place for everyone. ASAT's comprehensive, pragmatic

approach to the challenges of autism endeavors to provide a road map for a happier life. We're grateful for their efforts in such a demanding field, and always happy to work with David Celiberti of the Association for Science in Autism Treatment and the entire Rock'n 4 Autism Awareness crew of volunteers here in Hoboken."

- Chris Halleron, Publisher hMAG

"As an ASAT extern, I was excited to help out during the hMAG event in April. The entertainment, music, food, and the raffle to raise money really opened up the necessary conversation about Autism Spectrum Disorders (ASD) and effective treatment with the local

Hoboken community. I'd like to send a big thank you to h-MAG and the Little Town Social for the opportunity to raise money and awareness. It was a great turnout!"

- Briana Ostrosky, MA, BCBA, ASAT Co-Coordinator

Tommy Strazza — LIVE @ Little Town Social on Thursday, April 21st



We would like to thank the following businesses, organizations and individuals who have contributed to the success of our 6th Annual Rock'n 4 Autism Awareness Campaign.

BENEFACTOR LEVEL - \$1,000+

Autism New Jersey
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ALLIANCE LEVEL - \$500-\$999

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Different Roads to Learning
Hartshorn Portraiture
Riverside Pediatrics
Erika Muller

PATRON LEVEL - \$200-\$499

ABA Piano Lessons
Anthony Pino (Bin 14 and Anthony David's)
BCB Bank
Broadway Comedy Club
Caesars Entertainment
Choc-O-Pain
Data Make the Difference, LLC
Devotion Yoga
Dr. Bobby Newman
Dr. David Celiberti (as a baker)
Hotel Edison
Jump on In
Local Barre
My Gym Hoboken
NYSABA
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Santiago Dance Kids
State Farm
The Saltair Inn
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Target
Wicked Wolf Tavern
Wonderworks Orlando

Join us for our 2017 Rock'n 4 Autism Awareness Campaign! Some of the benefits we can offer to our sponsors and donors include various forms of promotion through social media outlets, ads on ASAT's webpage and newsletter. If you know any organizations or individuals who would like to donate to this important campaign in early 2017, please email us at auction@asatonline.org.

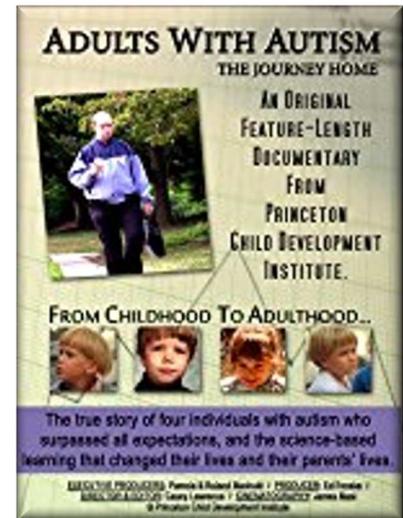
CONSUMER CORNER

Review of Adults with Autism: The Journey Home

Alana Vogl, MEd, BCBA
Daniela Fazzio, PhD, BCBA-D

Hats off to the Princeton Child Development Institute that has produced a film to address the needs of adults on the autism spectrum who continue to require applied behavioral analytic (ABA) programs throughout the lifespan. The film showcases the lives of four adults and is worth viewing for families who wonder what the future could hold for their child who has benefitted from a scientifically validated treatment program, and for those who would like to gain access to best practices treatment for their child. As an added bonus, the film highlights the critical role of parents in determining the trajectory of their children's futures.

Sabrina Freeman, PhD
Consumer Corner Coordinator



All too often the emphasis on early intervention for young children with autism means that there is little attention paid to the services and lives of adults on the autism spectrum. This can leave many families of adolescents and young adults with autism scrambling to find services and options for living situations, employment, and leisure activities that ensure a quality of life well into adulthood.

The Princeton Child Development Institute (PCDI) has created a compelling documentary that tells the stories of four adults with autism receiving Applied Behavior Analysis services. Through interviews with parents and individuals with autism as well as videos that show what ABA services look like from childhood into adulthood, the documentary captures a wide range of positive outcomes that are a direct result of scientifically validated ABA interventions.

The most critical take-aways of the film for parents, practitioners, and the general public are:

- Clear and definitive assertion that ABA is the only validated treatment for individuals with autism.
- Data collection is an essential component of any effective ABA program and parents should review data regularly with interventionists to observe progress.

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- An analogy with physicians' use of data in the form of lab tests, weight, and blood pressure to inform decisions about medications and treatments illustrate why data collection is an equally important part of ABA interventions.
- That individuals with autism should be described in terms of their abilities, rather than disabilities.
- Accurately describes the progression from childhood to adulthood and how long it can take for behavioral changes to occur.
- Adults can continue to learn and develop skills and may continue to require support in the workplace to ensure that new skills are acquired.
- Targeting life skills that will be needed throughout adulthood begins early with skills such as responding to name, following a schedule, and appropriate eating.
- Choosing a work placement should not just be based on proficiency with tasks, but also based on the individual's preferences (an example in the film of how to conduct such a work place preference assessment may be helpful for those working with adolescents and adults).
- While there is a range of outcomes for individuals with autism and not every individual will live and work 100% independently, every individual has the ability to make progress and develop skills.

Furthermore, specific attention should be paid to the way that the film positions parents in authority as essential team members. By having them describe procedures and how important data collection and data based decision making was to ensure their child's progress, the film gives weight to family's involvement. The parents' accurate descriptions of procedures using non-technical language is an important reminder to practitioners that parents must be integrally involved in the intervention from the beginning. Additionally, these examples provide a strong message to parents that their involvement and understanding of their child's intervention is a critical component to ensure generalization and maintenance of learned behaviors and skills and ultimately will impact the outcomes.

The documentary is accompanied by an additional DVD titled, "Additional Insights" which contains chapters that expand on topics presented within the documentary, many times with the parents featured telling additional anecdotes related to their journey through the diagnosis, intervention, parent training and making important decisions regarding the transition into adulthood. These chapters are described below.

Diagnosing Autism: Parents give a historical perspective of receiving an autism diagnoses 25 years ago when ASD was less common and pediatricians weren't as familiar with the signs and when there were less books and resources available.

Ed Fenske, retired Executive Director of PCDI provides another example of the difference between the medical model of intervention and a behavioral model of intervention in which data drives the decision making and the evaluation of the effectiveness of the intervention.

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What to expect from ABA: Dr. Gregory S. MacDuff, Executive Director of PCDI explains that while there is no cure for autism, with effective ABA services, every individual can make progress and learn new skills and improve the quality of their life.

Understanding ABA: Dr. MacDuff shares the belief that those opposed to behavioral services hold that ABA programs create robots. He carefully dismantles this idea by explaining that when done correctly, behavioral services should teach so individuals are responding to the same cues and their behavior is maintained by similar contingencies as anyone else.

ABA from a parent's perspective: Another example of parents clearly and expertly describing the science of ABA and the rationale for utilizing behavioral services instead of other treatments that are not evidence-based by describing examples of progress that came out of systematic instruction.

The importance of language: Mr. Fenske explains the value of teaching functional language skills, how to expand language over time, and the need to target language as a social skill.

The power of activity schedules: Parents describe a concrete teaching strategy that increases independence and the amount of time individuals spend engaged in productive activities and leisure skills.

Preparing for adulthood: Mr. Fenske shares the outcome that 40% of children who receive early intensive interventions with PCDI are mainstreamed in public school and the remaining 60% of children continue to need services through PCDI until age 22. Mr. Fenske's impresses upon parents that unlike the school age process, at age 22 parents will need to be the ones to seek out and identify adult services that their child will need in order to be as independent as possible. He also stresses that targeting skills that individuals will need in adulthood earlier will benefit them in the long run.

Dr. MacDuff outlines what the PCDI adult program looks like, giving parents aspects to look for when searching for programs. These include: a small ratio of staff to individuals (2:1), staff that are fully trained and college educated, interviewing employers prior to placement, and pre-training individuals with specific works tasks that they will be responsible for in the work setting. Furthermore, he stresses that a vocational placement should be based on an individual's interests and what they are good at with the understanding that these may change over time.

Preparing for public outings: Parents describe the challenges of taking a child with autism into different community settings, such as church, movies, mall, or the supermarket due to sensitivity to sounds. Using principles of applied behavior analysis such as positive reinforcement in the form of token boards and behavioral contracts parents explain how learning how to implement these tools led to an increase in appropriate behaviors in the community and the ability to participate in the community.

Preparing for residential options: Parents discuss the decision making process around having their child transition out of the home or remain in their home into adulthood. Parents relate the fear and anxiety that may arise when considering residential options due to concerns regarding safety, but also the happiness that comes from having a child with autism experience the "typical" adult transition to living outside of the home.

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Mr. Fenske's perspective that group homes should be seen as intensive learning environments to target life skills that will facilitate the most independent living possible, is valuable for parents considering this option for their children. Ideally, progress with skills targeted in a group home setting should then create the opportunity for different, more independent living situations. Safety concerns should be mediated by actively teaching how to respond to situations that do not occur on a regular basis.

Autism in other countries: Cultural norms and the currently accepted science and healthcare systems within different countries dictate the treatment options with ABA services not available in many countries.

Advice for parents: Parents of older adults with autism give hope to those who are just receiving an autism diagnosis for their son or daughter due to the current availability of ABA services.

In summary, we believe that *Adults with Autism: The Journey Home* is a valuable film for both families and practitioners to view. It is a reminder of the powerful resources the field of ABA has to change individuals' and families' quality of life. While it may be a film that families of adolescents or adults on the autism spectrum are drawn to, it should be recommended to families at early stages as a tool to understand the importance of using scientifically validated interventions as a direct correlation to outcomes that will impact their child throughout all stages of life.

Lawrence, C. D. (Director), & Machold, P., Machold, R., & Fenske, E. (Producers). (2015). *Adults with Autism: The Journey Home* [Motion picture on DVD]. United States: Princeton Child Development Institute.

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IS THERE SCIENCE BEHIND THAT?

Hyperbaric Oxygen Therapy

Kelley L. Harrison, MA, BCBA, LBA-KS
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Pseudoscientific treatments are those that have little to no empirical evidence of effectiveness, but yet are portrayed as having roots in science and logic that gives them the appearance of being a scientifically proven therapy. A glaring example of this is the use of hyperbaric oxygen therapy (HBOT) to treat autism spectrum disorders (ASD).

Hyperbaric oxygen chambers are pressurized containers in which individuals enter and breathe an increased level of oxygen (24%-100% times the normal level) while experiencing an increased atmospheric pressure (up to 1.3 times normal pressure). These chambers originally were used to treat decompression sickness of deep-sea divers (i.e., the bends), and are currently used with other medical conditions such as arterial gas embolism, severe carbon monoxide poisoning, smoke inhalation, and wound healing (e.g., Leach, Rees, & Wilmshurst, 1999; Feldmeier, 2003; Thom, 2011).

In the past 15 years, clinicians, medical doctors, and companies have promoted HBOT to treat ASD. Proponents of HBOT assert its positive effects on cognition, language, socialization, and anxiety. Proponents have included Defeat Autism Now!, the Autism Research Institute, Center for Autism Research and Education, and IHA (“Autism and its Growing Hyperbaric Movement,” 2005). HBOT can be provided at home by parents with very little training, offering a convenience that most autism therapies cannot (Buckley, 2005). It is a high priced therapy, with individual treatment sessions costing \$100 on average (Center for Autism Research and Education, 2016) with 40 treatments over a 3-month period costing around \$2500, and home chambers costing at least \$3,000 (Community Hyperbaric Mild Hyperbaric Oxygen Therapy, 2016).

What is the conceptual and scientific link between ASD and HBOT?

Dan A. Rossignol and colleagues have conducted several studies, published literature reviews, and given interviews on the effects of hyperbaric oxygen chambers on different symptoms of autism (e.g., Rossignol & Rossignol, 2006; Rossignol, Rossignol, James, Melnyk, & Mumper, 2007; Rossignol, et al., 2009). In their reviews of the literature, the authors cite neuroinflammation of the brain of children with ASD as one of the main reasons for using HBOT with children on the spectrum. For example, during an interview discussing how HBOT might improve autism symptomology, Rossignol noted that “a recent study” (no citation provided) found neuroinflammation of the brain in children with ASD (Rossignol & Small, 2006). As described by Rossignol, the danger of neuroinflammation is “hypoperfusion” (i.e., decreased blood flow to the brain), which could have negative effects such as limited cognition, poor attention, and other behavioral manifestations often associated with ASD. Rossignol pointed out that HBOT has been shown to increase the amount of oxygen that is carried via the plasma and infused into the tissues. He cited at least one animal study that showed HBOT to reduce inflammation; thus, possibly the same results could be obtained using HBOT with children with ASD. Rossignol ends his interview by saying,

“...I think that....the thing that excites me so much about hyperbaric oxygen therapy, is the anti-inflammatory effects, which I think is

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going to help a lot of conditions, not just autism... Certainly, it seems like a lot of people talk about increase in oxygenation of the brain as being the mechanism of improvement with autism” (p. 951).

Furthermore, to support the belief of neuroinflammation of the brain in children with ASD, and thus the use of HBOT, Rossignol and colleagues cited Vargas, Nascimbene, Krishnan, Zimmerman, and Pardo (2005), who were one of the firsts to find evidence of neuroinflammation in the brains of children with ASD. Vargas and colleagues conducted brain autopsies on 15 persons diagnosed with ASD, ranging in age from 5-44 years and compared the results to a control group of nine individuals with no diagnoses. Brain tissues from the subjects were collected and the researchers conducted numerous detailed medical analyses (i.e., immunocytochemistry, cytokine protein arrays, enzyme-linked immunosorbent assays). One of the major findings was “... an active neuroinflammatory process...” mostly in the cerebellum only for patients with ASD (2005; p. 67).

What does research have to say about HBOT and ASD?

Rossignol and colleagues have also published studies that purportedly show a positive causal relationship between HBOT and improved functioning of individuals with ASD in some areas. For example, Rossignol et al. (2007) assessed 18 children with ASD who underwent HBOT. They found that HBOT resulted in decreased inflammation and improved behavior. Rossignol et al. (2009) followed up with a large scale control group double-blind study. Results were measured by the (1) Aberrant Behavior Checklist-Community (ABC), (2) the Autism Treatment Evaluation Checklist (ATEC), and (3) the Clinical Global Impression-Improvement (CGI). All three measurements were based on parent or primary caregiver and/or physician report. No significant differences were found between groups for the ABC. A statistically significant difference was found between groups for the Sensory/Cognitive subscale of the ATEC, but not any other subscale. Finally, a significant difference was found between groups for both parent and physician reports on the CGI.

Although the above studies suggest HBOT may be a promising treatment for ASD, the designs and methods used, when critiqued against good scientific practice, cast doubt on the confidence of a causal relationship between the use of HBOT and changes in autistic symptomology. Perhaps one of the biggest methodological concerns is the lack of rigorous experimental control. The anecdotal reports were not objective behavioral measures (i.e., subjective and sensitive to placebo effects). The ATEC is not validated in the scientific community and the CGI was only conducted post-treatment, leaving an absence of a pre- and post-test. Thus, it cannot be determined if the reported statistical difference between groups existed before treatment occurred (Jepson, et al., 2011). Finally, it is possible that participants improved over time due to other simultaneous variables such as concurrent treatments.

Regardless of the findings of these group design studies, the response of a particular individual over time is arguably the most important factor to a clinician or parent. Lerman et al. (2008) completed the first controlled evaluation of HBOT using a within-subject design with three participants. This design allowed the researchers to look for individual differences within participants. They evaluated differences in skill acquisition, problem behavior, and spontaneous communication before and throughout exposure to HBOT. Results suggested a minimal increase in spontaneous communication for one participant and a small decrease in problem behavior for another participant. However, both of these findings were not replicated across participants, again weakening the confidence in the

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causal relationship between HBOT and the observed changes in behavior. This is problematic as efficacy is demonstrated by a clear connection between the intervention and improvement in the behaviors targeted for intervention with other explanations being ruled out.

The best demonstration of experimental control evaluating HBOT to date was Jepson et al. (2011), who completed the first large scale within-subject multiple baseline design evaluation of

HBOT involving 16 participants diagnosed with ASD. The authors directly measured stereotypical, aberrant, and adaptive behaviors. Each participant received 4-5 sessions of HBOT per week over an average of 56 days. Results demonstrated no difference between baseline and treatment for any of the 16 participants on any of the measured behaviors.

To date, results of studies evaluating the effects of HBOT as a treatment for ASD are, at best, mixed, making the standard of experimental rigor extremely important when evaluating results. Within-subject design studies allow for better experimental control and a better way to evaluate the effects of HBOT for specific individuals. Results of the current within-subject design studies suggest HBOT is not an effective treatment for ASD.

Furthermore, definitive negative side effects have been noted with the use of HBOT. The Mayo Clinic (2016) reports temporary myopia, middle ear injuries, lung collapse, and increase in likelihood of seizure activity. Johns Hopkins University (2016) warned that HBOT could result in oxygen poisoning and damage to the sinus.

Position Statements Concerning The Use of HBOT

The Food and Drug Administration (FDA; U.S. Department of Health and Human Services, 2016) has clearly stated that HBOT has not been clinically proven to be effective in autism treatment, nor has it been cleared as safe by the FDA.

Additionally, guidelines published by many insurance companies that fund HBOT show that treating autism with this therapy is not supported. For example, Gateway Health Company (2016) listed specific medical conditions that have evidence of being improved with HBOT, and autism is not included. Health Net, Inc. (2016) specifically listed autism as a condition for which HBOT is not medically necessary for any reason.

What is the bottom line?

The conceptual underpinnings of the logic of using HBOT with people with ASD seems to be built on poor science. As noted earlier, Rossignol and colleagues (2006; 2007; 2009) supported the claim of inflammation of the brain (of individuals with ASD) first made by Vargas and colleagues (2004; 2005). However, Vargas et al. were very limited in their conclusions and implications for clinical practice based on the inflammation hypothesis. In fact, they published a "[Frequently Asked Questions](#)" primer so that they could more easily explain the clinical limitations of their research.

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“At this time, there is no quality empirical research, meeting standards of good science, that support the claim that HBOT is effective as a treatment for ASD.”

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They emphasized that:

- It was not certain, based upon their study, that all persons with autism would in fact be found with neuroinflammation;
- Some persons may not, in fact, show any sign of this condition;
- Some of their subjects exhibited other neurological disorders (such as epilepsy and mental retardation), and thus the neuroinflammation might have been associated with those conditions instead of the autism;
- Such inflammation was not necessarily harmful to the brain. Although inflammation could be a cause of brain injury or dysfunction, Vargas and colleagues asserted that another explanation equally plausible might be that the inflammation was protecting the brain – “...there is strong evidence from experimental models that in some situations, both microglia and astroglia also contribute to the repair and restoration of neuronal connections and produce growth factors to maintain normal CNS function” (p. 1)

“ At this time, there is no quality empirical research, meeting standards of good science, that support the claim that HBOT is effective as a treatment for ASD.

In their FAQ, it is asked, “If there is neuroinflammation in the brain of some autistic patients, is treatment with anti-inflammatory or immunomodulatory medications indicated?” (p. 3). Their answer is clear – “At present, there is no indication for using anti-inflammatory medications in patients with autism” (p.3).

Pardo, Vargas, and Zimmerman (2005) also argued that treatment of neuroinflammation in children with ASD was not yet clinically indicated. They asserted that there was not yet a clear understanding of the role of neuroinflammation in autism, and it could be possible that neuroinflammation was in fact part of the healing process (Neuhaus, Archelos, & Hartung, 2003). These authors provided very clear and public limitations and cautions about how to use their research. Yet, Rossignol never included in his research papers these strong precautions disseminated by the authors, despite citing their findings of neuroinflammation.

In conclusion, at this time, there is no quality empirical research, meeting standards of good science, that support the claim that HBOT is effective as a treatment for ASD. Equally important, the logic and fundamental assumption of using HBOT with individuals with ASD (i.e., to treat inflammation of the brain) is not substantiated and deserves skepticism.

One could argue immunological deficiencies present in individuals with ASD may worsen with time. Therefore, there is a chance that larger improvements may be observed if adults were used as participants. Future research may warrant similar rigorous experimental tests with adults with autism. That being said, with the evidence available, HBOT should not be considered an effective treatment for children with ASD. It remains a pseudoscientific treatment that appears empirically sound, but has no scientific foundation of positive results.

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BOOK REVIEW

The Function Wheels

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Individuals with autism often demonstrate challenging behaviors in home, school, and community settings and, as a result, their service providers develop behavioral interventions to address these challenges. The effectiveness of behavioral interventions is predicated on consistency across people and settings. Aside from inconsistent implementation, one of the primary reasons for the failure of interventions targeting the reduction of challenging behavior is that the intervention does not adequately address the underlying function of the behavior. Behavior intervention plans can be conceptualized in one of three ways:



- Functionally relevant in which the intervention reflects the underlying function of the challenging behavior;
- Functionally irrelevant in which the intervention *does not* reflect the underlying function of the challenging behavior; and
- Functionally contraindicated in which the intervention includes components that may actually serve to reinforce the challenging behavior (e.g., a time out procedure for a behavior maintained by escape).

Function Wheels is a quick, easy-to-use resource that enables individuals working with students to better understand the underlying function of a student’s behavior and its direct implications for behavioral intervention. *Function Wheels* is a systematic approach that sequentially guides users through the process of identifying the function of a problem behavior, collecting data on the occurrences of problem behavior, developing a hypothesis based on the pattern of data collected, and implementing research-based interventions for each function. The purpose of the guide is to offer assistance when writing behavior intervention plans, with specific examples laid out in a step-by-step format.

Prior to providing a summary of the contents of this guide, we wanted to share a few cautionary statements with our readers. The *Function Wheels* is *not* intended to replace a more in-depth Functional Behavior Assessment (FBA) or Functional Analysis (FA) (Amerson, 2014). According to the author, “While *Function Wheels* is a handy and useful behavioral tool in the management of behavior, careful considerations should also be given when a more-in-depth and formal FBA or FA is

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warranted. In such cases, information using Function Wheels can be incorporated into the FBA or FA descriptive information". (A Guide to Behavioral Interventions, pg. 8). Though this guide provides conceptually systematic interventions, the author further recommends that if a multi-variable treatment package is used, which may be required for certain individuals, multiple treatments should be implemented in consultation with a Board Certified Behavior Analyst (BCBA) or licensed professional who possesses the clinical experience to design, implement, monitor, and/or modify the treatment package accordingly (Amerson, 2014).

As with any tool, the effectiveness is directly connected to the integrity and consistency demonstrated during implementation by the user. For this reason, users must be able to objectively assess their own ability and others' ability to follow each component of the intervention, and determine if they or the other persons have the skills necessary to effectively implement the intervention techniques. All users should be prepared to seek additional support and training if needed, or request consultation with a Board Certified Behavior Analyst or a licensed professional who possesses the clinical experience to train and support others in the implementation of intervention

Function Wheels Components

The Function Wheels system consists of separate components, meant to work as a whole, to help teachers proactively identify why problem behavior occurs so they can then follow the research-based interventions and strategies provided. The *Function Wheels* kit includes:

Guide to Behavioral Interventions: Provides research-based interventions and features conceptually systematic interventions that can be adapted and used as a resource to help identify specific management strategies. The first four sections of the *Guide to Behavioral Interventions* focus on the four main behavioral functions; behaviors with the function used to obtain attention, behaviors with the function to escape, behaviors with the function to gain access to preferred items, and behaviors maintained by automatic reinforcement. In addition to providing the user with a general knowledge of what the behaviors may look like, the authors also provide examples of how the behaviors may be displayed during specific environmental conditions or situations for different age ranges. When developing a behavior intervention plan, it is critical to match the intervention to the function of the behavior, or reason the behavior is being exhibited. If the function of the behavior is not determined, the intervention implemented could be ineffective or counterproductive.

This guide provides the user with intervention strategies for each function of problem behavior. Each intervention discussed throughout the guide has a brief overview of the history of the intervention and examples of the interventions being implemented. Intervention strategies for the four function areas include, but are not limited to: non-contingent reinforcement/attention, time-out, behavior contract/contingency contracting, reinforcement of successive approximations, contingent sensory access/breaks, sensory extinction, non-contingent reinforcement, and differential reinforcement of other behaviors. Research provided for the interventions ranges from 1969 to 2013. As the author mentioned, this guide is not intended to list all possible interventions, only to provide a sample of interventions available. As research in this field continues to grow, the research basis for the underlying techniques can be expanded upon to reflect the advancements that have been made in the field.

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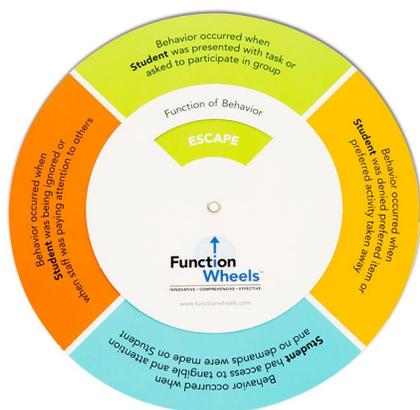
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Procedural steps are written out under the intervention. The procedural steps provide the reader with the sequence in which the intervention should be implemented. These procedures include data collection, environmental setup, and reinforcement and consequence dependent on behavioral response. In addition, the author also includes a *Key Notes* section, which provides the user with additional knowledge of directions/instructions to be considered when implementing the particular intervention.

User Guide: The *User Guide* describes how to use the Function Wheels system, step-by-step. Before determining any functions or implementing any interventions, it is essential for the user to feel comfortable with their abilities, and have a solid understanding of all the pieces to this kit. As mentioned previously, it is noted that when looking at the *User Guide*, the sequence of the steps would lead one to believe that *Writing Descriptive Notes* (step 5) would take place after the function has been calculated (step 4). In order to determine the function of a behavior, one must fully evaluate the description of the behavior, the antecedent (triggering event) and the consequence (maintaining event). This would be followed by the identification of the function.

Function Wheel: A double-sided wheel features eight research-based conditions. One side of the wheel displays antecedent conditions and the other side displays consequent conditions. Turning the wheel allows each user to align an environmental event with the function(s) of the behavior. The smaller, inner wheel represents the presence of a behavior (attention, escape, tangible, automatic), while the larger, outer wheel represents the environmental event, or condition, that triggered and/or maintained the behavior. The function wheel is designed to be a straightforward way of determining the function behind a problem behavior; however, in order to prevent any confusion, it would be helpful to differentiate the side of the wheel designed to help identify the trigger from the side designed to help identify the maintaining event.

Student Screening Sheet: Provides a template for tracking each incident of the problem behavior. The *Student Screening Sheet* allows for up to 15 behavioral events to be recorded. Fifteen recordings across at least three observations are recommended to provide an adequate sample to help identify the function of the problem behavior. The *Student Screening Sheet* has three distinct sections: Description of Observable Behavior, Functional Categories, and Descriptive Notes (detailed information about the antecedent and consequent condition for each observable behavior recorded). Though the *Student Screening Sheet* offers its user a simplistic way to track data on behavior, the arrangement of the screening tool could mislead one to believe the function of the behavior is determined prior to examining antecedent variable and consequent/maintaining variable. When in fact, the function of a behavior should not be determined prior to the examination of all variables.



Intervention Wheels: The four *Intervention Wheels* are Attention, Escape, Tangible, and Automatic. The specific *Intervention Wheel* directly related to the identified function provides recommended research-based treatments across 6

intervention areas. In addition to providing the user with research-based treatments across the intervention areas, the authors have placed ‘Facts to Remember’ on the front of each *Intervention*

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Wheel. The facts offer broad tips that are beneficial when working with any behavior despite the function, but it may be more beneficial to connect function. Although this guide provides conceptually systematic interventions, the author further recommends that if a multi-variable treatment package is used, which may be required for certain individuals, multiple treatments are implemented in consultation with a Board Certified Behavior Analyst or licensed professional who possesses the clinical experience to design, implement, monitor, and/or modify the treatment package accordingly (Amerson, 2014).

Utilizing the Function Wheels System

The Function Wheels system can be used two ways, the Function Wheels *Brief Method* or the Function Wheels *Extended Method*. Both methods can be utilized by any individual working with students. The Function Wheels *Brief Method* includes collecting data using the *Student Screening Sheet* to capture functions of behaviors as they occur, then based on the information obtained, proceeding to the corresponding *Intervention Wheel* to read about interventions which could minimize the occurrence of problem behavior and reduce any unwanted, inadvertent, or unintentional reinforcement of the problem behavior. A limitation of the *Brief Method* noted by the author, involves careful consideration of the tentative hypothesis formed about the function as it is not verified prior to intervention when the *Brief Method* is employed.

The second method, Function Wheels *Extended Method* utilizes the same framework but with more detail. Time is taken to meet as a team to define the target behavior and discuss data collection. Following the data collection process, the team meets again to discuss and analyze the variables associated with the unwanted problem behavior, determine the behavior's function, and what potential interventions can be employed. The difference between the two methods is the time spent collecting data, which during the *Extended Method* takes place over several sessions or days. This will allow for confirmation or provide the team with an opportunity to test the hypothesis regarding the function(s) of the student's challenging behavior and more importantly, to engage in a validation process prior to the start of any intervention.

Conclusion

The Function Wheels kit is an easy-to-use resource that provides service providers who have a basic knowledge of learning principles and the communicative intent of challenging behavior and its functions with a way to quickly determine appropriate interventions for problem behaviors based on the function of the behavior. For effective implementation of behavior intervention plans, it is essential for the user to have clinical knowledge and experience, or access to working directly with a more qualified professional. A concern with the utilization of this kit with those who are less experienced or knowledgeable would be the counterproductive effects it can have on students who are already struggling. Secondly, the research basis underlying techniques includes many citations from decades ago, which may give the reader the impression that no other research has been published related to that intervention and that the field has not advanced. Nonetheless, the responsible use of the Function Wheels kit may aid in the quick and effective identification of functions and a comprehensive array of interventions that would benefit many students. We applaud the author for compiling this resource in such an innovative and meaningful manner.

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RESEARCH SUMMARIES

Effects of Weighted Vests on the Engagement of Children With Developmental Delays and Autism & Effectiveness of Sensory Integration Interventions in Children With Autism Spectrum Disorders: A Pilot Study

In this issue of SIAT, we summarize two studies involving children with autism spectrum disorder. The first looks at the effects of weighted vests on social engagement during group learning at school. The second compares a sensory integration intervention (SI) to a fine motor intervention and aims to improve on methods used in previous outcome studies of SI. We hope this information is helpful.

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



Effects of Weighted Vests on the Engagement of Children With Developmental Delays and Autism

Reichow, B., Barton, E. E., Sewell, J. N., Good, L., & Wolery, M. (2010). Effects of weighted vests on the engagement of children with developmental delays and autism. *Focus on Autism and Other Developmental Disabilities, 25(1)*, 3-11.

Reviewed by: Briana Tingler, MA, BCBA and Karen Fried, PsyD, BCBA-D

Why research this topic?

Weighted vests were developed as a treatment for individuals with autism and developmental delays and are intended to improve behavior by regulating and organizing sensory input. Although weighted vests are popular, their effectiveness remains unclear. The present study aimed to use a strong experimental design to examine outcomes of weighted vests.

What did the researchers do?

Participants were three boys, age 4 to 5 years, two diagnosed with autism and one with developmental delay. They attended a university-affiliated, inclusive early childhood center and were already using a weighted vest before the study, which their teacher considered beneficial. Sessions occurred in each child's usual classroom during morning table-time. Three different conditions were alternated across the 5-day study: (1) wearing a weighted vest (5% of child's body weight per guidelines in occupational therapy literature), (2) wearing an unweighted vest (padded with foam so

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that it appeared similar to the weighted vest), and (3) wearing no vest. Five behaviors were measured: (1) engagement (purposeful, appropriate manipulation of materials or attending to a teacher or peer), (2) non-engagement, (3) repetitive behavior or mouthing materials, (4) problem behavior (crying, aggression, hitting, kicking), and (5) face out of view. Data were recorded every 10 seconds on the occurrence or non-occurrence of the behaviors during the first 10 minutes of table-time.

What did the researchers find?

Two participants showed no differences in any behavior across the three conditions. One participant displayed more problem behavior and slightly less stereotypic behavior when wearing a weighted vest than in the other conditions.

What are the strengths and limitations of the study?

This study used a rigorous experimental design with well-defined behaviors, clear description of experimental procedures, and use of “imposter weights” made of foam to keep observers blind to the condition. Limitations were the inclusion of only 3 participants and a short study period (5 days), preventing the detection of longer-term or delayed effects (if any).

What do the results mean?

These results, obtained from a well-designed study, do not support the use of weighted vests as a treatment for children with autism or developmental delays.

Effectiveness of Sensory Integration Interventions in Children With Autism Spectrum Disorders: A Pilot Study

Pfeiffer, B., Koenig, K, Kinnealey, M., Shepperd, M. & Henderson, L. (2011). Effectiveness of sensory integration interventions in children with autism spectrum disorders: A pilot study. *American Journal of Occupational Therapy, January/February 2011, 65, 76-85.*

Reviewed by: Melissa Taylor, BCaBA and Karen Fried, PsyD, BCBA-D

Why research this topic?

Sensory Integration (SI) theory posits that atypical behavior in ASD is due to inadequate neurological processing of sensory stimuli. SI interventions are intended to provide controlled sensory experiences to help the child’s nervous system produce adaptive responses. These interventions are widely used for children with autism spectrum disorder (ASD) despite a lack of evidence showing effectiveness. This study aimed to use a strong design to evaluate the effects of SI intervention on children with ASD and to function as a model for future SI research.

What did the researchers do?

The participants were 37 children, ages 6 to 12, diagnosed with autism or pervasive developmental disorder, not otherwise specified (PDD-NOS). All participants attended a particular, summer

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therapeutic activities program and were identified as having a sensory processing disorder based on a parent-completed rating scale and evaluation by an SI clinician. Participants were randomly assigned to receive either SI intervention or Fine Motor (FM) intervention for 18, 45-minute sessions over six weeks at the summer program. To measure outcome, evaluators completed the Quick Neurological Screening Test (QNST-II) and clinical observations while the parents completed three questionnaires before and after intervention. Also, before intervention, clinicians and parents collaborated to set measurable goals using the Goal Attainment Scaling (GAS) system. After intervention, the researchers reviewed the GAS with parents over the phone to determine progress toward the identified goals. The evaluators and parents were not privy to the group assignments.

What did the researchers find?

The SI and FM groups both improved on the GAS, but the SI group made larger gains than the FM group. The SI group also scored significantly lower than the FM group on parent-reported autistic mannerisms. No other significant differences were noted between the two groups.

What were the strengths and limitations of the study?

Strengths of the study included random assignment to groups, multiple measures of outcome, and checks on whether SI and FM were carried out as intended (i.e., treatment integrity). However, only a few sessions were checked for adherence to intervention procedures (as few as one of the 18 sessions that a participant received). Also, there may have been overlap in procedures between the groups. For example, SI clinicians were required to create a “playful context” to collaborate with the child on “activity choice” and to foster “therapeutic alliances.” Although not required in FM, FM clinicians may have naturally incorporated these strategies anyway, unintentionally blurring the difference between the two treatments. A key limitation is that most of the pre- and post-measures were based on parent reports rather than direct observation by independent observers. While parent reports can be valuable, they are prone to bias and therefore should not be the most prominent source of data. An additional limitation is that the researchers did not conduct evaluations to confirm participants’ ASD diagnoses.

What do the results mean?

The current study improves on the methodology used in previous studies of outcome in SI by including random assignment to groups, multiple measures of outcome, and treatment integrity checks, but the results are inconclusive because of the limitations in its design. Further research is needed to determine whether or not SI is effective as an intervention for children with autism spectrum disorder.

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★ 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.

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Organization for Research and Learning (O.R.L.)

The mission of O.R.L. is to provide very high quality services to the clients served, to contribute to the larger behavior analytic community through their activities as scientist-practitioners, and to act as advocates for the autism community. O.R.L. was originally formed in 1998 as Fabrizio/Moors consulting, and re-organized itself as O.R.L. in 2007. Beginning as a small organization in Seattle with two staff members who served four children with autism during their first year, O.R.L. has since grown to include 17 clinical staff members serving dozens of children and their families.

O.R.L. works primarily with children, adolescents, and young adults from all points along the autism spectrum in the Puget Sound area. Their clients are as young as 18 months, and currently their oldest client is 24 years old. In addition to working with individuals with autism, O.R.L. also works with a small number of youth who have severe learning disabilities in the areas of reading, writing, or mathematics. Beyond their clinical work with youth and young adults, O.R.L. also consults with other ABA agencies across the United States to help them improve the quality of the clinical services that they provide their own clients.

Their philosophy about the applied behavior analysis (ABA) services they deliver is rooted firmly in the principles of behavior analysis and espouses the following beliefs:

- **All children can learn:** Regardless of what diagnosis a child has or how affected by their disability they may be, their philosophy states that all children are capable of learning and progressing toward a more normalized, self-determined future.
- **Children have the right not only to effective intervention but also to efficient intervention:** The ABA services that a child receives should not only help ensure that they make meaningful progress, but also that they make that progress as rapidly as possible while still ensuring their happiness through the process.
- **Children have the right to intervention that is based on science and that has been shown to be effective through scientific study:** Wherever possible, children should receive intervention services that have been thoroughly researched and proven to be effective.

- **Families have the right to receive services individually tailored to the unique needs of their children and their family as a whole:** No two families are exactly alike and because of this, families should expect that the ABA services their child receives are designed to fit comfortably within the lives of all members of the family.
- **Clinical practice should inform applied research and applied research should in-form clinical practice:** The exchange between ABA research and practice should be rich and continuous so that clinical practice constantly evolves and improves.

For more information about ORL, please visit www.o4rl.com/

Melmark

The mission of Melmark is to serve children, adults and their families affected by a broad range of intellectual disabilities. We provide evidence-based, educational, vocational, clinical, residential, healthcare, and rehabilitative services, personally designed for each individual in an environment of



warmth, care and respect. Melmark’s vision is to continue to grow our national and international reputation as a Center of Excellence. Melmark’s services will always be comprised of evidence-based best practices, designed and validated by recognized leaders in the field. We will continue to generate and disseminate knowledge through research, publications, presentations, and training. We will always be “The Home That Love Built” in all aspects of what we do.

Background

Melmark was established in Berwyn, PA in 1966 by the Krentel family in order to provide a warm and loving educational and residential environment for their daughter, Melissa, who was born with Down syndrome. Melmark grew through the years and continues to serve children and adults in this population, along with others, by providing educational day, vocational and residential programs. Melmark New England, founded in 1998, is dedicated to serving children, adolescents and adults with severe autism spectrum disorders (ASD), neurological and neuro-developmental disorders, acquired brain injuries, and severe challenging behaviors.

Melmark now has a combined staff of 905 people, and serves 1,000 children and adults with developmental and intellectual disabilities, autism, brain injuries, and genetic diagnoses in divisions located in Pennsylvania and Massachusetts. Recognized as one of the leading providers in the country, Melmark continues to encourage individuals to achieve their maximum potential by offering progressive and dynamic clinical programs in an environment of warmth, care and respect.

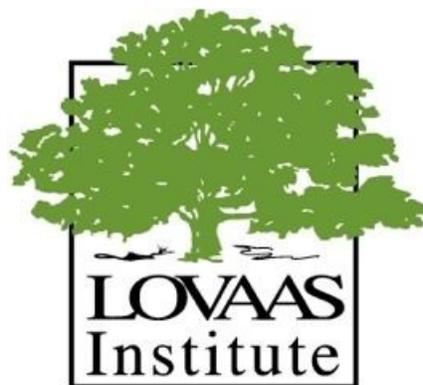
The hallmarks of Melmark include a highly credentialed professional staff (Bachelor's degree level or higher), staff to student ratios nearing 1:1 in many instances, vocational training, integrated rehab services (PT, OT, Speech, Primary Care and Nursing), and most importantly, the utilization of evidence-based Applied Behavior Analysis as the clinical model. In addition, more than 1,000 children are positively impacted each year through our outreach, home-based and school Consultation Services. Graduate training programs and an Expert Speakers Series (open to educators, clinicians and the general public) are conducted in our new lecture hall on the Melmark New England campus - The Clavin Center for Professional Development. This outreach extends Melmark's impact far beyond the walls of the school, to hundreds of educators and thousands of children.

For more information about Melmark, please visit www.melmarkne.org/

Lovaas Institute Midwest

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

The Lovaas Model of applied behavior analysis has undergone rigorous research at UCLA under the direction of Dr. Lovaas, proving its effectiveness in treating children with autism, through long-term outcome data published in peer-reviewed journals, and replicated by additional long-term outcome research as recently as 2006. The Lovaas Institute Midwest is currently organizing and analyzing its extensive body of multi-modal clinical data collected on the treatment of over 200 children over more than a decade.



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

Intervention is based on shaping behavior through reinforcement of successive approximations, prompting and fading procedures, and use of positive reinforcers that are child-specific and functional (i.e., serve the intent of increasing behavior). Initially, simple reinforcers are selected to result in the most engagement with treatment and resulting acceleration in response to treatment. As

intervention progresses, reinforcement is expanded, whenever possible, to include more natural and complex social reinforcers. The intervention is structured so that appropriate behaviors are maximized through the most effective schedules of positive reinforcement. Debilitating behaviors are reduced by managing the schedules of reinforcement and teaching alternate, more socially acceptable means of attaining the child's needs.

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

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

For more information, please visit the website of [Lovaas Institute](#).

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