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## Using the Maine Report to Look at the Emperor's Clothes: Is there Science behind this treatment? By Daniel Mruzek, Ph.D., BCBA-D

A colleague recently passed along a website that illustrates how Maine's recently published *Interventions for Autism Spectrum Disorders: State of the Evidence* can be used as a resource for evaluating potential treatment options

handling. The website contains examples of common proclamations

often found in the marketing of non-validated treatments, including lavish testimonials, boldly proclaimed (yet subtly qualified) benefits, science-like phrases and vague references to research findings. One claim in particular on the website caught my eye: "New Study Shows 97% of Children Improving with Omega-3 and Vitamin E Nutritional Formulation". Indeed, this new study (Morris & Agin, 2009), published in the journal *Alternative Treatments* and linked at the product website, reports that 181 out of 187 participating families reported "dramatic improvements in a number of areas, including speech, coordination, eye contact, behavior, sensory issues, development of pain sensation, and GERD

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(see Lora Perry's summary on p. 4 of this issue). The website (<http://www.speechnutrients.com/Default.aspx>) is maintained by a company called Nourish Life and showcases a nutritional supplement called Nourish Life Speak™, "a nutritional product designed and formulated to support normal speech development and maintenance." The "starter kit" for this supplement costs \$49.95 + shipping and

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

Happy New Year! It is hard to believe that we are now distributing our *third* issue of *Science in Autism Treatment (SIAT)*. As you may recall, I shared some of our 2009 accomplishments in the previous issue. Although we have no paid staff, and rely exclusively on volunteers, we are very proud of our past work and looking forward to continuing to carry out our mission. As we move into a new year, we have outlined an array of goals and initiatives.

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## Using the Maine Report to Look at the Emperor's Clothes continued....

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[gastroesophageal reflux disease] symptoms" following use of Vitamin E and polyunsaturated fatty acid supplements (p. 36).

Though these results seem compelling at first glance, weaknesses in this retrospective study greatly limit conclusions that can be derived from it. The most important features of good treatment research, including random selection of study participants and use of a "no treatment" comparison group, were not used. Rather, the study participants were reportedly parents of children with apraxia who provided, via a questionnaire on a web site or "personal communication," an after-the-fact opinion regarding their use of a supplement. It is reasonable to assume that people voluntarily responding to an on-line questionnaire at a particular web site

or communicating to an expert in the field of nutritional supplements may have an especially strong and/or unique opinion to share. For this reason, it is impossible to know how a more representative group might have rated the pills.

No mention is made of an assessment of the reliability of the data, such as blind "double-checks" to ensure that the questionnaire results are tallied properly, or attempts to ensure the validity of the data, such as examining whether particular responses on a web-based questionnaire are actually associated with improvements in a child's health or behavior. There is no indication that participant histories, such as other interventions they used with their children, are accounted for or even recorded.

Furthermore, the study includes very little information regarding the

nature of the questionnaire or personal communication data (e.g., response to multiple-choice questions that may bias a response, open-ended questions that may be hard to quantify or characterize) or how these data were analyzed. In fact, the description of the study methodology (how it was conducted) was so sparse, that independent researchers would not be able to replicate it to verify the results.

The authors briefly acknowledge these limitations: "Many of our conclusions are speculative in the absence of controlled clinic trials" (p. 41). In other words, despite the touting that the study receives at the Nourish Life Speak™ website, possible benefits derived from the supplement

"In other words, despite the touting that the study receives at the Nourish Life Speak™ website, possible benefits derived from the supplement remain unproven."

remain unproven.

By the way, a disclaimer noted on the first page of the Morris and Agin study indicates that the first author maintains a patent application for a nutritional formula licensed to Nourish Life, a relationship that further highlights the need for objective measures and other key scientific controls to measure the validity of the research.

Faced with a variety of marketing tactics, how can parents confidently investigate possible treatments for their children? One way is to ask the marketer or practitioner, "What is the scientific evidence that this treatment is effective?" A legitimate marketer or practitioner will appreciate the question and accurately report the state of the science. However, some may not be forthcoming in their response and, instead, rely on testimonials and often misleading research claims to

state their case. A second strategy parents can utilize is speaking to a trusted professional with an understanding of the scientific background of the treatment in question. The professional can report on the state of the scientific evidence with regard to a treatment under consideration or recommend others who are more knowledgeable in a specific area. Maine's recently published *Interventions for Autism Spectrum Disorders: State of the Evidence* highlights a third option that, like the Scientific Summaries On Interventions On Autism available at the ASAT website ([http://www.asatonline.org/about\\_asat/about\\_asat.htm](http://www.asatonline.org/about_asat/about_asat.htm)), may be viewed as a "quick reference" approach to investigating new treatment options. For example, Omega-3

Fatty Acid supplements were judged by the Maine panel as having insufficient

evidence, because available scientific data are limited in scope and inconclusive in findings (p. 33). Given that the Nourish Life Speak™ nutritional supplement appears to have Omega-3 Fatty Acid as a key ingredient, a parent can use this information as an important consideration in evaluating the claims made by the company marketing this product.

Parents have a right to know the "state of the science" for treatments they are considering for their son or daughter with autism. Reports such as the *Interventions for Autism Spectrum Disorders: State of the Evidence* provide a quick means of cross-checking information provided to them about a particular treatment. Parents do not have to rely on the information provided by merchandisers for decisions regarding treatments for

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their children and their hard earned dollars - whether merchandisers provide that information on a web site or through "personal communication"!

Do you have a particular treatment topic that you would like considered for a future edition of Science Corner? Feel free to send your ideas to [Daniel\\_Mruzek@urmc.rochester.edu](mailto:Daniel_Mruzek@urmc.rochester.edu).

References

Maine Department of Health and Human Services & Maine Department of Education (2009). *Interventions*

*for Autism Spectrum Disorders: State of the evidence.* Portland, ME: University of Southern Maine.

Morris, C. R., & Agin, M. C. (2009). Syndrome of allergy, apraxia, and malabsorption: Characterization of a neurodevelopmental phenotype that responds to omega-3 and vitamin E supplementation. *Alternative Therapies*, 15, pp. 34 – 43.

SpeechNutrients™ by Nourish Life. (n.d.) *Nutritional support for health speech development.* Retrieved from <http://www.speechnutrients.com/Default.aspx> on December 30, 2009.

**Consumer Corner: The National Autism Center releases the results of the National Standards Project**

The National Standards Project (NSP) convened a panel of 45 experts in the field of autism intervention to evaluate the scientific literature of treatments for autism spectrum disorders. The panel of expert reviewers, representing diverse fields of study and theoretical orientations, reviewed and analyzed 775 research articles, narrowed down from over 6000 potential studies. Research studies were reviewed for ASD treatments that generally addressed the main symptoms of autism and some related features. The studies analyzed interventions conducted in a variety of settings and across a number of disciplines (e.g., behavioral, speech and language pathology, etc). The model for data collection and analysis was based on evidence-based practice guidelines from other health and psychology fields, and in consultation with methodologists and feedback from the expert panel.

Reviewers scored research articles for both their scientific merit and the effectiveness of the intervention. Once all the studies were scored, the results were combined to ascertain the level of research support for each intervention. Based on these results, a total of 38 treatments were identified (e.g., comprehensive behavioral treatment for young children, modeling, schedules, etc).

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

A daunting task faced by both professionals and families of individuals with autism is sorting through the myriad treatments for autism to identify ones that are supported by empirical research. However, as discussed in the next two articles, that is precisely what the National Standards Project and the Maine Department of Health and Human Services and the Maine Department of Education have set out to do. In this installment of Consumer Corner, we have a summary of the National Standards Project and Lora Perry summarizes the findings of the Maine State report.

The 38 treatments were then analyzed to determine if they were:

1. **Established** – indicating that sufficient evidence is available for the intervention
2. **Emerging** – indicating that although one or more studies suggest that the treatment may produce favorable outcomes, additional studies are needed before being fully confident the treatment is effective
3. **Unestablished** - indicating little or no evidence to draw firm conclusions about the treatments effectiveness
4. **Ineffective / harmful** – indicating that there is sufficient evidence that a treatment is ineffective or harmful for individuals with ASD.

Not surprisingly, the results of the NSP strongly indicated that treatments from the behavioral literature have the strongest research support at this time. Approximately two-thirds of the **Established Treatments** were developed exclusively from the behavioral literature (i.e., applied

behavior analysis) and of the remaining one-third, 75% represent treatments for which research comes mostly from the behavioral literature. Several of the interventions determined as **Established** for autism spectrum disorder are Comprehensive Behavioral Treatment for Young Children, Self-management, Joint Attention Interventions and Peer Training Packages.

The National Autism Center is to be commended for convening a diverse group of experts, and for synthesizing years of scientific study to arrive at a set of evidence-based practice guidelines for autism spectrum disorders. In a market flooded with promises and sales pitches, the summary of findings of the National Standards Project will help parents and clinicians make crucial decisions regarding autism interventions. Readers are encouraged to visit the National Autism Center’s website to obtain a copy of the *National Standards Project Findings and Conclusions*. [www.nationalautismcenter.org](http://www.nationalautismcenter.org).

## Consumer Corner: Maine Releases Report on Evidence-Based Practice for Autism

### Lora Perry, M.S., BCBA

Science in Autism Treatment

Volume 6, Fall, 2009

**Summary of:** Beaulieu, A., Tweed, L., & Connolly, N. (2009, October). *Interventions for Autism Spectrum Disorders: State of the evidence. (A collaboration of the Maine Department of Health and Human Services & the Maine Department of Education.)*. Augusta, ME: Muskie School of Public Service and the Maine Department of Health and Humans Services.

Applied Behavior Analysis (ABA) has the most robust evidence of effectiveness for early intervention, challenging behavior, and communication in individuals with autism spectrum disorders. “Established Evidence” is also reported for the Picture Exchange Communication System (PECS), as well as the drugs haloperidol (Haldol) for aggression, and methylphenidate (Ritalin) for hyperactivity.

These findings were released in the report *Interventions for Autism Spectrum Disorders: State of the Evidence*. Released in October 2009, the report is the result of an 18-month collaboration between the Maine Department of Health and Human Services and the Maine Department of Education. In addition, the report serves to update the Report of the MADSEC Autism Task Force released in 2000 by the Maine Administrators of Services for Children with Disabilities.

**Level 1: Established Evidence**

**Level 2: Promising Evidence**

**Level 3: Preliminary Evidence**

**Level 4: Studied and No Evidence of Effect**

**Level 5: Insufficiently Studied**

**Level 6: Evidence of Harm**

### Rating Method

To determine levels of evidence, the Children’s Services Evidence-Based Practice Advisory Committee adapted the *Evaluative Method for Determining Evidence-Based Practice in Autism* (Reichow, Volkmar, & Cicchetti, 2008). The method includes standards by which to evaluate both experimental group research and single subject research, including primary quality indicators and secondary quality indicators.

Primary quality indicators assess controls associated with research validity, and are ranked as *strong*, *acceptable* or *unacceptable*. Secondary quality indicators assess quality not critical to validity, and are ranked as *evidence* or *no evidence*.

The Committee then determined a level of evidence for each treatment based on an expanded version of the *Evaluative Method* rating scale (Reichow, et al., 2008) The Committee added several levels to the rating scale to meet the needs of the review: *preliminary evidence*, *studied and no evidence of effect*, *insufficient evidence*, and *harm* (these levels will be described below).

At least two Committee members and one research staffer reviewed studies for each intervention to help ensure reliability and objectivity, although formal efforts to assess inter-rater reliability were beyond the resources of the Committee.

According to the report, studies had to meet several requirements to qualify for review:

- (1) Studies must be published in a peer-reviewed, scholarly journal.
- (2) Research samples in the study must include only children with Autism, PDD/PDD-NOS, and/or Asperger’s Syndrome. Children described with diagnoses of mental retardation, developmental disability, or other conditions without a concurrent ASD diagnosis excluded the study from review.
- (3) The intervention addressed the core symptoms of ASD and/or associated issues, such as aggression or self-injurious behavior.

Literature searches were conducted using databases including the Academic Search Premier, ERIC, Medline, Pubmed, Cochrane Database of Systematic Reviews, CINAHL, PsychLit, PsychInfo, and SAGE Journals Online. The references in qualifying articles were also examined to identify additional studies. Main keywords included autism, Asperger’s, PDD, and terms specific to the treatment being reviewed.

The complete list of findings are:

**Level 1, Established Evidence:** The following treatments have been proven effective in multiple strong or adequately rated group experimental design studies, single subject studies, or a combination. Results must be replicated in studies conducted by

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different research teams.

- Applied Behavior Analysis for challenging behaviors
- Applied Behavior Analysis for Communication
- Applied Behavior Analysis for Social Skills
- Early Intensive Behavioral Intervention (UCLA/ Lovaas model)
- Haloperidol (Haldol)—found effective for aggression
- Methylphenidate (Ritalin)—found effective for hyperactivity
- Picture Exchange Communication System (PECS)
- Risperidone (Risperdol)—Found effective for irritability, social withdrawal, hyperactivity and stereotypy.

**Level 2, Promising Evidence:** The following interventions have been shown to be effective in more than two strong or adequately rated group experimental design studies or at least three single subject studies. Additional research is needed by separate teams to confirm that the intervention is effective across settings and researchers.

- Applied Behavior Analysis for Adaptive Living Skills
- Cognitive Behavioral Therapy (CBT) for anxiety
- Voice Output Communication Aid (VOCA)

**Level 3, Preliminary Evidence:** The following interventions have been shown to be effective in at least one strong or adequately rated group or single subject design study. More research is needed to confirm results.

- Applied Behavior Analysis for Academics (selected interventions)
- Applied Behavior Analysis for Vocational skills
- Atomoxetine (Strattera) - Found effective for attention deficit and hyperactivity
- Clonidine – Found effective for hyperactivity, irritability, inappropriate speech, stereotypy, and oppositional behavior
- Cognitive Behavior Therapy (CBT) for anger management
- Developmental, Social-Pragmatic models
- Hyperbaric treatment
- Sign language

**Level 4, Studied and No Evidence of Effect:** Numerous (two or more) strong or adequately rated studies have determined that the following interventions have no positive effect on the desired outcomes.

- Dimethylglycine (DMG)
- Secretin

**Level 5, Insufficiently Studied:** Conclusions cannot be drawn on the efficacy of the intervention due to a lack of quality research, or mixed results in several studies.

- Applied Behavior Analysis for academics (selected interventions)
- Auditory Integration Training
- DIR/Floortime
- Facilitated Communication
- Gluten-Casein Free Diets
- Intravenous Immunoglobulin
- Naltrexone
- Melatonin
- Omega 3 Fatty Acids
- RDI
- SCERTS
- Sensory Integration Training
- Social Skills Training
- Social Stories™
- SSRIs—Fluoxetine, Clomipramine
- TEACCH
- Valproic Acid

**Level 6, Evidence of Harm:** Studies or published case reports indicate significant harm or risk of harm, including injury and death.

- Intravenous Chelation using edetate disodium

It is important to remember the Committee’s criteria for inclusion of a study for review stipulated that the subjects must have included only children with Autism, PDD/PDD-NOS, and/or Asperger’s Syndrome. Children with diagnoses of mental retardation, developmental disability, or other condition without a concurrent ASD diagnosis excluded the study from review. It is also important to note that the Committee’s charge was to examine evidence of effectiveness of interventions for children, and not for adults.

The full report is available at <http://muskie.usm.maine.edu/Publications/cutler/autism-spectrum-disorders-report2009.pdf>

Reference:  
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## Clinical Corner: How Can Adolescent Learners With Autism be Prepared for Employment?

Answered by:

Erin Richard, M.A. BCBA, and  
Karissa Masuicca, M.S.Ed., BCBA  
Alpine Learning Group, Inc.  
Paramus, New Jersey

Preparing adolescents with autism for future employment is important. It is essential to shift the focus of programming from academics to more functional life skills and prevocational tasks. Federal mandates require the individualized education programs of learners age 16 and older to include a statement of transition needs, although state codes may require a transition statement at a younger age. Therefore, their educational goals need to focus on preparing them for employment and adult life.

In order to meet these transition requirements, learners' IEPs begin to emphasize such curriculum areas as vocational, work, community, communication, and self-care skills. Of course, many of these areas will have been addressed in the past; but now, the goals should be specifically aimed toward enhancing employment opportunities.

*Vocational skills* are the production aspects of jobs, such as setting tables at a restaurant or filing paperwork at a doctor's office. While some of this teaching should take place in community settings, there are several reasons why it is also beneficial to work on vocational tasks at school. First, when teaching in a simulated environment such as school, teachers can be more systematic about instruction and freely use prompts (e.g., manual guidance), which might be stigmatizing in a community setting. In addition, it is likely that a greater variety of tasks can be presented within the school setting. Since many learners with autism will not be able to verbally indicate their job preferences, it is

important that learners sample a wide variety of these tasks to determine what they are good at and what jobs they may prefer.

While job production skills are the most obvious ones required for employment, other curriculum areas are just as important. For example, *work skills* (i.e., skills other than job production related to maintaining employment), are also important in preparing adolescents with autism for work. Unlike vocational skills, which are job-specific, work skills will assist learners across all job settings. Some examples include learning to take a break, keep appointments, work without direct staff supervision, and increase physical endurance.

Acquiring essential *community skills* will increase a learner's general independence in the community and increase their likelihood of obtaining community-based employment. For example, using a public restroom, maintaining appropriate distance from others when walking, and using an elevator are important community skills that will likely be relevant to a learner at an employment site.

Another important curriculum area to focus on when preparing learners for employment is *communication skills*. In particular, it is important to increase a learner's ability to communicate with his/her supervisor and co-workers. For example, learners should be taught to greet other employees at work, respond to comments while they are working, speak politely, and ask for additional supplies when needed. For learners to be employed without constant supervision from a support person, they must be able to communicate independently with people at their job. For some learners, this may include the use

This section of the newsletter highlights questions regarding important clinical issues and responses from prominent professionals. We hope you enjoy their insights and recommendations! Each issue of Science in Autism Treatment will showcase two Clinical Corner responses.

**Lori Bechner, M.A., BCBA**  
**SIAT Clinical Corner Coordinator**

of an augmentative communication device or a textual exchange system.

Teaching *self-care skills* is important for employment because these abilities will increase learners' independence in getting ready for work, as well as influence how employers and co-workers will perceive them. In fact, maintaining a neat appearance and following a dress code are requirements of most any job. At Alpine Learning Group (ALG), we teach learners to monitor their appearance by following written or pictorial schedules, which prompt them to go to the restroom and check how they look. Learning to dine alongside fellow employees during lunch time is also an essential skill. Thus, we focus on teaching young adults with autism to eat neatly and at an appropriate pace, which increases the likelihood that they will be perceived positively by their co-workers during mealtime and snack breaks.

Of course, in addition to having the skills necessary to perform a job and assimilate into the work environment, it is equally important that a learner's behavior is appropriate for the setting. Consideration of a tolerable level of problem behavior depends on the environment of the worksite. For example, employees at libraries must have near-zero levels of loud

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or disruptive behavior. On the other hand, if someone is employed in a large, busy packaging warehouse, moderate rates of vocal stereotyping may be acceptable.

At Alpine Learning Group, a large part of preparing our learners for employment is accomplished through our Supported Internship Program. The goal of this program is to prepare learners for community-based employment by having them intern at local businesses. It is a job sampling, rather than job training, program—so learners are not being prepared for only one specific job. Rather, between the ages of 16 and 21, learners rotate through a variety of positions so we can assess their strengths and job preferences. Our internship sites currently include 16 different community businesses, such as retail stores, restaurants, hospitals, and offices. The jobs include a variety of tasks (e.g., sedentary jobs, positions in noisy environments), require various skills (e.g., filing, packaging, cleaning), and are appropriate for learners with different skill sets.

All of our learners attend their internships with a support person who is a staff member from the learner’s classroom at school (i.e., either a teacher or

instructional aide). The support staff persons collect data on the learners’ acquisition of the job and the occurrences of any problem behavior. Importantly, support staff persons also obtain information on learners’ job preferences, either by asking their opinions or, for learners with limited communication, observing how much they appear to enjoy the job. Supervisors make frequent visits to help problem solve, provide training to staff, and monitor progress.

As the learner approaches graduation and permanent employment is sought, the data and observations collected at internships will be used to help learners, together with their families and service providers, make informed decisions about potentially fulfilling and productive employment options. With some forethought and planning, employment, with varying levels of support, can be a reality for many adults with autism.

Reference

Meyer, L. S., Taylor, B. A., Cerino, K. E., Fisher, J. R., Moran, L. M., & Richard. E. (2006). *Alpine Learning Group*. In J. S. Handleman & S. L. Harris (Eds.). *School-age education programs for children with autism* (pp.1-47). Austin, TX.

**Clinical Corner: Who Should Participate In an Inclusive Setting and How Does the Process Work?**

**Answered by :**  
**Audrey Meissner, M.Ed., BCBA**  
**New Haven Learning Centre**  
**Toronto, Canada**

Including a child with autism into a regular education classroom is the hope of many parents and professionals alike. Early intensive intervention based on the principles of applied behavior analysis (ABA) permits some children to participate successfully in regular education settings. Why do certain children benefit from these settings, and others not? Using readiness criteria as an assessment tool can help determine who should participate in the inclusive setting. Specifically, knowing what the child is expected to be familiar with in the regular education classroom and ensuring that those skills (or a portion of them) have been acquired, will increase the likelihood of success. Observation of the less-restrictive environment is critical for determining the skills the child with autism will need to have in order to

benefit from that setting. Observing the inclusive setting will also aid in the selection of individualized goals to add to the child’s Individualized Education Plan (IEP), to help prepare the student for the new classroom. Teaching necessary skills in advance of the classroom placement will give the student an advantage and will help ensure a smooth transition.

Evaluating skills students should possess in order to benefit from less restrictive settings can help professionals make educated decisions when placing students with autism in regular education classrooms. These readiness criteria can be developed by directly observing the potential classroom setting, as well as by reviewing the provincial or state curriculum requirements, and can help predict whether or not the child will learn and play an active role in that classroom.

Readiness criteria should include several domains:

- Receptive language – e.g., follows two-step and other complex instructions, responds to generalized instructions and is able to learn from novel instructors
- Expressive language – e.g., asks simple questions to obtain information from adults and peers; recalls experiences
- Academic – e.g., completes or shows potential to complete grade level curriculum; retains information taught during group instruction
- Social skills – e.g., engages in simple exchanges of conversation with peers and teachers; responds to and initiates peer play activities
- General behavior – e.g., engages in low to zero rates of stereotypic and disruptive behavior

However, readiness criteria are not yet research-based and should not necessarily preclude a student from enrolling in a regular education classroom. Consequently, these

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## Clinical Corner: Who Should Participate In an Inclusive Setting continued...

(Continued from page 7)

criteria should only be used as a guide. Relevant data (e.g., group instruction, academic skills, social skills, inappropriate behavior, etc.) from the child's current educational placement can also be used to help predict whether or not a student has the necessary skills to successfully participate and benefit from an inclusive setting. These criteria can also be used as a monitoring tool in the inclusive setting to assess whether the child is acquiring new skills.

Once it has been determined that a child is a good candidate for an inclusive placement, then an appropriate school needs to be selected, preferably in the child's neighborhood, so that he/she can be close to new friends and other community activities. An appropriate school is one that:

- accepts children with autism
- is open to the principles of applied behavior analysis
- has school staff who are amenable to having a trained support person in the classroom
- has a suitable teacher (e.g., uses structured lessons, is able to provide subtle prompts if needed, encourages problem solving, follows through on demands, communicates openly with shadow both to give and receive recommendations, has the ability to effectively adapt or modify curriculum to meet the students' needs, etc).

It is important to meet with school staff to discuss the student's strengths, areas where the child will need support, educational goals selected for student, the role of the support person versus the role of teacher and to review data sheets as well as data collection.

Once inclusion has begun, an individual with ABA expertise can provide ongoing collaboration, training and support for the teacher and school staff, as well as support for the student. Data collection occurs daily at the inclusion site to ensure the student is acquiring pre-selected goals, and it will help determine when to systematically fade support, based on student performance.

When goals are selected, a data sheet is created for the shadow and/or teacher to use within the inclusion classroom. Data are graphed and analyzed daily. Data analysis focuses on areas that can help determine if the child is benefiting from the

If you enjoyed reading the Clinical Corner responses presented in the last few issues, please visit our website at [asatonline.org/helpdesk/clinician.htm](http://asatonline.org/helpdesk/clinician.htm) for responses to prior questions:

- What should be done when a child masters skills but loses them?
- What is the relationship between autism and mental retardation?
- What can I do to stop my child from putting everything in his mouth?
- My son with autism has developed aggressive behavior, and his doctor is considering whether medication could help. What can I do to prepare for this conversation?
- I have an adolescent with autism and want to know how his IEP goals should prepare him for adult life? Is ABA still useful?
- I am a speech language pathologist in a school-based program that relies heavily on Applied Behavior Analysis (ABA). What is important to know about this approach and its implications for my role? In what ways can I support this school-based program?
- My 8-year-old son is currently enrolled in a school-based ABA program. We are in the process of moving into a new district and are being presented with an array of options. What are the pros and cons of a school-based ABA program versus a center-based ABA program?
- I am a parent of a 7-year-old with autism who has responded well to her early intervention program based on ABA. I would like her educational program to address social skills more extensively. Do you have any suggestions?
- Do you have any suggestions for building collaboration within a home ABA program?

We invite you to submit your questions about science-based interventions to [newsletter@asatonline.org](mailto:newsletter@asatonline.org). Although ASAT cannot answer specific questions for a particular child, sight unseen, we attempt to help by giving examples of techniques and strategies that have proven helpful for other children and adults who may have faced similar issues.

**Lori Bechner, M.A., BCBA , SIAT Clinical Corner Coordinator**

placement. Specifically, it is important to assess if the child is following teacher directions, responding to peers, learning the information presented to the group, following classroom routines, as well as measuring the child's level of independent functioning versus how often the child requires prompting.

Realistically, not all students are able to transition to a regular elementary classroom, due in part to the challenging academic curriculum, as well as the social demands. In light of this, inclusion in less restrictive settings need not only involve general education classrooms, but can also include special education classrooms or private schools. Transition to private schools for children with learning disabilities can also be very successful, given that the curriculum may be modified and tailored to the needs of the student and more time may be spent with each subject. In addition, the student-teacher ratio is usually smaller, which allows more individualized attention.

In the end, there is no exact formula to assess who should participate in an inclusive setting; however, taking the time to assess the child and the placement can make the transition as smooth as possible. Setting realistic expectations can help students (and parents) avoid frustrations that any child can encounter when faced with change. Using readiness criteria and data-based decisions can help make a student's experience in an inclusive setting successful.

# ASAT is proud to unveil its 2010.... Real Science, Real Hope Sponsorship Initiative. ....Please join us!

ASAT needs your help. In the weeks ahead, we will be launching our 2010 sponsorship initiative and are writing to ask for your participation. ASAT believes that individuals with autism have the right to effective treatments that are scientifically demonstrated to make meaningful, positive change in their lives. It can be challenging for families to find accurate information about the efficacy of various interventions for autism. For that reason, central to ASAT's mission, is the goal of disseminating accurate information about autism treatments. ASAT works toward a time when all families will be empowered to identify and choose the most effective, scientifically-validated interventions for their child, and all providers can be

guided by science when selecting and implementing their interventions. There are many organizations, who, along with ASAT, 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. In 2009, the organizations listed in the box below had indicated their support for ASAT and its mission to disseminate accurate, scientifically-sound information about autism and treatments for autism, and to improve access to effective, science-based treatments for all people with autism, regardless of age, severity of condition, income or place of residence.

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 funds provided by the ASAT sponsors will help support a number of directed efforts undertaken by ASAT this year (e.g., a pediatrician education program, a journalist/media education program, and

public awareness of our newsletter and website).

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.

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 becoming a 2010 sponsor, please visit the sponsor page on our website at [http://asatonline.org/about\\_asat/sponsors.htm](http://asatonline.org/about_asat/sponsors.htm)

## Participating 2009 Sponsors in Real Science, Real Hope

### CHAMPION \$2,000

Ask a Behaviorist

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Rethink Autism

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New England Center for Children  
New Haven Learning Centre for Children  
Virginia Institute of Autism

### PATRON \$200

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Brooklyn Autism Center Academy  
Connecticut Center for Child Development (CCCD)  
Educational Partnership for Instructing Children (EPIC)  
Evergreen Center  
Institute for Educational Planning  
Lizard Children's Learning Centre  
Reed Academy  
Room to Grow  
SKF Books  
Somerset Hills Learning Institute

## ASAT's Mission

**Our mission is to disseminate accurate, scientifically sound information about autism and treatments for autism and to improve access to effective, science-based treatments for all people with autism, regardless of age, severity of condition, income or place of residence.**

**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.

## Media Watch: ASAT's Contribution to Responsible Journalism

### Barbara Jamison, Lead

Science in Autism Treatment

Volume 6, Fall, 2009

Many consumers turn to the media for information about autism and its treatment. Sadly, the media's portrayal of autism treatment is fraught with inaccuracies and misinformation. Media Watch, one of the most recent initiatives of ASAT's Public Relations Committee, is intended to improve upon the accuracy of media representations.

Media Watch has three main purposes:

- 1) Educating the public about effective autism treatment through proactive contact with the media,
- 2) Responding to both accurate and inaccurate information or portrayals of treatments reported by the media, and
- 3) Increasing awareness of both scientific evidence and scientific methods that can lead to real hope for those touched by autism.

Media Watch would not be possible without the participation and efforts of a number of individuals. As you can see below, we have representation from our board of directors but have also

#### ASAT wants to thank our wonderful team of Media Watch writers

Regina Claypool-Frey, B.S.  
 Geoff Debery, M.A., BCBA  
 Florence DiGennaro Reed, Ph.D., BCBA-D  
 Daphna El-Roy, Ph.D., BCBA-D  
 Hannah Hoch, Ph.D., BCBA-D  
 Robert LaRue, Ph.D., BCBA-D - ASAT Board Member  
 Daniel W. Mruzek, Ph.D., BCBA-D ASAT Board Member  
 Joshua K. Pritchard, M.S., BCBA - ASAT Board Member  
 Sharon Reeve, Ph.D., BCBA-D - ASAT Advisory Board Member  
 Bridget Taylor, Psy.D., BCBA-D - ASAT Board Member

supplemented this team with others who help us to respond in a timely manner.

Through Media Watch, we provide written feedback to journalists and other media professionals who write about autism and its treatment. Many members of ASAT's Board of Directors are behavior analysts who know that in order to increase a behavior, it must be reinforced. Consequently, if there are accurate depictions of autism

intervention based on the current state of the science, we strive to acknowledge the efforts of those individuals responsible for educating the public with sound, accurate information. However, when an autism intervention is portrayed inaccurately, we provide feedback to media professionals to encourage correction of the inaccurate information in the article or more careful consideration when writing future articles.

Inaccurate portrayals of autism treatments in the media include, but are not limited to:

- Exaggerating the research support for an intervention for which no research exists,
- Ignoring the research basis that may already exist for the treatment in focus,
- Disregarding the relevance of science,
- Disregarding position statements from various professional organizations that warn against or discourage the use of a particular treatment, and
- Failing to acknowledge research that does NOT support a particular intervention

Media Watch responses in 2009 include (Click dates to read full replies):

□ The Chicago Tribune published ASAT's response to their article, "Autism Treatment: Science Hijacked To Support Alternative Therapies" ([November 23, 2009](#)). ASAT commended Tribune writers Tsouderos and Callahan for their article, but also stated:

"While we especially appreciate your review of the research and court testimony demonstrating the lack of empirical support for these alternative therapies, we wish that you would have emphasized how important it is for parents to rely on science-based treatments for their children with autism. For example, many of the interventions grounded in the principles of Applied Behavior Analysis (ABA) have copious scientific

evidence supporting their efficacy for children with autism." (Treating autism, [December 9, 2009](#))

□ Melissa Lafsky of Discover Magazine wrote an article on [March 4, 2009](#) about autism intervention in which applied behavior analysis (ABA) was referred to as a "risky treatment," while behavior therapy was also referred to and described as a research-based treatment. We clarified the terminology and asked them to print a correction.

□ We commended CNN on their story, "Study: Early Autism Intervention is Effective" ([November 30, 2009](#)) for the accurate portrayal of an intervention that is based upon scientific evidence.

□ Internet article, "Discover Autism - A Wide Range of Therapy Programs," claims that applied behavior analysis is "overly robotic" and "doesn't really encourage the child to be spontaneous." However, research has clearly shown that ABA includes teaching techniques to facilitate language, choice-making, socialization, joint attention, and independence. Studies have also documented gains in these areas across settings, people, and materials. ([September 28, 2009](#))

Please take a look at some more correspondence between Media Watch and the media at: [http://asatonline.org/media\\_watches](http://asatonline.org/media_watches). Check back often for more Media Watch updates on our webpage.

*We wholeheartedly welcome you to join our efforts. You could be involved by alerting us of articles or media pieces that may warrant our attention or you could assist us with tracking information more formally by setting up an alert system to identify important articles as they come out. If you would like more specific information about how to participate in Media Watch, you can reach us at [MediaWatch@asatonline.org](mailto:MediaWatch@asatonline.org). We hope to hear from you!*

Article: Lerman, C.L., Sansbury, T., Hovanetz, H., Wolever, E., Garcia, A., O'Brien, E., & Adedipe, A. (2009). Using behavior analysis to examine the outcome of unproven therapies: An evaluation of hyperbaric oxygen therapy for children with autism. *Behavior Analysis in Practice, 1*, 1-9

### Research Review: Using Behavior Analysis to Examine Outcome of Unproven Therapies

Reviewed by Kathleen Moran, M.A.  
Caldwell College

#### Why research this topic?

One under-researched treatment that has gained attention as a possible intervention for children with autism spectrum disorders (ASD) is hyperbaric oxygen therapy (HBOT). HBOT involves inhalation of oxygen inside a pressurized chamber in order to promote dissolution of oxygen in the blood, with the goal of repairing dormant or injured tissue in the body. However, HBOT is expensive (\$15,000 per person) and is known to have a risk of side-effects including seizures, oxygen toxicity, pain, rupture, or hemorrhage in the ear. The current study is the first of its kind to evaluate the potential benefits of HBOT for 3 children at their parents' request with a physician's prescription and medical release.

#### What did the researchers do?

Three children with ASD who were receiving intensive behavioral intervention participated in HBOT sessions three times per week, for a total of between 27 and 40 sessions per child. During each session, the child entered the HBOT chamber for 60 minutes and had access to favorite toys during that time. The researchers videotaped instructional sessions before HBOT sessions for two children and after sessions for the third child. They observed the videotapes to see whether sessions would result in any changes in task engagement, language, and problem behavior.

#### What did the researchers find?

HBOT treatment did not improve task engagement or decrease problem behavior beyond that provided by ongoing behavior analytic services. HBOT was also not associated with changes in spontaneous communication for two of the three

participants, though the remaining participant may have shown an improvement in this behavior.

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

This study showed that there were few or no significant changes in behavior as a result of HBOT. Although the study was important, there were a few limitations, such as a small number of participants, limited range of outcomes that were measured, and the implementation of HBOT concurrently with intensive behavioral intervention rather than as a stand-alone treatment. Based on the results of this study, we recommend that interventionists working with children with autism present HBOT as experimental and advise parents considering this intervention to evaluate it carefully.

Consistent with our efforts to make research comprehensible, the Research Corner section of the newsletter will summarize current research findings written in non-professional language and a structured format. **Sharon A. Reeve, Ph.D., BCBA-D, SIAT Research Corner Coordinator**

### Research Review: Randomized, Controlled, Crossover Trial of Methylphenidate in PDD with Hyperactivity

Reviewed by Kathleen Moran, M.A.  
Caldwell College

#### Why research this topic?

Many children with autism spectrum disorders (also called pervasive developmental disorder, or PDD) have problems with hyperactivity, distractibility, and impulsiveness. In children who display these problems but do not have PDD, a primary treatment is the use of stimulant medications such as methylphenidate, which is sold under names such as Ritalin, Metadate, and Concerta. However, only two small studies have tested methylphenidate for learners who have PDD accompanied by hyperactivity. This study was designed to provide a larger and more rigorous test of this medication.

#### What did the researcher do?

Participants were 72 children with PDD and hyperactive or impulsive behaviors, aged 5 to 14. All participants started with a 1-week trial period to check whether they tolerated methylphenidate. For each of the next four weeks, they received a different dose of the drug: none, low, medium, or high. The order of these doses was random and differed across participants. Investigators, clinicians, participants, and families did not know what dose the participants were receiving because the pills looked the same every week. At the end of the four weeks, participants continued for another 8 weeks on the dose that had worked best for them. Participants' hyperactive and impulsive behaviors were measured with checklists

completed by teachers and parents, as well as clinician ratings.

#### What did the researchers find?

Thirty-five of the 72 participants (49%) were classified as methylphenidate responders, meaning that their hyperactive and impulsive behaviors decreased, according to their teachers, parents, and clinicians. However, the other participants were classified as non-responders, and 13 of 72 subjects (18%) stopped taking the medication before the end of the study because of negative side-effects. Lethargy and social withdrawal were common problems at the high dose. The investigators tested whether four characteristics of participants (IQ, age, diagnosis, and weight) predicted who would be a responder. They did not, however, find reliable associations.

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

Overall, the study showed that methylphenidate was effective in improving inattention, distractibility, hyperactivity, and impulsivity for some children with PDD. However, the medication appeared to be less effective and more likely to have side-effects than it is for children who display these behaviors but do not have PDD. The authors suggest that methylphenidate may be a reasonable choice to target hyperactivity in PDD but caution that this medication is only sometimes effective and can produce unacceptable side-effects.

Research Units on Pediatric Psychopharmacology Autism Network (2005). *Randomized, controlled, crossover trial of methylphenidate in pervasive developmental disorders with hyperactivity. Archives of General Psychiatry, 62*, 1266-1274.

Cohen, H., Amerine-Dickens, M., & Smith, T. (2006). Early intensive behavioral treatment: Replication of the UCLA Model in a community setting. *Journal of Developmental and Behavioral Pediatrics*, 27, 5145-5155.

## Research Review: Early Intensive Behavioral Treatment

Reviewed by Kathleen Moran, MA  
Caldwell College

### Why research this topic?

In 1987, Ivar Lovaas reported a study on a behavioral treatment that took place 30-40 hours a week for two years, beginning before the age of 4. The treatment resulted in large IQ gains and placement in general education classrooms for half of the group of 19 children with autism who received it. A follow-up study of the same children showed that the gains were maintained. Lovaas's study, however, was conducted in a university setting, and many people questioned the feasibility of offering treatment at such intensity in a community setting. This concern grew as mixed results were obtained in subsequent studies of Early Intensive Behavioral Treatments (EIBT) implemented in the community. Because treatment in most of these studies was less intensive and less closely supervised than in Lovaas's study, Cohen et al. sought to replicate Lovaas's model more closely in a community setting and evaluate outcomes.

### What did the researchers do?

The study consisted of 42 children with autism and PDD-NOS. Children were split into two different groups, each group receiving a different treatment. Parents chose

which treatment his/her child received. One group received early intensive behavioral treatment based on Lovaas's previous study for 35-40 hours of behavioral intervention, 47 weeks per year for 3 or more years. As children gained skills in this group, their early intensive behavioral treatment progressed from one-to-one home instruction to a focus on peer play and finally to inclusion in a general education classroom. The other group of children received services from a local public school for 3 to 5 days a week for up to 5 hours a day for three or more years. Children in this group also received related therapies such as speech and language therapy varying from 0 to 5 hours a week from community agencies. Children from both groups were assessed before treatment began and after the first, second, and third year of treatment on measures of IQ, language, nonverbal skills, adaptive behaviors, and classroom placement.

### What did the researchers find?

The early intensive behavioral treatment group had significantly higher IQ and adaptive behavior scores than the other group. It also had higher scores on communication and daily living skills, though this advantage was not statistically reliable. At the end

of the study, 6 children from the early intensive behavior treatment group were fully included into a general education classroom and 11 were included with support. Only 1 child from the other group was placed in a general education classroom.

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

This study showed that Lovaas's early intensive behavioral treatment could be effectively used in a community setting with similar results to his original study, in that children who received this treatment obtained higher test scores and were much more likely to attend a general education classroom than children in the other group. One reason for the especially large difference in classroom placement could be that the early intensive behavioral treatment group received social skills training while the other group did not. A limitation of the study was that groups were not randomly assigned but placed in one group or another by their parents; thus, pre-existing differences between groups such as family factors may have contributed to the differences observed in the outcome assessments.

## **ASAT is a beneficiary of a new nonprofit fundraising organization, Songs of the Spectrum**

On November 19th, 2009, SingSOS! released an album of original songs about autism. This group is a 501c3 nonprofit organization that enlists the power of music to spread the word about ASD and the importance of early detection and intensive intervention.

The music is available in digital download and CD form at [singsos.org](http://singsos.org). On the album and at the site, there is also a hand-selected set of high-quality information items for parents and educators about autism in free downloadable form, including excerpts from books by leading experts.

The album can be downloaded at [www.singsos.org](http://www.singsos.org) for a \$15 donation, or ordered as a CD for \$20. It will be available through major online outlets including iTunes and Amazon. All proceeds go to a nonprofit group chosen by the donor. So help support SOS and ASAT—get your copy today!



**RAISING AWARENESS ABOUT  
AUTISM SPECTRUM DISORDERS  
BY RAISING OUR VOICES**



# New Haven Learning Centre 10th Annual Conference Autism in the School System February 5, 2010

This year's conference will focus on the important issue of effectively educating children with autism in the school system. Given that many families are losing their government funding in Ontario and being forced onto a school system that is not yet equipped to effectively teach children with autism this conference is of paramount importance for parents and providers alike.

This conference will take you through the process of advocating for an appropriate placement for your child, getting your child ready for the school system, effectively transitioning them into the classroom, and training educators to effectively teach children with autism.

The conference will feature a keynote address by Dr. David Celiberti, President, Association for Science in Autism Treatment, entitled "Components of High Quality Public School Programs for Learners with Autism: Creating

opportunities and Overcoming Obstacles;" as well as Lindsay Moir who will present on "Current Issues in Autism Education" and has over 30 years experience at the Ministry of Education and now provides advocacy services to parents of children with autism.

There will also be numerous breakout sessions sharing information and strategies related to specific facets of educational programming:

- ▷ Training Teachers to Effectively Incorporate ABA into the Classroom: Beyond a two day workshop
- ▷ Group instruction in an IBI setting: Getting Kids Ready for School
- ▷ Collaborating to Support Successful Transitions to School
- ▷ Implementing Effective Strategies Based Upon the Principles of Applied Behaviour Analysis (ABA) in the Public School Setting

### ABOUT THE NEW HAVEN LEARNING CENTRE

New Haven is a private, non-profit education and treatment centre for children with autism and their families. All teaching and intervention strategies used at the Centre are based on the principles of Applied Behaviour Analysis, focusing on the development of academic, language, social, leisure, play, community and motor skills, through research-based teaching procedures.

When New Haven opened in 1998, it was the first ABA centre-based program for children with autism in Ontario.

For more information about the "Autism in the School System" conference, please visit their website at [www.newhavencentre.com](http://www.newhavencentre.com)

"Our greatest natural resource is the minds of our children."

—Walt Disney



### ASAT's Guiding Values

**ASAT is committed to science as the most objective, time-tested and reliable approach to discerning between safe, effective autism treatments, and those that are harmful or ineffective.**

**ASAT supports all scientifically-sound research on the prevention, treatment and cure of autism, as well as all treatments for autism that are shown to be effective through solid scientific research, regardless of discipline or domain.**

## Healthcare for Children on the Autism Spectrum: A Guide to Medical, Nutritional, and Behavioral Issues

Reviewed by Megan Atthowe, MSN, RN, BCBA, Member of ASAT's Board of Directors

As many of our [Science in Autism Treatment](#) readers are well aware, there is a tremendous amount of misinformation and unverified information about the medical basis of autism and the implications this may have for biomedical treatment. A vast array of medical treatments lack any scientific support yet are made available to parents and their children by some health care providers who seem to take a risky, non-science-based, and potentially exploitative approach to their work with this population. In a marketplace of seductive biomedical approaches to autism, it can be difficult for parents and other consumers to separate the misinformation from sound medical advice. Few of us, as health care consumers, are taught how to work within our complex health care system and how to make the most of our interactions with different medical professionals. Educated consumers with a more solid understanding of health care utilization will likely be better able to make sound, safe, and effective treatment choices. Such fundamental information, expert education, and timeless advice for families and other caregivers are what make [Healthcare for Children on the Autism Spectrum](#) as relevant today as when it was first published in 2004.

Drs. Fred Volkmar and Lisa Wiesner, a child psychiatrist and a pediatrician respectively, have written a unique and valuable resource that clearly reflects the union of their experience, expertise, and areas of specialty. Parents and providers will find a wealth of background information and how-to suggestions for accessing health care services for individuals with autism spectrum disorders and for

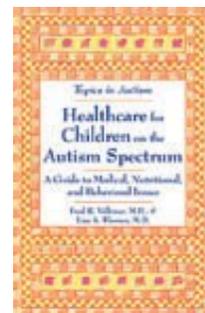
helping them achieve optimal health and wellness. The book is an excellent store of knowledge not only for health care consumers but also for those in the health care system who would like to learn to provide more creative, effective services to families or who want a starting point in learning to work with individuals on the spectrum. Those who have given up on reading commonly-available books with "medical" and "autism" in the titles will find Volkmar and Wiesner's book a refreshing source of sound medical information.

The authors have organized the book well into manageable chapters on each topic (e.g., sleep, nutrition, dental health). Overall, the content is factual and informative but also enjoyable to read and easy to digest. Information on child development and basic health care is interwoven with helpful tips and considerations relevant to children with autism and other pervasive developmental disorders (PDDs). Essential information and supplemental text are broken out into tables and boxes, and a few graphs are used to illustrate data. Each chapter ends with a summary of the most important points and a few frequently asked questions (and answers). The answers typically apply key points to real-life scenarios, and in addition to reiterating important information, sometimes shed light on a new aspect of the subject matter at hand. In other words, they are not to be missed. Throughout the text, the authors refer to additional books and other resources that are listed in two of the appendices. Other appendices include a glossary of more technical words and the diagnostic criteria for each of the PDDs. Finally, a unique feature of the book is an appendix describing the key features of different models of health insurance (e.g., HMO,

PPO), the pros and cons of each, and some tips on how to be an informed, assertive consumer of their services.

The book's organization is reader-friendly and certainly lends itself to serving as an ongoing reference. One can easily dip in and out to find information as needed. The authors cross reference other chapters frequently and occasionally repeat some information, so one need not sit down and read the chapters in order to benefit from the book's content. However, since much of the book's message has to do with prevention and preparation in advance, it would be unfortunate to wait until a problem or a crisis to read a relevant chapter.

Drs. Volkmar and Wiesner open the book with clear explanations of each PDD diagnosis and of how assessments are conducted to arrive at a diagnosis. They provide a succinct historical background and a conceptually clear description of the diagnostic categories; give a rational explanation for the increased incidence of autism spectrum disorders (i.e., increased public awareness, changes in diagnostic systems and methods, and confusion among labels used to obtain services versus those used for diagnosis); and summarize neurological, genetic, and environmental research findings related to the cause of these disorders. The chapter on assessment describes the process and players as well as many common tests used. It provides guidance to parents about interpreting the information gathered given the limitations of assessment tools. Helpful hints for parents about ways to assist the team to make an accurate



*(Continued on page 15)*

*(Continued from page 14)*

assessment and ways to advocate for appropriate assessment as well as the inclusion of tables for more technical information were helpful features. The authors provide additional, more specific information on the assessment and diagnosis of the less common PDDs (Rett’s disorder and childhood disintegrative disorder) in a later chapter covering developmental deterioration.

Chapters on visits to the primary care provider, the emergency room, and the dentist provide information on what to expect during these visits, as well as tips on how to prepare the child and the provider for a successful visit. Suggestions for ways to modify a typical health care encounter to accommodate the needs of an individual with autism are also provided. The importance of a collaborative working relationship between the parent and provider is clear. While the authors acknowledge that individuals with autism may have challenges that make routine office visits challenging, one theme repeated throughout the book is an emphasis on the importance of getting routine well-child care. Children who spend time in medical and dental settings when they are not sick or in need of dental work can have an easier experience later when such care is needed. Other topics the authors discuss include ways that individuals with PDD may communicate pain, risk factors for dental disease specific to this population, common childhood medical problems, and practical hints and adaptations for home care of the sick child.

Chapters on nutrition, safety, sleep, and adolescence and sexuality provide sound guidance and background information that all parents would do well to have; they also address unique issues that many parents of children with autism face, such as unusual food preferences, impulsivity, sleep problems, and social challenges. The

authors provide numerous useful suggestions, including information about whom to consult if initial tactics do not work. A later chapter is devoted to sensory issues, including hearing loss, vision loss, and sensory sensitivities, with a brief discussion of each. A chapter on seizure disorders provides an overview of the most common kinds, explains the evaluation

do the authors provide an overview of the major classes of drugs used to treat the symptoms of PDDs. The discussion includes how they work, their common side effects, what they are intended to do, how long until they take effect, and other considerations such as the need to taper doses, for example. The authors provide things to think about when considering using

**“In a marketplace of seductive biomedical approaches to autism, it can be difficult for parents and other consumers to separate the**

process and treatment approaches, and describes how to respond to a seizure. An important part of this chapter’s message is maintaining realistic expectations for medication management. For example, seizures may continue to occur, finding an appropriate drug and dose may take time, and that consistency in giving the medication will be needed.

Two chapters address challenging behaviors, specifically stereotyped behaviors, self-injury and aggression, rigidity and perseveration, over-activity and attention problems, and mood problems. The authors describe behavioral interventions as the first approach for addressing challenging behaviors. Suggestions include looking for patterns, noting antecedents and consequences, reinforcing appropriate behaviors, planning ahead, following through, providing a structured and consistent environment, and determining the function of the behavior. These general principles are then discussed as applied to the specific groups of behaviors. SIAT readers will appreciate the importance of sharing data on challenging behaviors with medical professionals as part of a collaborative, productive professional/patient relationship. Only after covering behavioral approaches

medication and discuss tips for ensuring medications are used safely. The chapter is written with a balanced account of both the reasons for and against using particular medications. The authors also provide a summary of the research, when it exists, as well as the straightforward acknowledgement of the prevalence of off-label use.

Finally, the authors dedicate a chapter to complementary and alternative treatments, which is another way of referring to those treatments that are not scientifically-based and that are used instead of, or in addition to, standard, science-based treatment. The authors explain why these therapies are ubiquitous for individuals with autism spectrum disorders and how the scientific method can be (has been and should be) used to test new ideas to see what works. They provide guidance on how to judge the quality of research and information in the media and on the internet, and suggest warning signs that indicate a treatment might be unsound. If parents are considering using a complementary or alternative treatment, the authors provide a list of questions to ask themselves (and the providers) before becoming involved in what could be an expensive, time-

*(Continued on page 16)*

**Book Review continued...***(Continued from page 15)*

consuming, or even risky endeavor. The authors' ability to draw meaningful comparisons to everyday scenarios makes the content easy to relate to. Numerous checklists and tables make what could be intimidating information visually contained, and repetition helps to drive home important points. Finally, the authors describe several specific treatments and the theories behind them, the evidence (or lack thereof) to support their use, and the potential benefits or risks to a child from using them (including the medical risks). The interventions discussed include: facilitated communication, various dietary interventions, high doses of vitamins, chelation, plasmapheresis, secretin, anti-convulsant medications, steroids, anti-infective agents, intravenous immunoglobulin g, auditory integration training, central auditory processing treatment, FastForWord, visual therapies, body manipulation therapies, and the Options Method. Since 2004, of course, additional such therapies have come into existence/popularity, and it seems wise of the authors to include those most controversial, most popular, or most risky rather than to attempt a laundry list.

Throughout the book, Drs. Volkmar and Wiesner are clear about the value of scientific evidence and practices that are evidence-based, yet they note repeatedly that each individual and his or her family are different—touching on the “practice” element of evidence-based practice. They provide a considered perspective to health care for individuals on the spectrum, stressing that an analysis of the risks and benefits to the individual is always important. It may or may not be worth treating a problem, depending on what the problem is, the treatment, and the individual. In some cases, parents may prioritize and decide that the challenges of care may outweigh the benefits. In others, and with the sound, practical suggestions of these good doctors, the benefits of care may well be realized.

While this is not the place to turn for the most up-

to-the-minute medical information (research on the use of medications and genetics have continued to advance since the book's publication in 2004, for example), that is not the purpose of this book. Instead, it serves as a solid base of background knowledge. The only real concern is a wish that more of the web resources listed and portions of the chapter on sensory issues (specifically, sensory sensitivities) better reflected the same commitment to science-based practice as the rest of the book. However, this is mostly a reflection of the need for the practice community to demonstrate scientifically the effectiveness of specific methods (e.g., sensory integration). Finally, while the authors mention it in the afterword, an excellent addition to a future edition would be a chapter on the health care considerations for the growing population of adults with pervasive developmental disorders.

In summary, Healthcare for Children on the Autism Spectrum will go a long way toward helping parents be informed participants in health care encounters and health care providers be better helpers. By partnering together and planning ahead, parents and providers can set the occasion for a positive experience for individuals with PDDs in the health care environment—and one hopes, for good health.

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*In addition to our Advisory Board, a number of individuals lend their time and talents to support ASAT's mission and initiatives.*

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**Interview with a Board Member: Barbara Wells  
by David Cellbertl, Ph.D., BCBA-D**

The autism community knows very well that significant outcomes are achieved when parents and professionals work in partnership. ASAT is no exception. In fact, parents played a significant role in the creation of ASAT over 10 years ago. Currently, ASAT has five wonderful parents on our board and I recently had the opportunity to interview one of them. Barbara Wells has served on the ASAT Board for four years.

**Barbara, I am delighted to have this opportunity to interview you. Before we talk specifically about ASAT, can you tell us a little about your family?**

I am a single mom with three kids ages 29, 24 and 18. My oldest is a marine who just returned from Afghanistan. My daughter graduated in May from Temple University with her BS in Social Work. She is currently a social worker for Princeton Hospital. My youngest, who has autism, recently turned 18 and attends a public school. I am in the process of applying for guardianship for him.

**We thank you and your son for his service to our country. I understand that you recently participated in a marathon that tied in at least two aspects of your family life. What led you to take this on?**

I try to stay as healthy as possible which helps me deal with the daily stress of being a single parent with a child diagnosed with autism. I started running because it was an exercise that I could fit in when I



had the time and there was very little expense. Linda Meyer, Executive Director of Autism New Jersey, has been my mentor and she ran her first marathon when she was 50. She challenged me to run in the Marine Corps Marathon. As I was training, I kept thinking about my oldest son and the courage it took

for him to enlist in the Marine Corps and to serve our country in Afghanistan, and the courage it takes for my son with autism to deal with life every day. I

completed the Marine Corps Marathon in 5 hours and 29 minutes. I will turn 50 this June.

**That is wonderful. Your family must have been very proud of you!**

**Your youngest son was diagnosed in the mid 90s. Can you tell us a little about your early experiences navigating the many many treatments for autism?**

Back in the Stone Age when computers were not so commonplace, information on treatments for autism was sparse and not widely available. Most of the information I received was through other parents. I did not realize the breadth of the spectrum of autism. I thought most kids were alike and therefore what worked for one child would work for all children. My early experiences involved watching what other parents did and choosing treatments I could emulate. The New Jersey Center for Outreach and Services for the Autism Community (COSAC), now Autism New Jersey, provided a great parent training that focused on applied behavior analysis. Over the years, I have been able to incorporate what I learned at the parent training into a program for my son.

During this time, we tried the gluten/casein-free diet at home. We did not inform my son's school that we were pursuing this diet and no change in behavior or ability was noted. It was very expensive, time consuming and stressful on our whole family. The testing was particularly hard on my son. Visits to the DAN practitioner, forcing him to take supplements and not allowing access to preferred foods was a nightmare. I justified the torture because I wanted to find a cure for my son. As is the case with many parents, I wanted to believe that there was a quick fix.

It is also important to note that 10 years ago ABA services were not readily available. Teachers with experience were few and far between. During the course of one year, my son had six different teachers. After a struggle with the school district that ended in mediation, my son was transferred to a private school. His first few months were a struggle, but after an initial adjustment period, he made significant gains in language and ability. Behavioral challenges finally started to decrease. At the age of 15, he returned to a self-contained class in our local public school.

**Your experiences are sadly not unique in that the lack of availability of evidence-based practices has certainly increased the attractiveness of other**

*(Continued on page 18)*

## Interview with a Board Member: Barbara Wells continued...

(Continued from page 17)  
treatments.

**What do you think is different now for parents of newly-diagnosed children? What is easier and what is harder?**

Information regarding autism treatment is much easier to find. Treatment summaries, found on ASAT's website, provide parents and professionals with the most current information. Book reviews, article synopses, links to relevant sites and answers to frequently asked questions provide information that would have taken hours to research on my own. Colleges are offering course work that supports the field of autism which, in turn, has expanded the pool of professionals available to work with our children. Medical professionals are more proficient at diagnosing autism allowing children access to services at an earlier age. In many regards, there has been much improvement.

What I find harder is that many parents continue to struggle with school districts that drag their feet in providing appropriate services. As a parent of a young adult, I also find it hard to find services such as

respite, employment and housing for adults

with autism. Increased funding streams for research into the causes of autism have produced tremendous advances, but it is harder to find funding for programs for individuals currently in need of support. Finally, it is important to note that with abundance of information on the internet, is an abundance of bad information that can be incredibly distracting, particularly for parents of newly

diagnosed children. I appreciate the role ASAT plays in helping parents with their ever so important decision making.

**Why have you remained so involved with ASAT?**

Those famous words, "If only I knew then what I know now" bear tremendous relevance to me. I want to help parents use science to help make decisions regarding treatment, not emotions, and ASAT is a wonderful forum through which I can do just that. When my son was younger, I had an overwhelming need to do something...I could not just stand by and watch the slow progression of skills that ABA produced. I realize now that clever marketing had a more powerful impact on the treatment decisions I made than common sense. I wasted a lot of time, money and energy on treatments that had no scientific basis.

**What are the various hats you have worn as a board member?**

Over the years, I have served on almost all of ASAT's committees such as Public Relations, Finance, and Website. More specifically, I have been involved in updating

the Conference page, helping to redesign the website, monitoring the ASAT mailbox and coordinating and processing donations. I look forward to assuming the role of ASAT Treasurer later this year.

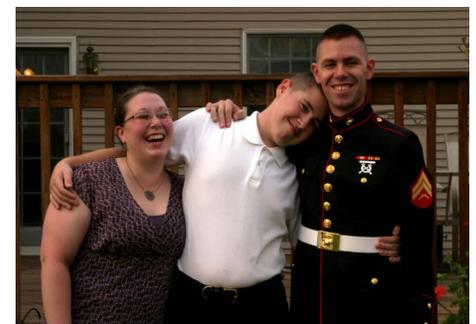
**What advice do you give parents of newly diagnosed children?**

Take a very close look and then a second look at the treatments you are considering. When deciding on

a treatment, take the time to research claims regarding outcomes. Are the claims based on data that support a change in behavior or ability? Is the claim based on belief that the treatment will produce a change? I can now read

statements such as "based on a survey by users", "thousands of people have stated" or "we asked hundreds of users" and question claims that are biased to sell products. Learn how to take data and make decisions based on what is working for your child.

**That is all excellent advice. Thank you for taking the time to share your experiences. More importantly, thank you for all you do to help make ASAT a success!**



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As ASAT grows, we are reaching out to more people every day united in their commitment to science in the treatment of autism.

Join our [facebook Fan Page](#) and invite your friends to join as well. Our fan page contains:

- ASAT organization announcements
- Recent developments with our Media Watch campaign (described on page 10 of this issue of the newsletter)
- Relevant information about our newsletter, [Science in Autism Treatment](#).
- Inspiring stories and lively discussion

We are looking forward to hearing what you have to say!

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## Treatment Summary: Hyperbaric Oxygen Therapy (HBOT)

**Description:** An intervention in which oxygen is delivered in a pressurized chamber, with the goal of increasing oxygen absorption in bodily tissue.

**Research Summary:** One study suggested that hyperbaric oxygen therapy may produce positive behavior changes in children with autism spectrum disorder (Rossignol et al., 2009), but another study, which was small but well-designed, found no benefit (Granpeesheh et al., 2009). There have been no studies with strong experimental designs on hyperbaric oxygen therapy for individuals with autism spectrum disorders. The equipment poses a fire risk and has caused serious injury, and the intervention may have significant side effects such as damaging the middle or inner ear and raising blood sugar levels (Liptak, 2005).

**Recommendations:** Researchers may wish to conduct studies with strong scientific designs to evaluate Hyperbaric Oxygen Therapy. Professionals should present this intervention as under-researched as a treatment for autism spectrum disorders, describe the potential risks, and encourage families who are considering this intervention to evaluate its effects and side-effects carefully.

### Systematic reviews of scientific studies:

Liptak, G. S. (2005). Complementary and alternative therapies for cerebral palsy. *Mental Retardation and Developmental Disabilities Research Reviews*, 11, 156-163.

### Selected scientific studies:

1. Granpeesheh, D., Tarbox, J., Dixon, D. R., Wilke, A. E., Allen, M. S., & Bradstreet, J. J. (in press). Randomized trial of hyperbaric oxygen therapy for children with autism. *Research in Autism Spectrum Disorders*. Advance online publication. doi:10.1016/j.rasd.2009.09.014
2. Rossignol, D.A., Rossignol, L.W., Smith, S., Schneider, C., Logerquist, S., Usman, A. et al. (2009). Hyperbaric treatment for children with autism: a multicenter, randomized, double-blind, controlled trial, *BMC Pediatrics*, 9, 21, doi 10.1186/1471-2431-9-21

## Letter from the Co-editor: Josh Pritchard, M.S., BCBA



Having just finished our first publication of 2010, I wanted to thank you for your continued support and encourage you to help us spread the word about ASAT and this newsletter, Science in Autism Treatment. At the end of 2009, we had over 3000 subscribers. This is

exciting, but we are well aware that this is only a small portion of the families that need information to help them make science-based decisions for their child with autism.

I just returned from a trip to South Africa on which I was working with some children with autism. It was there that I realized two things: lions **do bite** and 3000 subscribers just was not enough. There are places affected by autism that do not have available adequate information or science-based treatment. Therefore, our goal this year is to double our number of subscribers, and we cannot do it without your help! Perhaps you know of families or professionals working with children with autism, who may not be aware of this free newsletter. Simply forward this newsletter to them, and provide them with the link to sign-up as a subscriber ([www.asatonline.org/signup](http://www.asatonline.org/signup)).

Your simple action will give them access to the entire year of free SIAT newsletters, e-mail updates, and may help them better access effective treatments.

Imagine if you were the person who helped a family learn to wade through the mounds of treatment options and choose those which have been scientifically proven to work?

In addition to the immediate family members of children with autism, this newsletter can greatly benefit distant family members like aunts/uncles and grandparents. We have had many parents tell us that one of the difficulties of using science-based treatment is the massive amount of pressure by relatives to adopt non-science based treatments. These people are desperately trying to help, but can often be unaware of the difference between science-based and unsupported treatments. One of the goals of the newsletter is to readily provide the reader with this distinction and understanding.

We can't do it without you—help us reach as many people as we can. Thank you!

Yours in Science,



Josh Pritchard, MS, BCBA

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

*(Continued from page 1)*

Some of our 2010 goals include:

- To distribute four comprehensive, information-packed issues of Science in Autism Treatment in 2010.
- To have articles related to science and autism treatment published in other newsletters frequently read by professionals and consumers.
- To continue to update the treatment summaries on our website, [www.asatonline.org](http://www.asatonline.org), for biomedical, behavioral and non-behavioral treatments.
- To include video examples of evidence-based treatment on our website.
- To develop consumer-friendly features such as a web page for parents who are new to autism treatment.
- To assess the needs of pediatricians and related medical providers and to identify appropriate goals and strategies. Direct involvement of medical professionals will be solicited to accomplish this goal.
- To increase distribution of ASAT’s printed materials at state, regional, and national conferences.
- To expand upon the number of opportunities in which Media Watch provides feedback in response to accurate and inaccurate portrayals of autism treatment.
- To offer media education for journalists through the development of a media page on our website.
- To develop a media award to recognize the efforts of individuals who accurately portray autism treatments.
- To play an active role in internet representations of autism treatment and evidence-based practices (e.g., developing, refining, and correcting Wikipedia information).
- To pursue grant writing as a mechanism to fund specific ASAT initiatives.
- To continue to provide meaningful opportunities for volunteers to participate in various endeavors.
- To develop and expand upon ASAT’s facebook.
- To gain 3000 new subscribers by the end of this year.

As I did in my Fall 2009 column, I will end this letter with an appeal. The ongoing success of ASAT is predicated on the financial support and generosity of our donors. We are committed to maintaining and updating our website ([asatonline.org](http://asatonline.org)) and to distributing this free quarterly newsletter; however, we can not carry out our important work without your financial support, particularly in these tough economic times.

If you support our mission, believe in the promotion of science, and recognize the need for accurate information about autism treatment, and we believe you do, please join our efforts by completing the donor panel on page 19 or donating online through Pay Pal (found on the lower left corner of our home page at [asatonline.org](http://asatonline.org)).

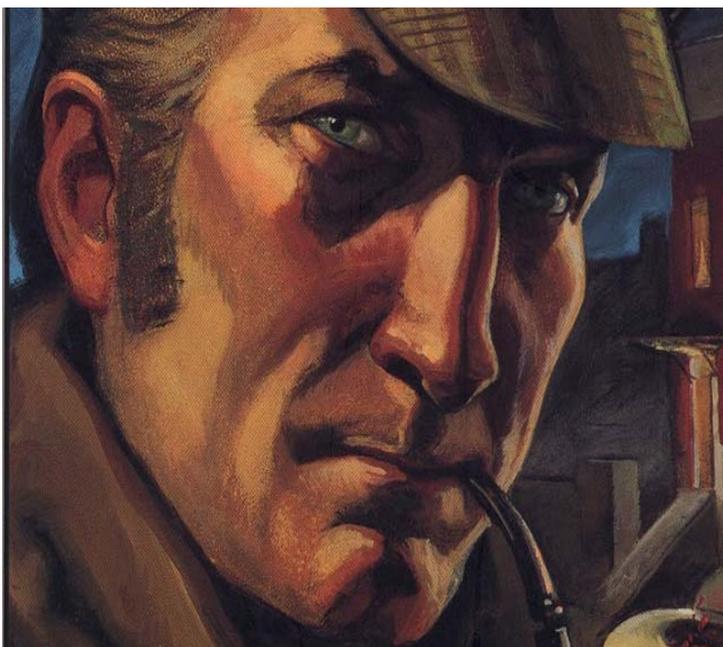
In addition, if you are affiliated with an organization that shares ASAT’s commitment to science in the treatment of autism, I invite you to consider becoming a 2010 Real Science, Real Hope Sponsor. Last year 20 organizations became sponsors and our goal is to be even more successful in obtaining sponsorships in 2010. Please see page 9 for more information.

I wish you all a happy and healthy new year.

Best,

*David Celiberti*

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



**“It is a capital mistake to theorize before one has data”**  
Brilliant words from Arthur Conan Doyle, Sr., 1859-1930  
Writer/creator of the detective Sherlock Holmes