



# SCIENCE IN AUTISM TREATMENT

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## Apophenia: One Explanation for the Adoption of Fad Treatments in Autism by Thomas Zane, Ph.D., BCBA-D

As the prevalence of Autism Spectrum Disorder (ASD) continues to increase, there seems to be a corresponding increase in the number of treatments, stemming from widely varying perspectives. As just one example, Green et al, (2006) surveyed parents of children with ASD and categorized dozens of treatments along several theoretical approaches, such as “skills based” (e.g., visual schedules, facilitated communication), “physiological” (e.g., sensory integration, conductive education), “applied behavior analysis” (ABA; e.g., behavior therapy, discrete trial training), and “medication” (e.g., antihistamine, Prozac).

The recent movement toward evidence-based practice in autism has underscored the long-standing

concern about the effectiveness of many treatments. Through careful scientific evaluation, it is clear that some autism therapies are ineffective, but the frustrating reality is that, for some reason, these therapies often remain popular and continue to be used. For example, although facilitated communication (FC) was thoroughly vetted and found to be completely ineffective in the 1990s, recently there has been a resurgence of this technique. This question of why ineffective treatments continued to be advocated and used by caregivers needs exploring. Why do people continue to adopt fad treatments (those treatments that have little to no evidence of effectiveness)? The consequences of adopting ineffective

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## Message from ASAT President, David Celiberti, Ph.D., BCBA-D



Hope this issue of *Science in Autism Treatment* finds you well. This marks the 2nd anniversary of the return of ASAT's newsletter. Josh and I are so grateful to our incredible newsletter team and, of course, to the thousands of readers worldwide who are committed to ensuring that science remains in the forefront of the conversation about autism treatment.

ASAT has had a very productive year thus far with progress made on many of our goals. We will write more about our recent accomplishments in the Fall issue of *Science in Autism Treatment*. In the meantime, I

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## Apophenia continued...

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treatments are very clear (e.g., Zane, Davis, & Rosswurm, 2008); the person with ASD is unlikely to benefit, and there is a waste of financial resources and instructional time that can little be afforded.

One possible reason why fad treatments persist is the concept of “apophenia,” which refers to the tendency to see patterns in unrelated or random stimuli (sometimes called “patternicity,” Shermer, 2008). This phenomenon is illustrated in many ways. One form of apophenia is “pareidolia,” the detection of images in random stimuli. Seeing faces in the clouds illustrates this – the type of meaningfulness detected there (i.e., facial features) is actually random stimuli (parts of the cloud). Seeing an image of Jesus Christ on a slice of toast (First Coast News, 2008) is another example. The pattern here (of Jesus) is detected in the (obvious) randomness of the bread and how it was toasted. It is clear that humans tend to often notice what they believe to be meaningful patterns when, in fact, none exist.

Moving beyond “finding” images and apophenia, more generally, we may also “detect” patterns in

other types of random or unrelated stimuli or events.

As one example, consider a basketball coach who wears the same socks to every game for “good luck”. The type of meaningfulness assumed there (i.e., winning due to the socks) is actually based on the co-occurrence of random stimuli that are completely unrelated to the winning. In science, an example of apophenia is what is known as the “Type 1” error (e.g., Fraenkel & Wallen, 2009). Essentially, it is the belief that something is real when it is not (Shermer, 2008). For example, in experimentation, researchers often hope that the results of an experiment are such that the dependent measure (what is hoped to change as a result of the experimental intervention) shows positive change. If so, then there is an assumption that the

results are due to the experimental intervention. However, a Type 1 error occurs when such results happened independent of the treatment, and thus are simply random results or caused by some other variable – illustrating how a pattern is perceived (believing the experimental intervention explains the results) when in fact it does not.

This concept relates to autism treatment and helps to explain the beliefs that many people have regarding the effectiveness of treatments that, in fact, are wholly ineffective. When a treatment is applied to a person with ASD, and positive results occur, there are at least two possible explanations – either the treatment was responsible for the change or the improvements were caused by something else. If the latter explanation was true, but the results are attributed to the treatment, then apophenia is illustrated. To apply this concept in autism treatment, consider a situation in which FC is used with a child. The facilitator works for hours with a child on communication effort, with whatever device is best suited for the child (e.g., keyboard, computer) After a period of time, the child spells a sentence. There is an automatic belief that since the FC intervention preceded the spelling of words, that the two are connected (“post hoc, ergo propter hoc” – “after this, because of this”). However, since FC has been shown to have no positive effect on language or communication, this appearance of meaningfulness (the language was due to the FC), is, in reality, wrong.

Some hypothesize that apophenia performed some evolutionary function (e.g., Dennett, 2006); natural selection favors finding patterns. For example, while walking through dark woods, being able to discern the shape or face of a bear in a dark outline behind a tree may allow escape and safety; to fail to discern those features may lead to death. Some argue that humans need to find order and patterns; that is the way we learn. Without such a tendency to find patterns or connections, humans would not benefit from their experience, from past learning history. Shermer (2008) argues that the “cost” of believing that a “false pattern” is real is less than not believing a real pattern. For example, walking around a ladder rather than under it provides clearer safety than walking under a ladder and potentially having something fall and cause injury. This trait of apophenia thus provides humans with the capacity to make sense of the world. Unfortunately, on some occasions (as in the examples given above about seeing faces in clouds and other inanimate objects), it also leads us to ascribe meaning and evidence for

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## Apophenia continued...

relationships among variables that in fact do not exist. So, although apophenia may have had some evolutionary benefit, this trait does provide some “false positives” – meaning that there is an assumption of meaningfulness when in fact none exists.

The reality is, sometimes “A” is connected to “B;” sometimes it is not. If humans have this tendency to assign meaning or connection when there really is none, how is this prevented? What rules are to be followed to see relatedness among, say intervention and improvement in behavior, when it is true that the intervention caused the change in the behavior, but not to see relatedness when in fact none exists? One of the best and proven ways to prevent this tendency is to adhere to the basic tenets of science. The scientific method comprises several practices that minimize the likelihood of assuming meaning when there is actually none. And although all of the methods of science are important, practicing skepticism is crucial to protecting oneself from assuming connections between things when in fact none exists.

Skepticism is not a view that promotes the disbelief of every truth or claim (Normand, 2008). Skepticism is more refined. Merriam Webster Online (2010) defines it as, “an attitude or doubt or a disposition to incredulity either in general or towards a particular object” (emphasis added). Kurtz (2010) stresses this perspective with his discussion of “skeptical inquiry,” an approach that promotes the examiner to “...seek, when feasible, adequate evidence and reasonable grounds for any claim to truth in any context” (p. 21, as quoted in Normand, 2008). Simply put, skepticism is the position of objectively evaluating, by looking for empirical evidence, the validity of any claim of cause and effect (Normand, 2008).

Apophenia (the tendency to see relationships among stimuli) is common. This trait is beneficial in many ways. However, it causes trouble when it results in parents and caregivers claiming that a particular treatment approach has benefited their children, when in fact no such relationship existed. The methods of science, with its perspective and practice of skepticism and controlled experimentation, allow us to most ably discriminate between patterns that actually exist, and what are believed to be patterns or meaning when in fact no such conclusions should be drawn.

## References

- Dennett, D. (2006). *Breaking the spell: Religion as a natural phenomenon*. New York: Penguin Group.
- DiCarlo, C. (2009). The roots of skepticism: Why ancient ideas still apply today. *Skeptical Inquirer*, 33(3), 51-55.
- First Coast News (2008). “South Florida man finds Jesus in his toast.” Retrieved November 11, 2008 at [www.firstcoastnews.com/news/florida/news-article.aspx?storyid=123367](http://www.firstcoastnews.com/news/florida/news-article.aspx?storyid=123367)
- Fraenkel, J. R., & Wallen, N. E. (2009). *How to design and evaluate research in education. Seventh edition*. New York: McGraw-Hill.
- Green, V. A., Pituch, K. A., Itchon, J., Choi, A., O'Reilly, M., & Sigafoos, J. (2006). Internet survey of treatments used by parents of children with autism. *Research in Developmental Disabilities*, 27, 70-84.
- Hubscher, S. L. (2007). Apophenia: Definition and analysis. Retrieved July 12, 2011 at [www.dbskeptic.com/2007/11/04/apophenia-definition-and-analysis/](http://www.dbskeptic.com/2007/11/04/apophenia-definition-and-analysis/)
- Kurtz, P. (2010). Exuberant skepticism. J. R. Shook (Ed.), Prometheus Books, Amherst, New York.
- Merriam-Webster Online (2010). Retrieved August 16, 2010 at: [www.merriam-webster.com/dictionary/skepticism](http://www.merriam-webster.com/dictionary/skepticism).
- Normand, M. P. (2008). Science, skepticism, and applied behavior analysis. *Behavior Analysis in Practice*, 1(2), 42-49.
- Pigliucci, M. (2009). The moral duty of a skeptic. *Skeptical Inquirer*, 33(6), 18-19.
- Shermer, M. (2008). Patternicity: Finding meaningful patterns in meaningless noise. *Scientific American*. Retrieved July 11, 2001 at: [www.scientificamerican.com/article.cfm?id=patternicity-finding-meaningful-patterns](http://www.scientificamerican.com/article.cfm?id=patternicity-finding-meaningful-patterns)
- Zane, T., Davis, C., & Rosswurm, M. (2008). The cost of fad treatments in autism. *Journal of Early and Intensive Behavior Intervention*, 5(2), 44-51.



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## ASAT Fundraising Goes Biocoastal by Denise Grosberg, M.A., BCBA, Event Writer

Something sweet is going on in California...Manager Eric Rockwell of Yogurtland in Claremont, California has teamed up with ASAT to raise money for the organization. At Yogurtland in Claremont, CA, guests help themselves to 15 different types of yogurt and toppings beyond your wildest dreams (think anything from yogurt covered pretzels to Captain Crunch). The summer months in Claremont can be scorching, ranging from 90-110 degrees in the hot sun. This means big crowds and even bigger yogurts for melting customers coming through Yogurtland's doors. Eric Rockwell, an avid supporter of local charity organizations, is committed to using this increase in business to raise money for organizations in need: "The main reason we decided to get involved with ASAT here at Yogurtland was simply because awareness is key to initiating any kind of change. If we want growth to happen then we must reach out to those who may not be directly affected by autism, and I hope that our participation acted as a catalyst for just that." With his support, ASAT has been receiving donations made at Yogurtland over the last couple of months and the company will continue its efforts through the Fall. So in the true spirit of summer, we raise a spoon to Eric Rockwell and his team at Yogurtland for their ongoing support for ASAT and commitment to more donation success in the hot summer months to come.



## From the Archives

*In this issue of "From the Archives" we highlight a list of warning signs that your child's therapy may be pseudoscientific. This list, first published in 1999, still holds true even today. A copy of this article can be found on our website: [www.asatonline.org/intervention/articles/evaluate.htm](http://www.asatonline.org/intervention/articles/evaluate.htm)*

*Sara Gershfeld, M.A., BCBA  
SIAT From the Archives Coordinator*

1. High "success" rates are claimed.
2. Rapid effects are promised.
3. The therapy is said to be effective for many symptoms or disorders.
4. The "theory" behind the therapy contradicts objective knowledge (and sometimes, common sense).
5. The therapy is said to be easy to administer, requiring little training or expertise.
6. Other, proven treatments are said to be unnecessary, inferior, or harmful.
7. Promoters of the therapy are working outside their area of expertise.
8. Promoters benefit financially or otherwise from adoption of the therapy.
9. Testimonials, anecdotes, or personal accounts are offered in support of claims about the therapy's ef-



- fectiveness, but little or no objective evidence is provided.
10. Catchy, emotionally appealing slogans are used in marketing the therapy.
11. Belief and faith are said to be necessary for the therapy to "work."
12. Skepticism and critical evaluation are said to make the therapy's effects evaporate.
13. Promoters resist objective evaluation and scrutiny of the therapy by others.
14. Negative findings from scientific studies are ignored or dismissed.
15. Critics and scientific investigators are often met with hostility, and are accused of persecuting the promoters, being "close-minded," or having some ulterior motive for "debunking" the therapy.

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## Advancing Futures for Adults with Autism by Cyndy Hayes, MS, MBA, DBA

We've all read the statistics. A child with autism is diagnosed every 20 minutes, 1 in every 110 children is diagnosed with autism; autism is more common than childhood cancer, juvenile diabetes, and pediatric AIDS combined. It is believed that one and a half million individuals in the U.S. and tens of millions worldwide are affected by autism. But you may not know that it is estimated that 80% of those diagnosed are under the age of 22. These children with autism will soon become adults with autism.

This increase in prevalence has created an increased demand for effective services for adolescents and adults with autism and for accurate information on what constitutes appropriate evidence-based intervention and practice. Unfortunately, the need continues to far exceed the available resources leaving a generation of people with autism and their families in a programmatic, financial, and personal limbo and society-at-large economically diminished.

Advancing Futures for Adults with Autism (AFAA) was established by thirteen national autism organizations including the Alpine Learning Group, Autism Speaks, The Autism Program of Illinois, The Daniel Jordan Fiddle Foundation, Easter Seals, Global Communities of Support, Hallmark Community Solutions, Organization for Autism Research, the New York Center for Autism, Re-think Autism, Southwest Autism Research and Resource Center, Trinity Services Incorporated, and the University of Miami-Nova Southeastern Center for Autism and Related Disabilities.

The purpose of AFAA is to determine how we, as a society, can support adults with autism achieve their rightful place as participating members of their communities. Among the pressing questions to be answered are:

Where are we? What is the current state of the art in residential, vocational, recreational, and transitional programming?

Where do we want to go? What new models can we design that will allow individuals to have full and meaningful lives?

How will we get there? What are the critical projects and initiatives, strategies, and policy changes that will get us there?

The work began with a report commissioned by the New York Center for Autism and authored by Peter

Gerhardt and the Organization for Autism Research outlining the current state of residential, vocational and community services in the US. This report was followed by a Think Tank held in New York City in January 2009.

The Expert Think Tank was made up of affected families and individuals, program directors, university professors, public policy authorities and specialists from both the public and private sectors. The participants identified gaps in current services and laid out strategies for filling them. They also brainstormed broad solutions, such as creating an information clearinghouse to connect the autism community, a national public awareness campaign to debunk myths about autism, and political strategies for getting the issue on a national policy agenda. The group discussed ideas on how to effectively address these areas and has posted a summary report as well as an addendum to that report.

The next phase of the initiative was a National Town Hall held in November 2009. Americans from across the country came together to create a policy agenda for addressing the needs of adults with autism. Over 1,200 people including caregivers, advocates, elected officials, family members, and adults with autism participated in the discussion and made recommendations on this important issue. The event was orchestrated from a central hub in Chicago

where a national discussion took

place via webcast with fifteen satellite sites as well as virtual participants from around the country. Based on the feedback from the Think Tank and Town Halls, a National Agenda was developed. In July 2010, AFAA hosted a Congressional briefing in Washington, DC that brought together federal legislators, national policymakers and advocates for adults with autism – including individuals who have autism – to discuss priorities for action in the public and private sectors that address the increasing and unmet demand for effective services for adolescents and adults with the disorder.

The honorary co-chairs of the Congressional briefing were Senator Robert Menendez (NJ) and Congressman Mike Doyle (PA). The briefing included an overview of autism and the array of needs of adults on the spectrum. A stakeholder panel – featuring a diverse range of adults on the autism spectrum as well as

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## Advancing Futures for Adults continued...

family members – shed light on the strengths, challenges, complexities and humanity of those most intimately affected by the condition.

The National Public Policy Agenda is one outcome of the AFAA effort. During the Congressional Briefing AFAA made the following recommendations to federal policy makers:

### **AFAA RECOMMENDATIONS TO FEDERAL POLICY MAKERS**

- ◇ Adults with autism need access to services and supports to develop skills to live safe, independent, and successful lives. AFAA urges federal policy makers to:
  - Amend the Individuals with Disabilities Education Act (IDEA) to include life skills/social skills training as part of individualized education programs (IEPs).
  - Enact the Frank Melville Supportive Housing Investment Act to design and develop new residential models.
  - Expand the capacity of Community Development Financial Institutions.
  - Expand the implementation and enforcement of the Americans with Disabilities Act (ADA) and Olmstead decisions to ensure least restrictive and most appropriate housing for adults with autism.
  - Expand the Workforce Investment Act (WIA) and Developmental Disabilities Assistance and Bill of Rights Act (DD Act) to encourage public/private collaborations that create meaningful and diverse vocational opportunities for adults with autism.
  - Expand Medicaid to include ongoing residential, vocational and community living supports.
  - Create/expand federal incentives to encourage investment in housing options for adults with autism.
  - Establish a new priority within the DD Act to provide appropriate and ongoing vocational supports for adults with autism.
- ◇ Adults with autism need access to skilled direct care personnel. AFAA urges federal policy makers to:
  - Prioritize the training of direct care workers to provide vocational and residential assistance to adults living with autism.
  - Expand the Combating Autism Act (CAA) to include training demonstration projects to teach service providers to work effectively with adults with autism.
- ◇ Adults with autism need access to and choice within the funding of services. AFAA urges federal policy makers to:
  - Change existing and establish new funding streams so that financial assistance follows the person and can be used to meet unique and evolving needs.
  - Expand both public and private funding for residential, vocational, and community integration services for adults with autism. Funding should follow the individual and be person centered to meet the varying and unique needs of adults with autism.
  - Enact the Achieving a Better Life Experience (ABLE) Act.
  - Increase the amount and flexibility of funding allowing individuals with autism and their families to make the most effective decisions.
  - Develop a cost effective process that allows cross-state portability and uniformity of person-centered funding.

On July 20, 2010 the AFAA steering committee met in [Washington, DC](#) to create public policy and to facilitate the development of quality programs and services for adults with autism. Recognizing that together we can do more, exactly one year later, on July 20, 2011, the committee met again in Washington DC with other autism organizations to expand the collaborative. For more information on AFAA visit [www.affa-us.org](http://www.affa-us.org).

## Letter from Josh Pritchard, M.S., BCBA

Science in Autism Treatment

Volume 8.3 Summer 2011

Dear Readers,

It has been two years since I joined ASAT and began working with David to revive our newsletter Science in Autism Treatment. I wanted to take a moment to talk about all the wonderful people that keep it going. First, I appreciate David's tireless effort to keep our pages filled. Amidst his enormous job of managing all the moving parts within ASAT, David is also responsible for recruiting and assisting many of our awesome volunteers.

Speaking of these awesome volunteers, over the past two years, I have had the privilege of working with an amazing cadre of contributors willing to share their effort and wisdom with you.

Dr. Daniel Mruzek has done an excellent job of motivating and cultivating great content along with Drs. James Todd and Tom Zane. These men have been willing to provide fodder for our newsletter each and every issue on topics touching on a variety of issues in science, fads, and pseudoscience in autism treatment.

Our research reviewers, under the guidance of Dr. Sharon Reeve, readily accepted the task of taking important research literature and creating easily-digestible summaries for you. Kathleen Moran was one of our first regular contributors and has now passed the torch to Amy Hansford.

Dr. Kate Fiske Massey has continued to ensure that our Consumer Corner spotlighted resources for autism treatment consumers. Equally important, our Clinical Corner has been manned [or womaned] by Lori Bechner who has recently handed off to Nicole Pearson. I look forward to the continued contributions in both of the corners.

We have recently added two new features. Sara Gershfeld searches deep in the recesses of the ASAT website and newsletters to bring you timeless nuggets in From the Archives. Kerry Ann Conde has provided us with

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## ASAT Committee Members

In addition to our Advisory Board, a number of individuals lend their time and talents to support ASAT's mission and initiatives. As you can see, we have individuals who support each aspect of our organization. If you want to assist, please email us at [info@asatonline.org](mailto:info@asatonline.org)

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## Clinical Corner: Food Selectivity

***I am a behavior analyst working with a 6-year-old child with a very limited food repertoire. Do you have any assessment and treatment recommendations that can guide my efforts to address this area?***

Answered by: Jill K. Belchic-Schwartz, Ph.D.; Pediatric/Child Psychologist, Childhood Solutions, PC, Fort Washington, PA

Food selectivity is a fairly common issue with children who have an autism spectrum disorder (ASD). Many children with ASDs have difficulties with rigidity and a need for sameness, and this holds true for their food preferences as well. This can be very distressing for parents and caregivers.

Often it is not a matter of the child actually disliking a new food but rather that s/he hasn't tasted it enough times to decide whether s/he likes it or not. Regardless of whether a child's selectivity is due to a lack of exposure to new foods, it is important to rule out any underlying medical conditions that may be perpetuating the child's feeding difficulties. Common medical concerns include gastroesophageal reflux disease (GERD) and/or food allergies or intolerances. Any underlying medical issues should be treated prior to implementing a feeding program. Once any medical treatment is underway, you can begin to tackle the child's food selectivity. If a multidisciplinary feeding clinic is nearby, encourage the parents of the child with whom you are working to consider scheduling an appointment for him/her to be evaluated.

When treating any child with food selectivity, the first step is to take a very detailed feeding history. Ask about the child's first experiences with baby food, how they handled the transition to more highly textured foods, and what they are eating now. Gather information about the setting in which the child eats. Does s/he sit at the kitchen table for all meals or is s/he allowed to graze throughout the day? Are meal times predictable? Do meals occur at regularly scheduled intervals and at the same time each day? Will the child eat only a specific brand of yogurt or will s/he eat any brand? Will the child eat only one flavor (e.g., strawberry/banana yogurt)? How is the food presented? How long is a typical meal? What are the child's refusal behaviors? The more specific the information the better!

There are a variety of techniques available that can be helpful in expanding a child's food repertoire. However, in order to identify the most appropriate treatment, you must first understand the etiology of the selectivity. For instance, is the child's food selectivity due to a frank refusal to try all new foods or is it due to a failure to progress to more advanced textured foods? The food refusal behavior may look the same (e.g., screaming, hitting, etc.), but the treatment would be quite different based on this information.

Once you are satisfied with your assessment, treatment can begin. Try to stick to a daily predictable schedule of meals and snacks and eliminate grazing/snacking in be-

*Routine tasks such as eating or going to the dentist can be problematic and unpleasant for many individuals with autism because these tasks require a tolerance for novel tastes, sounds, and environments. In this installation of Clinical Corner, we discuss how to make these experiences more tolerable for individuals on the autism spectrum. Our first response from Dr. Jill Belchic-Schwartz addresses how to assess and treat food selectivity in individuals with autism. She offers practical suggestions that both practitioners and parents can employ to expand a child's food repertoire and reduce feeding problems. In addition, Jennifer Hieminga provides specific program recommendations for teaching children with autism to cooperate with dental exams. She also lists a number of helpful strategies to enhance teaching efforts.*

*Nicole Pearson, M.A.*

*Clinical Corner Coordinator*

tween meals. Hunger can be a powerful motivator! It is also important to limit the child's access to liquids in between meals, as some children prefer to drink rather than eat. Set a 15-20 minutes time limit for meals. When introducing new foods for the first time, it is usually helpful to start with a "formerly preferred food," that is, a food that the child used to eat or a food that is similar in taste/texture to something s/he currently eats.

When presenting the "new" food to the child, start with a very small bite of the new food (e.g., sometimes as small as a pencil point) so as not to overwhelm the child and to ensure a greater likelihood of success. Some feeding therapists use the child's preferred food as a "reward" for eating the "non-preferred" food, while others use toys/activities as a reward for tasting the new food. What works for one child may not necessarily work for another. Therefore, in order to find the most salient motivators, several different options will likely need to be explored. Additionally, reward systems may need to be changed periodically in order to maintain their effectiveness.

When introducing new foods to a child, it is often easier to start with naturally occurring pureed or smooth foods first (e.g., yogurt, applesauce). The reasoning behind this suggestion is that once the child accepts a bite of pureed food into his/her mouth, swallowing it is almost guaranteed. With a piece of chopped food, the child may accept the bite into his/her mouth but chewing and swallowing may not necessarily occur and the child may expel the food. For instance, suppose you are introducing fruits and/or vegetables to a child who eats only carbohydrates. The child is more likely to demonstrate success with a ¼ teaspoon of applesauce than it is with a bite of an actual apple. Once the child is accepting a one-fourth teaspoon of applesauce consistently (e.g., nine out of ten opportunities), you can begin to increase the bite size to one-half teaspoon. Moving along in a systematic and stepwise fashion ensures a greater likelihood of success. Additional foods can be introduced in a similar fashion once the child is eating a reasonable volume of the new food.

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## Clinical Corner: Food Selectivity

Food selectivity is just one example of feeding problems that may be experienced by children on the autism spectrum. These difficulties often pose a significant challenge to parents, as nourishing typically developing children is expected to be one of the easier, and more enjoyable, tasks of parenthood. Help is available for parents experiencing this challenge, and behavior analysts are a great resource for assessing and treating these disorders because of their specific skill sets in understanding behavior and motivation. For more detailed information, a great resource is, "Treating Eating Problems of Children with Autism Spectrum Disorders and Developmental Disabilities" by Keith E. Williams and Richard M. Foxx.

### Suggested Resource:

Williams, K. E. & Foxx, R. M. (2007). Treating Eating Problems of Children with Autism Spectrum Disorders and Developmental Disabilities. New York, New York: Pro-Ed Inc.

sounds, bright lights, foreign tastes, painful sensations, sitting for long periods of time and physical touch. As a result, many children with autism display noncompliant or avoidant behavior in response to these stimuli or events. Fortunately, there is a growing body of research published in peer-reviewed journals describing effective strategies to target dental toleration. Several different behavior interventions and programs have been used to increase an individual's tolerance or proximity to an avoided stimulus or event, such as a dental exam. For example, the use of escape and reward contingent on cooperative dental behavior was shown to be effective for some individuals (Allen & Stokes, 1987; Allen et al., 1992). Non-contingent escape, in which the child was given periodic breaks during the dental exam, was also effective in decreasing disruptive behavior (O'Callaghan et al., 2006). Other strategies such as using distraction and rewards (Stark et al., 1989), providing opportunities for the individuals to participate in the dental exam (Conyers et al., 2004), and employing systematic desensitization procedures (Altabet, 2002) have been shown to be effective. Most recently, Cuvo and colleagues (2010) used a combination of interventions including, priming DVD, escape extinction, stimulus fading, distracting stimuli, etc. The board certified behavior analyst overseeing your daughter's program is likely familiar with these procedures.

Clinical practice suggests that dental exams can indeed be modified to teach children with autism component skills related to dental exams (Blitz & Britton, 2010). However, a major challenge to implementing such skill acquisition programs is the reduced opportunities to actually target these skills. One highly effective way to address this is to create a mock dental exam scenario in your home, as it provides opportunities to teach and practice the skills consistently and frequently. These scenarios should emulate, as best as possible, an actual dental office (e.g., similar tools, sounds, light, reclining chair), making it easier for the skills mastered in the mock teaching scenario to generalize to the dental office exam later on.

### Developing a "Cooperates with a dental exam" program

Following is a detailed example of the components involved with creating and implementing a "Cooperates with a dental exam" program.

1. Speak to your family dentist to determine all the components of the exam that your child will be required to participate in.
2. Based on the dentist's input, develop a detailed task analysis outlining each step of the dental exam. See sample task analysis provided in the next section below.
3. Collect necessary materials required for the exam. Many of these items may be obtained or borrowed from your dentist and may include:

## Clinical Corner: Cooperating with Dental Exams

**My daughter with autism was very resistant during her first dental visit. Are there any steps we can take to help her tolerate a dental exam? We were actively involved in her home-based early intervention program for the last two years and have a working knowledge of ABA. Our daughter's program is overseen by a board certified behavior analyst.**

Answered by Jennifer Hieminga, M.Ed., BCBA, Associate Director, New Haven Learning Centre. Toronto, Canada

For many individuals with autism, routine appointments such as medical, dental and haircuts can be extremely difficult to tolerate. There are many factors that may contribute to this intolerance such as novel environments, novel adults, novel or aversive



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## Clinical Corner: Cooperating with Dental Exams continued...

- Reclining chair (e.g., lazy boy)
- Dental bib
- Fluoride foam dental plates
- Electric Toothbrush with round head (to ensure polishing)
- Dental mask
- Dental mirror
- Plastic gloves
- X-ray plates
- Flossing pics

4. Take baseline data to determine your child's ability to cooperate with each step of the exam and to identify skills that need to be taught. For example, baseline data may indicate there is a skill deficit with tolerating novel noises at the dentist and not with the exam itself. In this situation, a specific program for tolerating novel sounds found in the dental office should be introduced. It cannot be overstated that an intervention to address this area would need to be individualized. However, for the purpose of this reply it will be assumed that your daughter presents with difficulty in all, or the majority of, the steps involved in a dental exam.

5. Lastly, before starting the program, establish highly-potent reinforcers which your daughter will access for correctly responding within this program, and collect the items that you will need to teach this skill.

### Sample Task Analysis

A comprehensive task analysis for your daughter may include the following steps; however, the behavior analyst overseeing your daughter's program will be able to develop a more relevant and individualized task analysis based on the baseline data and skills assessment.

**Mock Dental Exam at Home:** Please note this program is taught as a chain (i.e., each step builds on the previous step)

- Cooperates while sitting in a mock dental chair
- Cooperates while wearing a dental bib
- Cooperates with the instructor wearing a dental mask and gloves
- Cooperates with the instructor using a dental mirror in their mouth
- Cooperates with the instructor counting/touching their teeth with a rubber tip
- Cooperates during a mock dental exam for 1 minute
- Cooperates during a mock dental exam for 2 minutes
- Cooperates while the instructor gently flosses teeth with pic\*
- Cooperates with biting down on a fluoride foam dental plate lined with toothpaste
- Cooperates with biting down on an x-ray plate for 30 seconds
- Cooperates during a mock dental exam for 5 minutes
- Cooperates during a mock dental exam for 10 minutes

Cooperates during a mock dental exam for 15 minutes

Cooperates during a mock dental exam for 20 minutes

\*Please note that procedures such as flossing would not be suitable for a public school setting.

### Dental Exam at the Dentist:

Prior to the next actual dental exam, try to schedule an appointment to bring your daughter with autism to the dental office so that you, or one of your instructors, can do several short practice runs to promote the generalization of mastered skills in the actual setting. Most dental offices will be amenable to booking an appointment, either after hours or when they are not busy, to allow you use of the office and chair.

Again, the task analysis will need to be tailored to each individual. Some learners with autism will not require a task analysis as detailed as the example above, while others may require an even more detailed and systematic (e.g., increase time intervals in 1 minute increments) task analysis. There are a number of additional strategies which may enhance the overall success of your efforts. These include:

- Withholding a highly-potent reinforcer(s) that your daughter is able to access only for success in this program and at no other time.
- Gradually increasing the amount of time that your daughter has to cooperate with a particular procedure.
- Using a timer to indicate how much time your daughter has left until the exam will end.
- Modeling the actions that your daughter is to complete (e.g., opening your mouth). In some cases, it may be helpful to allow her to perform some of the actions on an adult.
- Using shaping strategies by differentially reinforcing close approximations to the target that you are trying to teach.
- Increasing reinforcement for aspects of the sequence with which your daughter is struggling.
- Allowing your daughter to watch a preferred movie as a form of distraction during the dental exam. Remove the preferred movie if and when she

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## Clinical Corner: Cooperating with Dental Exams continued...

is engaging in noncompliance or other maladaptive behavior, and allow her to gain access to it again when the behavior has ceased.

Teaching children to tolerate all of the noises, the tastes, the touch, and the sensations involved with a dental exam can be very difficult. However, taking the time to teach the skill systematically can prove highly effective and contribute to better oral hygiene!



### References

- Allen, K.D., Loiben, T., Aleen, S.J., & Stanley, R.T. (1992). Dentist-implemented contingent escape for management of disruptive child behavior. *Journal of Applied Behavior Analysis*, 25, 629-636.
- Allen, K. D., & Stokes, T.F. (1987). Use of escape and reward in the management of young children during dental treatment. *Journal of Applied Behavior Analysis*, 20, 381-390.
- Altabet, S. (2002). Decreasing dental resistance among individuals with severe and profound mental retardation. *Journal of Developmental and Physical Disabilities*, 14, 297-305.
- Blitz, M. & Britton, K. C. (2010). Management of the uncooperative child. *Oral and Maxillofacial Surgery Clinics of North America*, 22 (4), 461-469.
- Cuvo, A.J., Godard, A., Huckfeldt, R., & Demattei, R. (2010). Training children with autism spectrum disorders to be compliant with an oral assessment. *Research in Autism Spectrum Disorders*, 4, 681-696.
- O'Callaghan, P. M., Allen, K. D., Powell, S., & Salama, F. (2006). The efficacy of noncontingent escape for decreasing children's disruptive behavior during restorative dental treatment. *Journal of Applied Behavior Analysis*, 39 (2), 161-171.
- Stark, L. J., Allen, K. D., Hurst, M., Nash, D. A., Rigney, B., & Stokes, T. F. (1989). Distraction: Its utilization and efficacy with children undergoing dental treatment. *Journal of Applied Behavior Analysis*, 22, 297-307.

ASAT would like to continue to recognize those individuals and organizations who strive to support our mission. Specifically, we would like to thank and send a "shout out" to...

- ☐ Dr. Michelle Spader, for recommending ASAT's website and newsletter as a resource for families of children diagnosed with autism spectrum disorders.

### Shout Outs, Accolades, and Appreciation!

By Kerry Ann Conde, M.S., BCBA



- ☐ Dr. Jill Belchic, a pediatric psychologist from Childhood Solutions PC in Fort Washington, Pennsylvania, for sharing information about our newsletter with families of chil-

dren with autism. We encourage psychologists, physicians, and other providers to share the wealth of information found on the website and newsletter with their clients as well.

- ☐ Deb Harris, Executive Director of the ELIJA School, for including a brief overview of ASAT and a link to our website in their June newsletter reaching 3300 subscribers in the New York area. Click here to view <https://app.e2ma.net/app/view/CampaignPublic/id:39874.9482936522/rld:85fdc28c7ddea12bff50b39fcc1d10f3>
- ☐ Dr. Lisa Wajsblat, for her volunteer assistance with the Media Watch subcommittee. She helped to identify potential publishing outlets so that ASAT can reach out to other autism and child development resource agencies and periodicals.

If you would like to share information about any initiatives you have undertaken to support ASAT please write us at [publicity@asatonline.org](mailto:publicity@asatonline.org).



We have four new article summaries in this newsletter, the first two on the effectiveness of pharmacological interventions aimed at treating specific symptoms of autism and the last one on a type of Early Intensive Behavior Intervention. The articles on pharmacological interventions looked at specific types of medications (i.e., Citalopram and Risperdal) on the treatment of primarily repetitive behavior and aggression. The third and fourth article summaries are investigations with toddlers and adults, respectively. The third article evaluated the effectiveness of a specific model of Early Intensive Behavioral Intervention, the Early Start Denver Model, which combines developmental intervention techniques with an applied behavioral analytic approach called Pivotal Response Treatment on the overall improvement in the skill level of toddlers with autism. The fourth article investigated the prevalence of Autism Spectrum Disorders among adults and compared it to younger populations as a way in which to investigate the potential causes of autism. I hope you enjoy reading these as much as we did summarizing them! **Sharon A. Reeve, Ph.D., BCBA-D, SIAT Research Corner Coordinator**

### **Research Review: Epidemiology of Autism Spectrum Disorders in Adults in the Community in England**

Traoloch, B.S., McManus, S., Bankart, J., Scott, F., Purdon, S., Smith, J., Bebbington, P., Jenkins, R., & Meltzer, H. (2011). Epidemiology of autism spectrum disorders in adults in the community in England. *Archives of General Psychiatry*, 68(5), 459-466. **Reviewed by:** Chris Manente. M.Ed.

#### **Why this topic?**

The prevalence of Autism Spectrum Disorders (ASD) is an issue that has sparked a great amount of debate in recent years. The majority of discussion and inquiry in this area has focused on increasing estimates of the prevalence of the diagnosis of ASD. At the heart of the discussion are debates as to whether the reported increases are due primarily to changes in diagnostic criteria and an overall greater awareness of ASD, or whether the increase in prevalence reflects a real increase in the prevalence of the disorder, possibly caused by genetic, environmental, or immunological factors. It has been suggested that if the prevalence of ASD is in fact on the rise, the rate of ASD among older adults should be lower than among younger populations. The authors of the current study offer that it is likely to be the first to investigate the potential answer to this compelling question.

#### **What did the researchers do?**

The current study utilized a multistage sampling procedure and multistage assessment protocol in assessing the prevalence of ASD among adults within the general population in England. Initially, the results of the Adult Psychiatric Morbidity Survey conducted in England were used to identify the potential places of residence for adults living with ASD. Then, each household identified as being potentially eligible to take part in the study was visited by a member of the research team to verify the presence of at least 1 eligible adult. Of the 13,171 eligible addresses visited, 7,461 (56.6%) agreed to take part in a phase 1 interview. Of these individuals, 849 were selected for phase 2 interviews, of which 630 (74.2%) actually participated and completed the second round of screening.

#### **What did the researcher find?**

The data suggested that there was no evidence of a statistically significant reduction in prevalence of ASD as a function of age. This result may indicate that the causes for Autism Spectrum Disorders may be temporally constant and that the recent apparent rises in prevalence may reflect variations among measurement strategies rather than some new environmental toxin.

#### **What were the strengths and limitations of the study?**

#### **What do the results mean?**

The researchers in the current study designed a means of identifying adults with ASD living in the general population that was both reliable and cost effective. Additionally, the researchers developed a diagnostic instrument similar to those previously used to identify ASD among children to ensure that the results were relevant to their original research question of whether the prevalence of ASD among adults is similar to that which has been observed among children. One of the limitations of this study was that the survey used to identify adults with ASD was not appropriate for those individuals with profound disability. Although the researchers note that this particular population represents a small percentage of the overall population of adults with ASD, it may be important for future studies concerning the prevalence of ASD among adults to design more sensitive diagnostic tools that are appropriate for identifying those across the spectrum. Overall, the findings suggested that the prevalence of ASD is neither rising nor falling significantly. This study represents an important milestone in shifting perceptions related to the possible causes for the perceived increase in the prevalence of ASD.

**Research Review: Randomized, Controlled Trial of an Intervention for Toddlers with Autism: The Early Start Denver Model** Dawson, G., Rogers, S., Munson, J., Smith, M., Winter, J., Greenson, J., Donaldson, A., & Varley, J. (2009). Randomized, controlled trial of an intervention for toddlers with autism: The Early Start Denver Model. *Pediatrics*, 125 (1), 17-23. **Reviewed by:** Amy Hansford, Rutgers College

### Why study this topic?

Prior research has shown that early behavioral intervention may improve overall functioning and produce significant gains in IQ for children with autism who enter treatment at age 2-3 years. With the recommended screening age for autism spectrum disorders recently being lowered to 18 months, there has been an increased need to identify intervention approaches that are effective for this younger age group.

### What did the researchers do?

The researchers in this study evaluated the effectiveness of the Early Start Denver Model (ESDM) - a behavioral model designed for the treatment of young children with autism from infancy to preschool age. The ESDM combines developmental intervention techniques and an applied behavior analytic (ABA) approach called Pivotal Response Treatment (PRT). Developmental interventions aim to promote social communication by making highly motivating items available to the child, being responsive to what the child does (e.g., imitating or commenting on the child's activities), and encouraging ongoing interaction around these activities. PRT aims to increase a child's motivation to learn, monitoring of his/her own behavior, and initiations of communication with others.

Forty-eight children between the ages of 18 and 30 months, with a diagnosis of autistic disorder or pervasive developmental disorder, not otherwise specified (PDD-NOS), participated in this investigation. Participants were randomly assigned to one of two groups, and received their assigned intervention for two years. The first group was assigned to ESDM, which included twenty hours per week of intervention from clinicians and parent. The second group (assess-and-monitor group) was a "treatment as usual" model, including comprehensive assessments as well as

treatment recommendations and referrals to providers in the community.

Children were assessed at three time points: before the start of the assigned intervention, after one year of intervention, and then after two years of intervention, or when the child turned forty-eight months (choosing the later point). At each time point, measures were taken to assess diagnosis, cognitive ability (IQ), adaptive skills, and repetitive behaviors.

### What did the researchers find?

Although the ESDM group and the community treatment groups did not differ significantly on most measures at the one-year timepoint, the ESDM group outperformed the community group on measures of cognitive skill and adaptive behavior at the two-year time point. The ESDM group was also more likely than the community group to show improved diagnostic status (for example, going from a diagnosis of full autism to a diagnosis of PDD-NOS, indicating fewer symptoms of autism), though the groups did not differ from each other in overall diagnostic severity scores.

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

The researchers concluded that children receiving ESDM showed greater overall improvements than those in the assess-and-monitor group. Specifically, gains were seen in diagnostic category, IQ, and adaptive behavior. These results indicate that the ESDM model may be a beneficial treatment for toddlers with autism spectrum disorders. The results require replication by independent investigators but are significant in that they provide evidence that ESDM is effective for children with autism as young as 18 months old, and because they suggest that an intervention model combining developmental and ABA approaches may be successful.

## Research Review: Lack of Efficacy of Citalopram in Children with Autism Spectrum Disorders and High Levels of Repetitive Behaviors

King, B.H., Hollander, E., Sikick, L., McCracken, J.T., Scahill, L., Bregman, J.D., Donnelly, C.L., Anagnostou, E., Dukes, K., Sullivan, L., Hirtz, D., Wagner, A., Ritz, L. (2009). Lack of efficacy of citalopram in children with autism spectrum disorders and high levels of repetitive behaviors *Archives of General Psychiatry*, 66 (6), 583-590. **Reviewed by:** Amy Hansford, Rutgers University

### Why study this topic?

Medication to treat the symptoms of autism spectrum disorders has become increasingly frequent. One commonly prescribed class of medications are the selective serotonin reuptake inhibitors (SSRIs), which have been used in an effort to reduce repetitive behaviors. However, little research is available on the effectiveness of this treatment.

### What did the researchers do?

The researchers in this study conducted a randomized clinical trial at six centers in the United States to test the effectiveness of the SSRI citalopram hydrobromide (Celexa) for reducing repetitive behaviors. Participants were 149 children between the ages of five and 17, with a diagnosis of autism, Asperger's disorder, or pervasive developmental disorder, not otherwise specified, and displayed at

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## Research Review: Lack of Efficacy of Citalopram continued...

least moderate levels of repetitive behaviors at the start of the study.

Each participant received either liquid citalopram (Celexa) or a non-medication placebo over a 12-week period. In order to minimize bias, neither the participants nor the study doctors were told which substance the participants were taking during the course of the trial. Study doctors monitored the participants for safety, as well as for changes in overall functioning, repetitive behaviors, aggression, and irritability. Parents were also asked to complete a questionnaire at every visit regarding their child's repetitive behavior.

### What did the researchers find?

Researchers found no significant improvement in repetitive behavior or overall functioning for the participants taking citalopram compared to those taking

the placebo. The citalopram group did show a decrease in irritability, but the change was very small and was not considered clinically significant. In addition, the citalopram group was much more likely to experience side-effects than those on the placebo, with 97.3% of participants reporting at least one side-effect.

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

#### What do the results mean?

Researchers concluded that citalopram was no more beneficial than placebo for children with autism but was more likely to produce side-effects. Given the large number of study participants and careful research design, this study suggests that citalopram is unlikely to reduce repetitive behavior, and the results highlight a need to further evaluate other commonly prescribed medications for their safety and effectiveness.

## Research Review: Medication and parent training in children with pervasive developmental disorders and serious behavior problems: results from a randomized clinical trial

Aman, M.G., McDougle, C.L., Scahill, L., Handen, B., Arnold, L.E., Johnson, C., Stigler, K.A., Bearss, K., Butter, E., Swiezy, N.B., Sukhodolsky, D.D., Ramadan, Y., Pozdol, S.L., Nikolov, R., Lecavalier, L., Kohn, A.E., Koenig, K., Hollway, J.A., Hall, K.L., Dzuir, J., Ritz, L., Trollinger, S., Yu, S., Vitiello, B., & Wagner, A. (2009). Medication and Parent Training in Children with Pervasive Developmental Disorders and Serious Behavior Problems: Results from a Randomized Clinical Trial. *Journal of the Academy of Child and Adolescent Psychiatry*, 48 (12), 1143-1154. **Reviewed by:** Amy Hansford, Rutgers College

### Why study this topic?

The Food and Drug Administration has approved the drug risperidone (Risperdal) for the treatment of aggression and irritability associated with autism. There is also evidence that applied behavior analytic (ABA) interventions can be helpful in treating these problems. This study is the first large-scale investigation of whether a combination of Risperdal and ABA intervention is more efficacious than Risperdal alone.

### What did the researchers do?

The researchers evaluated the effectiveness of combining medication treatment (using Risperidone) with parent training that focused on teaching parents to use ABA principles for improving adaptive skills and reducing problem behavior (e.g., frequent tantrums, self-injury, and aggression). Parent training included at least 11 sessions with a trained clinician; sessions focused on teaching and applying principles, role-playing, and homework for the parent to implement ABA procedures

with the child with autism. One hundred and twenty-four children between the ages of four and 13 were enrolled in this study across three sites. Participants were randomly assigned to one of two groups for the 24-week trial: with one group receiving both daily doses of Risperidone and a parent training intervention (75 participants), and one receiving medication only (49 participants).

Children were assessed for several outcomes, including changes in maladaptive behavior and irritability, and adaptive skills using parent questionnaires and clinician ratings.

### What did the researchers find?

The researchers found that participants in the combined group (medication with parent training) showed significantly greater improvements than those in the medication only group at the end of the trial. These improvements were seen within measures of maladaptive behavior, aggression and irritability, as well as stereotyped behaviors.

The researchers also found that at the end of the 24-week trial, participants in the medication only group were on higher doses than those in the combined group.

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

Overall, researchers concluded that a combined treatment with medication and parent training yielded greater behavioral improvements than medication alone and that the improvements in the combined group were achieved using lower medication dosages, which may reduce the possibility of harmful side effects.

While showing improvements in reducing problem behaviors, the researchers did note that the greater contact with therapists experienced by the combined group may account for some of the improvements seen in this study. This then highlights the need to further evaluate the parent training component of this study for its effectiveness.



## A Review of *Transition Resources for Adolescents and Adults with Autism* by Daniela Fazio, Ph.D., BCBA-D, St. Amant and University of Manitoba

Science in Autism Treatment

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Parents and caregivers of children with autism often worry about the services that will be available to their children as they reach adolescence and adulthood. The common reaction for many parents is to feel lost in the “service gap.” While there are a number of provisions for funding and accommodations up to the high school level, once an individual reaches adulthood, services are more difficult to learn about and access, and can vary across the states. Funding and services that are available through the Individuals with Disabilities Education Act ([IDEA](#)) are no longer available once a student graduates with a high school diploma or turns 21 years old. This article serves to summarize resources and tools that are available to parents planning for their child’s transition to adolescence and adulthood.

Autism Speaks offers a series of documents within the [Transition Tool Kit](#), an online guide for families preparing for transition from IDEA services to adult services. Transition from services is a formal process, outlined in IDEA, and includes a coordinated set of activities to be started no later than when the student turns 16 years-old. The transition plan must be done within the Individualized Education Program ([IEP](#)), include the student and his or her family, and focus on “improving the academic and functional achievement of the child to facilitate movement from school to post-school activities, including postsecondary education, vocational education, integrated employment, continuing and adult education, adult services, independent living, or community participation.” To include the student as much as possible in the process and prepare him or her for the actual transition IEP meeting, the Transition Tool Kit suggests frequent discussions with the student about what he or she would like to do in the future. In fact, self-advocacy skills should be taught to the student, starting with explaining and discussing the nature of his or her disability. Of course, such instruction would need to be individualized for each student. The Transition Tool Kit suggests the following topics to discuss with the student in preparation for the transition meeting:

- What is a disability?
- Do you have a disability?
- What is the name of the law that allows you to receive special services from the school?
- What is an accommodation?
- Do you have any accommodations in your classes?
- What is an IEP?
- Do you have an IEP?

In the actual meeting, the student’s involvement can vary accordingly. In addition to the student and guardians, others involved in the transition planning process

*In this installment of the Consumer Corner, we continue to address the concerns of individuals with autism and their caregivers regarding the transition to adulthood and adolescence. As this transition approaches, those involved may be unsure of how to locate appropriate services and placements for the student. Here, Daniela Fazio summarizes available resources that can help caregivers navigate this exciting but often difficult period of the student’s life.*

*Kate Fiske Massey, Ph.D., BCBA-D  
Consumer Corner Coordinator*

can include teachers, school administrators, related service providers (e.g., behavioral consultants, speech and language pathologists), representatives of outside agencies (e.g., vocational rehabilitation), and other individuals who support the student.

According to the Transition Tool Kit, in preparation for the transition meeting it is important to have solid information about the student’s abilities and challenges so that plans are made based on his or her actual needs. Formal assessments done in advance can help identify those strengths and weaknesses. Most commonly, assessments fall in one of three levels: Level 1 assessments are questionnaires that help establish areas of interest and long term career goals, Level 2 assessments compare the child’s performance to a normative sample of same age peers, and Level 3 assessments are used for students who do not perform well under testing conditions and instead provide hands-on experience to assess how the student performs on a variety of tasks and environments. Results should inform preparation for and discussion in the meeting about the student’s future community participation, adult services, integrated employment, post-secondary education, vocational education, and independent living.

Additional resources that could inform the transition planning include the following:

- **A High School/High Tech Vocational Rehabilitation Program** is “a comprehensive transition program that uses a variety of activities and innovative approaches to expose transition-age youth with disabilities (ages 14 to 24) to careers in science, technology, engineering, and math (referred to as the STEM careers) and other technology-based professions” (Office of Disability Employment Policy, ODEP). It also encourages such youth to pursue postsecondary education and training. The [ODEP](#) maintains a list of states that provide such services and related outcomes.
- **One-Stop Career Centers** are available in many states, and offer information, training, and other employment-related services. For example, staff can guide individuals through [assessments](#) of their skills

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## Consumer Corner continued...

and interests, which are two important considerations when looking for a job or career. One of these assessments is an [employability check-up](#) by state. The website [CareerOneStop](#) has a wealth of information.

- **Disability Program Navigators (DPN)** provides information about work support programs available to the individual and also staff of the One-Stop Career Centers.
- The [National Center on Workforce and Disability](#) also provides valuable information on where to start and how to go about finding a job; read here about [Customized Employment](#).

The Department of Labor also lists supports: Personal Assistance Services, which “may involve such things as retrieving work materials that are out of reach or providing travel assistance for an employee with a mobility impairment, helping employees with cognitive disabilities in decision-making, reading handwritten materials to an employee with a visual impairment, or ensuring a sign language interpreter is present during staff meetings to accommodate an employee with a hearing impairment” (Office of Disability Employment Office). Other [reasonable accommodations](#) are a right under the American with Disabilities Act of 1990. Other resources for accommodations include the [Vocational Rehabilitation Agency](#), which “provides the client with the training and other services that are needed to return to work, to enter a new line of work, or to enter the workforce for the first time.” For those engaged in a job search, [Accessible Employment](#) is a job board geared towards workers with disabilities.

The [Federal Budget of 2012](#) promises an increase of several millions of dollars in funding to support people with disabilities in diverse areas including research, education, employment, housing, and transportation, which should be encouraging to families across the country ([autismvotes.com](#)).

For more details on the above-mentioned programs, browse the [Office of Disability Employment Program](#) website and do not forget about national and local advocacy agencies. For example, Autism Speaks has [this](#) comprehensive package of tips on transitioning from adolescence to adulthood, Autism New Jersey has [this](#) wonderful document on services in New Jersey; it details important aspects of the job search specific to that State and general information such as relevant sections of the Americans with Disabilities Act (ADA) of 1990, the Rehabilitation Act of 1973, and job search strategies.

## Letter from Josh continued...

the Shout Outs, Accolades, and Appreciation to recognize those supporting our mission.

And finally – I really want to pull back the curtain to shine the light on those working behind the scenes. Drs. Daniela Fazzio and Sage Rose have provided unwavering editorial support [largely catching my errors before they reach you]. Joining them on this team of proof-reading include Laurie Brophy, Ally Kearney, Germaine Ibrahim, Renita Paranjape and Lynn Faerber. On-top of this already impressive posse of proofreading people, many members of the ASAT board of directors also provide their time and energy as our release date nears. We couldn't do it without them.

Unfortunately, our amazing team of proofreaders can only fix things I've already typed; and I conclude this letter with the fear that I have failed to mention someone. I suppose this is the danger of having such an extensive network of hands each sculpting and molding SIAT into the best newsletter that ASAT can provide you. It truly is a pleasure to be surrounded by such great people.

For this, I am extremely grateful – thank you all!



## Fostering Positive Portrayals of Science-based Autism Treatment in the Media By David Cellbertl, Ph.D., BCBA-D

Thank you all for participating in this group interview. Interacting effectively with the media is something that may not come easily for those advocating for science in the treatment of autism. Many of our most skilled clinicians and prolific researchers have not mastered the requisite skills needed to interact with members of media who write about autism treatment. Andy, in your view, what is Job #1 when framing science-based autism treatment for the media?

**Dr. Andy Bondy:** Several interactions with members of the media from Delaware taught us to focus on how the Delaware Autism Program actually helped individual children or families. While trying to describe the broad educational goals of a comprehensive program is interesting to some, exciting changes in family life, job performance, and meaningful community involvement always gathered the most positive attention. Showing children happily engaged in activities that readers or viewers could understand immediately worked better than showing the "practice" time. Doing one-on-one work is often simply the preamble to getting the skill into a functional context -so we highlighted the functional, practical outcome for all ages of our students -including getting real jobs in the community. Boldly and enthusiastically talk about the positive changes your strategies bring about - talk about helping children and adults become happy (i.e., they smile and laugh more often, tantrum less often), assume greater independence/self-reliance (i.e., they initiate more, become less prompt-dependent), broaden their horizons (i.e., they participate in more varied experiences, increase the number of games they play and the number of playmates). Don't be concerned, while interacting with media representatives, that you are not holding to the strict definition of phrases they want to hear about - your colleagues will understand!

**Mary, can you share a positive experience you had with a member of the media? What made this such a positive experience?**

**Dr. Mary McDonald:** I really had a very positive experience with a photo journalist who did a television segment on a fitness program that we have developed for students with ASD. The reason I believe that it was positive is that we had discussions prior to the onsite interview and filming so that we were on the same page and he had some background information. The segment came through very well and really told the story that I was looking to tell. In addition, after completion of the piece I was able to share resources with the journalist for future reference (i.e., information about ASAT). The journalist was very interested in where to go for information as he stated that he was a "jack of all trades and a master of none."

**Ken, the Center for Autism and Applied Behavior Analysis at Caldwell College has recently received some nice publicity (see [http://www.nj.com/news/local/index.ssf/2011/04/college\\_corner\\_new\\_autism\\_cent.html](http://www.nj.com/news/local/index.ssf/2011/04/college_corner_new_autism_cent.html)). Can you share a not-so-positive experience you had with the media? What prominent lesson did you learn from this experience?**

**Dr. Ken Reeve:** A few years ago I was asked by a local newspaper reporter to comment on the lack of evidence surrounding the supposed link between vaccines and autism. To me, this

seemed like a wonderful opportunity to promote science to the general public, particularly given that this is a heated topic with profound public health implications. After describing numerous studies

that failed to find any link between autism and

"I still assert that it is important we assume the risks to promote science in autism treatment to the media. After all, if we don't do the talking, there are certainly many more people invested in pseudo- and anti-science autism issues who will."

vaccines, I was profusely thanked for my time and expertise by the reporter. I felt certain that the story would be a nice piece that would provide insights about the state of the science and better inform parents about whether to vaccinate their children. When the story came to print a few days later, however, I was mortified to see that a number of prominent anti-vaccine advocates had been given a large amount of print space to describe every "reason" in the book as to why vaccines did have a hand in causing autism. My comments were merely inserted, almost as a footnote, to provide some counterpoint, albeit a very watered down version of what I had said to the reporter.

Since that time I have learned to ask any reporter I speak to what the purpose of their article/story will be. Not all reporters, however, will let you know in advance how their story will eventually shake out. Some reporters will simply provide you with a forum to say your piece, while others may use your material as a token counterpoint to a much more controversial side of the story. Despite these risks, I still assert that it is important we assume the risks to promote science in autism treatment to the media. After all, if we don't do the talking, there are certainly many more people invested in pseudo- and anti-science autism issues who will.

**Dr. Mary McDonald:** There are times that those in the media may quote you inaccurately or, as Ken mentioned, may present something in a different light than you had intended. There was an occasion where I felt that what was printed was inaccurate and was not what was said during the interview. Because of this, I contacted a colleague to be sure that if they had read this media piece that they understood that the media had misquoted me. As a result of this experience, I am now very clear in what I share and I also ask to review the piece before it is finalized if possible.

**These are excellent suggestions and caveats. How can we better sell "science" to the media?**

**Dr. Andy Bondy:** Effective communication is defined by the listener, not the speaker. Therefore, we will be effective with the media when we speak in terms they already understand. We should not endeavor to introduce our terminology-jargon to the public via media. I would never use terms such as "stimulus control," "thinning rates of reinforcement," "stimulus generalization" or even "verbal behavior." Even if I take time to explain these terms I am immediately distancing myself from the audience. We teach skills that help children interact with

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## Fostering Positive Portrayals Interview continued...

teachers, family and peers in ways that make everyone involved happier and less frustrated. When we see a child doing things that are harmful or dangerous we teach alternative ways of handling similar situations.

Anyone planning to speak with anyone in the media should practice speaking without the use of jargon - for without practice, poor, hesitant performances are likely to occur. Perhaps talk to a group of parents or high school students and get some feedback on the best phrases to use to make your points relevant and succinct. When focusing on the broad topic of science, I first point out that science is a group activity - you can't do "science" alone. The process starts with observations of things everyone can agree took place. For example, I drop a pen and everyone agrees it falls to the floor. Without that agreement in what happened there is no science. Why did it fall? That is a different process: but one that we cannot move toward without first agreeing on what took place. And so it is

"Effective communication is defined by the listener, not the speaker. Therefore, we will be effective with the media when we speak in terms they already understand."

with behavior. First we must agree on what happened - he spoke, he hit, she smiled - then we can talk about why those things happened. Essentially, we must make science practical and available to everyone - not just PhDs.

**Dr. Mary McDonald:** I think it is important to remember that although our passion may lie in the science and data, the majority of people are interested in a great story. We often focus too much on the science and forget about the "heartfelt" story that lies within. These are the stories that most people want to read, these are the stories that sell papers, so these are the stories that the journalists are interested in sharing. It is important to tell the story that will be read and be sure to sprinkle in information about science as warranted.

**Professionals committed to evidence-based practices should be an integral part of the conversation about autism treatment. How can professionals better position themselves as resources for**

**journalists? In other words, how can they become a "go to" person within their communities?**

**Dr. Linda Meyer:** Be available. If there is an event that is rumored to be heavily covered by the media, be sure to attend and bring your business cards, as well as other informational materials. Introduce yourself as a resource and offer to be interviewed. Once the compelling interview is in print and/or on camera, other media outlets will be more likely to rely on that for follow-up stories and future pieces. Look for and/or set up photo opportunities for later use on your website and newsletter.

It is important to remember to respond to all media requests as promptly as possible. Reporters and producers all work under deadlines and if they don't get what they need, they will quickly move on; therefore, respond to deadlines. Opportunities come up on a moment's notice. You need to be ready to take advantage.

During an interview, speak in full sentences and frame your answer by echoing the question. This will make it easier for the reporter to plug your

"sound bite" into the final piece because it can stand alone. An example would be: Q: "Why should a parent call Autism New Jersey when their child receives a new diagnosis?" A: "Families should reach out to Autism New Jersey as soon as their child receives a diagnosis of autism because..."

After the interview, thank the reporter for his/her time and let them know that you are available for follow up questions, or stories in the future.

Writing a thank-you note after the story is run reminds the reporter of your contribution and may increase the likelihood of subsequent contact.

**Dr. Ken Reeve:** Within your neighborhood, you might be surprised to see how many opportunities there are to speak about science and autism treatment, particularly during April! To identify reporters who write about autism treat-

ment, research online archives of local newspapers to find stories related to this topic. Contact those reporters via email (which is usually available in online sources) and compliment them on their stories. You can then pitch some new stories to them about your activities or do so in a follow-up contact. At Caldwell College, we used this same strategy when we launched our ABA graduate programs and it was picked up in the *New York Times*!

As you establish a relationship with reporters, keep in mind that they tend to prefer interviewees with prior media experience. Once you have done a few stories, write a bio for popular consumption with bulleted accomplishments and what you can do (and where you have done it). For example:

- Can talk about effective autism treatments
- Can debunk fad treatments from real ones
- Can provide description of ABA treatment

Include in your bio all your media activities, with specifics, such as "interviewed by WFFM 1020 AM regarding vaccine controversy on August 10, 2009." There are a number of additional strategies on interacting with the media that my colleague Sharon Reeve and I contributed to a chapter in Jon Bailey and Mary Burch's wonderful book *25 Essential Skills for Behavior Analysts*.

**Those are great suggestions, Ken. Linda, based on your experiences, how can professionals pitch a story to the media? What other steps should they take?**

**Dr. Linda Meyer:** Write a compelling press release (keep it to one page), or e-mail the reporter or producer a detailed

"We often focus too much on the science and forget about the "heartfelt" story that lies within."

pitch letter. Pitching a story to the media starts with the question, "What makes my story different from others?" Answer this question: "Why should my readers/viewers care?" Within the first sentence of a pitch it is important to capture the attention of the reporter or producer.

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## Fostering Positive Portrayals Interview continued...

State exactly what the news is, or what event is being promoted. Keep it short, get to the point and relay the message so that it can appeal to a wide audience.

To avoid having reporters or producers delete an e-mail without looking at it, personalize it to each individual. Many reporters will delete messages sent to more than a few recipients. Don't send pictures, but state that photos are available and send press releases in the body of the e-mail, not as an attachment.

If you are passionate about individuals with ASDs, your work, and the science which supports your work, and think that others would benefit from additional information or another perspective, you may choose to write a letter to the editor of a newspaper. ASAT does this frequently through its Media Watch initiative.

There are clear guidelines and limitations given on the editorial page or letters-to-the-editor page. Follow the guidelines regarding length and format, especially regarding the length, which is usually about 250 words. Be sure to clarify at the opening of your letter, before the "Dear Editor" line, that you are willing to have your information edited. This increases your likelihood of being published, especially if the material is too long.

### Any other suggestions for interacting with reporters throughout the process?

**Dr. Ken Reeve:** As Linda Meyer mentioned earlier, once you earn an opportunity to speak with a reporter, you need to expect that you may be contacted for a story at a moment's notice. Reporters are often on deadlines and if they cannot get hold of you they may pass you by! This is not to say that you need to drop everything when a reporter comes-a-calling but you should try to get back to them that business day. Once you become a reliable "expert" who can be reached easily, you will be more likely to be asked to contribute to future stories. NEVER blow off an appointment with a reporter! A public relations colleague once informed me that you are placed on the proverbial black list if you do that. When you establish a relationship with a reporter, offer to give them suggestions about other professional contacts and

resources in the field. This will help the reporter with other stories they might be considering and they will (hopefully) remember your helpfulness.

**Dr. Linda Meyer:** Interacting with the media begins with confidence and knowledge. As the expert on a topic, professionals should be reliable and truthful. When a reporter calls about a particular topic, know the facts and have two or three points that you want to make. Be direct when answering your questions. Using technical language or jargon may confuse the issue and may lead to possible misinterpretation prior to publication. If a reporter asks a negative or loaded question, don't repeat the negative. Respond with positive sound bytes. Chances are, your response will be the headline or sound byte that makes the 5 o'clock news. Always tell the truth: Your credibility is all you have. Once a reported catches you in a lie you will never regain his/her trust. Even worse, your lying becomes the story.

Do not work very hard to establish your credentials as you wouldn't be the subject for the interview if someone didn't think you belonged there. Stating your credentials wastes time and makes you sound arrogant. If you are not ready and able to answer a reporter's questions, refer them to someone who can. Helping the reporter make other connections is often very much appreciated. Don't be creative: If you don't know an answer, say so and offer to get back to the reporter.

Remember, you control the interview. You

"There is a lot to learn from others who recount newsworthy stories in a compelling manner. Take notice and judge how well or how poorly people tell their stories."

can always steer an interview back to your topic of expertise by beginning your answer with, "The real issue is...", or, "More importantly..." Know the reporters' style and the influence they have in their own newspapers as well as with other reporters. One suggestion for getting a story published is to give the lead to a prominent reporter. Chances are when one influential reporter picks up a story, others will follow. We also know a

journalist who frequently inserts an unrelated, thought-provoking, and controversial question during an interview. Responding is at best a distraction and may even turn the interview into something very different. Remember, you're the expert. Hopefully, you came to the interview with a plan in mind. Be sure you focus and refocus on the message you want to deliver throughout the interview.

### Do you have recommendations for any resources that may help professionals improve upon their repertoire of skills for relating to journalists?

**Dr. Linda Meyer:** In preparation for working with journalists, take time to watch, read and listen to reputable news outlets. There is a lot to learn from others who recount newsworthy stories in a compelling manner. Take notice and judge how well or how poorly people tell their stories. Note the anchor's lead-ins to stories, and how in ten seconds or less, they tell listeners what the upcoming story will cover. Also pay attention to headlines and note how so few words can encapsulate an entire story.

If possible, spend the money and the time to get media training from a credentialed media specialist. You'll learn how to dress for a T.V. interview (no fabrics with bold patterns, avoid white), interview using a remote camera and ear bud (look right at the camera and assume that the camera is always on you), the importance of posture (keeping your back off the seat and leaning forward takes years off of your appearance). While interviewing remotely for a radio broadcast, consider standing up while being interviewed on the phone. It may keep you alert and give a lift to your voice.

On a broader note, develop a communication plan for your school or agency. Designate a spokesperson(s)-decide who can and should represent your school, program or agency. Take a few minutes to codify a description of your program (could be taken directly from your Federal 990 Form if you have reworked it recently), and identify current issues about which you may contribute input.

**Dr. Ken Reeve:** In addition to using Linda

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## Fostering Positive Portrayals Interview continued...

Meyer's great suggestions, I also recommend a very helpful book to any professional interested in promoting science-based autism treatment to the media. It's called *A Scientist's Guide To Talking With The Media: Practical Advice from the Union of Concerned Scientists*, by Hayes and Grossman. Although it doesn't focus on autism per se, the information in the book is generalizable to speaking to the media about any topic grounded in science.

"Disavow yourself of the view that being smart is equivalent to being a good public speaker."

**Dr. Andy Bondy:** I would advise looking for podcasts or other easily digestible material on public relations. Disavow yourself of the view that being smart is equivalent to being a good public speaker. Working effectively with individuals with autism and conducting a successful training workshop, talking to the media is a behavior that, like every other one, is

honed over time - it does not simply emerge following reading, watching or otherwise passively observing others. Seek out practice opportunities and refine your behavior over time.

**Mary, why is it so important for the members of the media to be better educated specifically when it comes to individuals with ASD?**

**Dr. Mary McDonald:** Because autism is such a popular topic in the media, it is rare that a week would ever go by without some sort of media coverage on au-

tism. Although media articles can be a helpful source of information, they also can mislead people in many ways. For example, when parents first learn that their child has an autism diagnosis, they can be overwhelmed and may not know where to begin. Often the media provides information about interventions for individuals with autism. However, this

information is often inaccurate or the interventions that are covered in the media are not based on empirical evidence. As parents typically do not have training in the scientific method, it is often difficult for them to differentiate between science-based and non-science based interventions. Therefore they are likely to waste time and money on unproven treatments, which can result in an emotional drain on the family. In addition, there is always potential harm to the child and thereby the entire family. ASAT sponsors Media Watch in order to respond to these types of media pieces and provide feedback to the writer. We are currently implementing our journalist initiative to try to take a more proactive approach and educate the media community about autism interventions before their stories "go to print".

**Thank you all for your insights and suggestions. I appreciate the time you took to share your diverse experiences with our readers.**

### About the Interviewees

**Andy Bondy, Ph.D.,** has over 40 years of experience working with children and adults with autism and related developmental disabilities. He served as the Director of a statewide program for students with autism for more than a dozen years. He and his wife, Lori Frost, pioneered the development of the Picture Exchange Communication System (PECS). He has designed the *Pyramid Approach to Education* as a comprehensive combination of broad-spectrum behavior analysis and functional communication strategies. This approach has been cited as a model program for preschool and school-aged children within public and private school settings. He has published numerous articles, several books, as well as been an invited presenter at conferences around the world. He is the co-founder of Pyramid Educational Consultants, Inc., an internationally-based team of specialists from diverse fields providing guidance and services throughout the world.

**Mary E. McDonald, Ph.D., BCBA-D** is an Assistant Professor in the CRSR Department (Counseling, Research, Special Education and Rehabilitation) where she teaches in the Special Education Program and directs the Advanced Certificate in Applied Behavior Analysis (an approved BACB course sequence). In addition to her role at Hofstra University, she also directs The Eden II/Genesis Outreach Autism Center. She has nearly 20 years experience directing programs for students with autism from early intervention through adulthood. She completed her Ph.D. in Learning Theory at the CUNY Graduate Center and is a Board Certified Behavior Analyst at the Doctoral level. Dr. McDonald currently serves on the Board of Council on Autism Services (CAS) and as Vice President of the Association for Science in Autism Treatment (ASAT). Dr. McDonald has published articles in areas such as: self-management, social reciprocity, inclusion and the use of technology in educating students with ASD.

**Linda Meyer, Ed.D., MPA, BCBA-D, CPT** is the Executive Director of Autism New Jersey and a consultant in private practice (Linda S. Meyer Consulting LLC). She is the co-founder of the Alpine Learning Group in Paramus, NJ and served as its founding executive director from 1989 until 2005. She serves on the professional advisory boards of several schools and agencies serving individuals with autism spectrum disorders. Linda has presented at regional, national, and international conferences, and authored articles and book chapters on various special education, nonprofit management, and personal fitness topics. She has taught doctoral and masters level students in educational and clinical psychology programs and is currently an adjunct professor at Caldwell College, in Caldwell, NJ. Linda is a member of the NJ Governor's Council for Research and Medical Treatment of Autism.

**Kenneth F. Reeve, Ph.D., BCBA-D** is Professor of Applied Behavior Analysis and Director of Research at the Center for Autism and ABA at Caldwell College, NJ. He is co-author of the book *Behaviorspeak: A Glossary of Terms in Applied Behavior Analysis* and was an invited contributor to a chapter on interacting with the media in Bailey and Burch's book *25 Essential Skills for Behavior Analysts*. Ken conducts research in concept formation, stimulus control, and teaching applications for children with autism and other developmental disabilities, and regularly publishes and presents his work on these topics.



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2. Service providers have a responsibility to rely on treatments that have been shown to be safe and effective in scientifically rigorous, peer-reviewed research studies.
3. Service providers should take steps necessary to help consumers differentiate between scientifically-validated treatments and treatments that lack validation.
4. Consumers should be informed that any treatment lacking scientific support should be pursued with great caution.
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Larger ads are allowed, as long as they are in the appropriate ratio (i.e., – a 9:7 ratio for a full-page ad) – sending larger files may allow for better ad quality.

Please ensure that your ad does not make unsubstantiated health or treatment claims, suggest endorsement by ASAT, or contain religious or political content.

2011 Advertising Rates	Non Sponsors	Champions \$2000/yr	Benefactor \$1000/yr	Alliance \$500/yr	Patron \$200/yr
	See Rates below	One Free Half page and then 50% discount	One Free Quarter page and then 40% discount	30% discount	20% discount
Full Page 9" X 7"	\$800/Issue	\$400/Issue	\$480/Issue	\$560/Issue	\$640/Issue
Half Page 4.5" X 7" [9"X 3.5"]	\$500/Issue	\$250/Issue	\$300/Issue	\$350/Issue	\$400/Issue
Quarter Page 2" X 7" [5"x 3"]	\$300/Issue	\$150/Issue	\$180/Issue	\$210/Issue	\$240/Issue

## Does your agency share ASAT's values?

ASAT believes that individuals with autism have the right to effective treatments that are scientifically demonstrated to make meaningful, positive change in their lives.

We believe that it should not be so challenging for families to find accurate information about the efficacy of various autism interventions.

ASAT works toward a time

..... when all families would be empowered with skills in identifying and choosing the most effective, scientifically-validated interventions for their child.

.....when the media would educate and not confuse parents by providing accurate information and asking the right questions.

.....when all providers would be guided by science when selecting and implementing their interventions.

## What it means to be a sponsor.....

ASAT's sponsors have indicated their support of the following tenets:

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

## .....Become a 2011 Sponsor Now!

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

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

If you are interested in joining our 2011 sponsors, please visit the sponsor page on our website at [www.asatonline.org/about\\_asat/sponsors.htm#learn](http://www.asatonline.org/about_asat/sponsors.htm#learn).

Thank you for your consideration!

### CHAMPION \$2,000

[Autism Partnership](#)

[Four Points, Inc.](#)

[Little Star Center](#)

[Central Valley Autism Project](#)

### BENEFACTOR \$1,000

[Different Roads to Learning](#)

[Rethink Autism](#)

[Accelerated Educational Software](#)

[Stepping Stones](#)

### ALLIANCE \$500

[Autism Research and Treatment](#)

[Autism Intervention Services](#)

[Autism New Jersey](#)

[Eden II Programs](#)

[ELIJA Foundation](#)

[ELIJA School](#)

[Providence Service Corporation](#)

[Quality Services for the Autism](#)

[Community \(QSAC\)](#)

[Quest Autism Program](#)

[Virginia Institute of Autism](#)

### PATRON \$200

[Aging with Autism](#)

[Alpine Learning Group](#)

[Autism Awareness](#)

[Behavioral Intervention Association](#)

[Brooklyn Autism Center](#)

[Child Study Center of Fort Worth](#)

[Connecticut Center for Child Development](#)

[Gary Mayerson & Associates](#)

[Institute for Educational Achievement](#)

[Kansas City Autism Training Center](#)

[Lizard Children's Learning Centre](#)

[New England Center for Children](#)

[New Haven Learning Center](#)

[NY Center for Autism- Charter School](#)

[Pyramid Educational Consultants, Inc.](#)

[Room to Grow](#)

[SKF Books](#)

**2011 Sponsors in  
Real Science,  
Real Hope Sponsorship Initiative**

**IMPORTANT DISCLAIMER:** ASAT has no formal relationship with any of the sponsor organizations. Furthermore, their stated endorsement of the above tenets is not verified or monitored by ASAT. Although ASAT expects that all sponsoring organizations will act in accordance with the above statements, ASAT does not assume responsibility for ensuring that sponsoring organizations engage in behavior that is consistently congruent with the statements above.

## Message from ASAT President David Celiberti, Ph.D., BCBA-D continued ....

wanted to share a few noteworthy updates with SIAT readers.

- Good news! The RESOURCES section of our website is filling in nicely with recent content. There you will find a plethora of research synopses, clinical corner responses, book reviews, interviews, articles, and essays. Please take a moment to check it out as over 100 pages of new content have been added to the Resources section alone. Please visit the RESOURCES section of our website at [www.asatonline.org/resources/resources.htm](http://www.asatonline.org/resources/resources.htm)
- We recently expanded our Board of Directors. Leigh Broughan, MS joined us in April and will be assisting with ASAT's fund raising efforts. Leigh is a BCBA working at the Little Star Center. She is also the proud older sister of Sam, a young man with autism. It is wonderful to have Leigh as part of the ASAT board and we all look forward to collaborating with her in the near future.
- Larry and Kathy Hannon, the amazing parents behind two full years of active fundraising at their 3 Dairy Queen locations, were awarded the "2011-2012 Parents/Advocates of the Year" by the Maine Administrators for Children with Disabilities. They were selected for their tireless efforts on behalf of children with disabilities in the State of Maine and for their staunch advocacy of science-based treatment and education. We are very proud of them!

Our myriad accomplishments would not be possible without the hard work and dedication a cadre of volunteers. Please see page 10 for a complete list. As you can see, volunteers support every aspect of our organization. I want to take this opportunity to congratulate a few of them on some recent accomplishments and milestones:

- Jessie Martin and Jets Player Mike Devito were married July 17<sup>th</sup> in Scarborough, Maine. As you may recall both Jessie and Mike worked tirelessly to ensure the success of our recent Rock'n 4 Autism Awareness concert this past April. Congratulations to Jessie and Mike! We wish this young couple many years of good health and happiness.
- Denise Grosberg recently earned her BCBA! Denise is a frequent contributor to our newsletter and will be co-authoring a book review with me to appear in the Fall issue of *Science in Autism Treatment*. We look forward to Denise's ongoing contributions to the newsletter!

I want to take this moment to acknowledge the generosity of the 35 organizations who participated in the 2011 Real Science Real Hope Sponsorship Initiative. We are pleased to report that we have three champion level sponsors this year:

- ⇒ [Autism Partnership](#)
- ⇒ [Four Points, Inc.](#)
- ⇒ [Little Star](#)

These 35 fine organizations are listed on page 25. Please

click on each of their links to be connected to their respective websites.

Your financial support, however small, can make a big difference in enabling ASAT to continue its mission to disseminate accurate information about autism and its treatment and to keep our resources free. Please make a donation by completing the donor panel on page 6 or donating online through Pay Pal (found on the lower left corner of our home page at [www.asatonline.org](http://www.asatonline.org)).

There are *other* ways to support ASAT:

- If you are affiliated with a professional organization that shares ASAT's values, there is still time to become a 2011 Real Science, Real Hope Sponsor. So far, we have 35 organizations that are 2011 sponsors. Please see page 25 for more information.
- If you are a business owner, or know of one, and would like to become a Community Sponsor or help raise monies for ASAT through donation jars or customer appeals, please write us at [donate@asatonline.org](mailto:donate@asatonline.org). We can provide you with information about how your business can take small easy steps to support ASAT. I turn your attention to page 7 where you can read about our small but much appreciated fund raising happening at Yogurt Land.

Best,



David Celiberti, Ph.D., BCBA-D  
President and Co-Editor

## ASAT Needs Your Help in 2011

We know that many of our readers are concerned about the plethora of treatments that lack scientific support - and the burden this then places on families and service providers who are struggling to make decisions about treatment.

Help us make a difference!

Become a 2011 Sponsor!



# Autism Social Skills Workshop

One of the most critical elements of the treatment plan implemented by Autism Partnership was the emphasis on teaching authentic social skills on multiple, complex levels. When all is said and done, improving the quality of life for a person with Autism Spectrum Disorder must be our most important objective.

Drs. Taubman and Leaf will share the success stories of clients who were once isolated, have developed meaningful friendships and have entered the world of dating and relationships. Through discussion, videos and case presentations, participants will be better able to assist their students, clients and children in greatly improving their quality of life.

## Crafting Connections Workshop Book Tour

Click on workshop date or location to register for event!  
All Workshops are from 9am-3pm

**September 12, 2011, Boston, MA** Hilton Embassy Suites  
**September 14, 2011, New York, NY** Hilton - New York  
**September 16, 2011, Washington, D.C.** Arlington Court Suites Hotel  
**September 17, 2011, Atlanta, GA** Hilton - Atlanta  
**September 19, 2011, Hurst, TX** Hurst Conference Center  
**September 21, 2011, Aurora, CO** University of Colorado Denver  
 School of Medicine, Anschutz Medical Campus  
**September 22, 2011, Chicago, IL** Holiday Inn & Suites  
**September 23, 2011, St. Louis, MO** Hilton St. Louis at the Ballpark  
**October 3, 2011, Seattle, WA** Warwick Seattle Hotel  
**October 4, 2011, Portland, OR** Holiday Inn Portland  
**October 5, 2011, San Francisco, CA** Hilton San Francisco Financial  
**October 6, 2011, Las Vegas, NV** The Platinum Hotel

Registration includes: A copy of the newly released *Crafting Connections* Social Skills Book, A Certificate of Attendance, Continuing Education Units for BACB, ASHA, MCEP



**Dr. Ronald Leaf** is a licensed psychologist who has over thirty years of experience in the field of autism. Dr. Leaf began his career working with Professor Ivar Lovaas, while receiving his undergraduate degree at UCLA. Subsequently, he received his doctorate under the direction of Dr. Lovaas.



**Dr. Mitchell Taubman** worked with Dr. Lovaas as an undergraduate at UCLA in the early 1970s. He treated children with autism, ADHD and other disorders. He then attended the University of Kansas, studying with such founders of Applied Behavior Analysis (ABA) as Dr. Donald Baer, Dr. Todd Risely, Dr. James Sherman, and his doctoral advisor, Dr. Montrose Wolf.



[www.autismpartnership.com](http://www.autismpartnership.com)

1-800-816-9293

ASAT

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