From the Archives: ASAT Formed to Meet Critical Needs
Catherine Maurice, Ph.D.

[Note: This essay appeared originally in the Spring of 1999, in the premier issue of Science in Autism Treatment. Catherine Maurice and SIAT editors have added some notes to update the discussion as follows.]

The Association for Science in Autism Treatment (ASAT) was formed by parents and professionals dedicated to ensuring that children and adults with autism lead lives filled with dignity, purpose, peace and independence. It is probably safe to assume that most parents and professionals who care about people with autism support this goal. But difficulties — even conflicts — may arise when people of good intentions differ with each other over the means of achieving goals they share. Currently, the field of autism is marked by a high degree of such conflict. Rather than ignore it, it may be a good idea to spell out clearly what ASAT is about so that others have the opportunity to support our mission based upon a clear understanding of what we stand for. We stand for science in autism treatment.

Two Historical Trends

To understand why ASAT has chosen such a focus, a brief description of the historical context in which we are launching our cause is in order. That history reveals two dominant trends: a troubling parade of ineffective treatment models, miracle cures and faddish “breakthroughs.” Often these are sensationalized by the media, fueled by the anxious love of mothers and fathers, and adopted readily by service providers, in spite of the absence of any evidence of effectiveness. The most

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Articles with this symbol are new recurring features that debut in this issue!

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Message from SIAT Co-Editors
David Celiberti, Ph.D., BCBA-D & Josh Pritchard, MS, BCBA

After publishing the second issue in our re-launch of Science in Autism Treatment Newsletter, we are eager to hear what you think!

We will regularly check and respond to e-mails sent to our newsletter: newsletter@asatonline.org so please share your feedback about the content and format of the newsletter.

We are proud to release several new features in this issue, and to help you identify them, we’ve placed a

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Science in Autism Treatment (SIAT) Team

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Talk About Ethics
Mary Beth Walsh, Ph.D.

Advertising
Marianne Clancy

Consumer Corner
Kate Fiske, Ph.D., BCBA-D

Treatment Summaries
Tristram Smith, Ph.D.

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Meet our Board Members: Interview with Long-Time ASAT Board Member, Joe Forgone, MBA
Conducted by David Cellbert, Ph.D., BCBA-D

Joe, it is a pleasure to interview you for this issue of Science in Autism Treatment, as you are the longest-serving member of the current ASAT board. You have been involved with ASAT since the early years and have actively participated in its growth and development.

As you know, many board members of organizations like ASAT are professionals who have chosen autism treatment as their career path. On the other hand, other members of our board are parents of children with autism who obviously did not choose this path, but the events of their lives have led them in this particular direction. You are neither a professional in the field nor a parent of a child with autism, however, your commitment to ASAT, its mission, and science-based treatment has been steadfast. Can you tell us a little bit about your background and perhaps some of your early influences and experiences that led you to ASAT?

I am not a professional in the field of autism, and, in fact, I have no children. I am 61 years old and the only child of two terrific parents. I was born in Brooklyn and raised in Brooklyn and Queens. I am married to a wonderful lady, Lydia. Getting married at the age of 57 and getting a puppy at age 59 - two firsts - is proof that you can, in fact, teach an old dog new tricks.

Autoimmune diseases have plagued me since I was a baby. I believe that the effort required to cope with chronic ailments has helped guide my life and shape my values. I recall quite vividly the enormous emotional strain on my parents when they saw me suffer and yet could do little to relieve my physical and emotional pain. Yet they never complained. Seeking effective treatment and sifting through the information about my autoimmune condition had always been in the forefront for my parents. Although autoimmune disease and autism are indeed different, and times have changed, the many parallels set the stage for me to get involved in an organization such as ASAT with its mission and focus championing scientifically-proven research and recommendations.

My grandparents were immigrants, and my parents had their education cut short by the depression. I was the first college graduate in my family. I hold a B.A. in political science and economics from Queens College, and an MBA from Fordham University. In college, I pledged Alpha Phi Omega, a national service fraternity (I was always a bit dull!).

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Clinical Corner: Early Detection and Intervention

Why is early detection and treatment important? How can this be accomplished?

Answered by Angela Smith, M.A., BCBA

Early detection of autism is essential in gaining access to treatment at the earliest point possible. With the rise in the incidence of autism, more and more families are faced with the challenge of accessing intervention programs for their toddlers with autism. As soon as a diagnosis is made, families should be provided with accurate, up to date information about science-based intervention options. In addition, parent training should be initiated at the point of diagnosis so parents can begin the process of facilitating skills for their child with autism.

Research indicates that the earlier the child gains access to quality behavioral treatment, the more likely they are to have a better long term outcome. The National Research Council (2001) published recommendations for educating children with autism. They recommend that a child receive intensive behavioral intervention for a minimum of 25 hours per week in a low student-teacher ratio, focusing on a variety of functional skills as well as targeting decreasing challenging behaviors (although it is important to note that much of the published research involved more than 25 hours per week). The report also indicates that parents should be able to easily access and participate in the intervention.

Unfortunately, research does not always dictate treatment. Often, once a diagnosis is obtained, precious months are wasted as families negotiate the maze of intervention alternatives. In addition, once families identify behavioral intervention as their treatment choice, they are often confronted with bureaucratic stumbling blocks to obtain funding and qualified service providers.

Assuming “early detection” means diagnosing an autism spectrum disorder before the age of three, then there are some options that are available for parents to access services for their newly diagnosed child. They can access early intervention services through the state, or they can go the alternative route and pay privately to have services started in the home. In addition to these two options, parents can go through parent training to learn to provide services themselves. Many families end up with a combination of all of these options. A privately funded intensive home program can range anywhere from $65,000 to $120,000 per year depending on how many hours are provided to the child. This enormous cost is not readily affordable for most families, so working with the state-directed early intervention system is usually the first step for families after diagnosis. Accessing early intervention can be challenging. An initial step to obtaining these services often involves an evaluation of the child by the early intervention team (which may include professionals such as an educator,

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Research Review: Early Intensive Behavioral Intervention: Outcomes for Children with Autism and Their Parents After Two Years

Reviewed by: Kathleen Moran, Caldwell College

Why research this topic?
A growing body of research suggests that early intensive and structured treatment based on applied behavior analysis (ABA) is more effective than standard community treatment and less intensive ABA. This study compared early intensive behavioral intervention (EIBI) to a standard special-education public school program and extended previous work by including more comprehensive assessments of changes in autistic symptoms and effects on families.

What did the researcher do?
Forty-four children with autism spectrum disorders between the ages of 30-42 months were assigned to groups based on parental preference. The first group received early intensive behavioral treatment that consisted of 1:1 teaching based on the principles of ABA for 25.6 hours per week. The students in standard special education received a variety of treatments, none of them intensive or reliant on 1:1 teaching.

What did the researchers find?
After two years, the children receiving intensive behavioral treatment had higher IQ scores, daily living skills and language as compared to the children in the standard public school program. They also displayed fewer autistic symptoms, and their parents reported more positive social behaviors. Six children in EIBI achieved reliable gains in IQ and approached the IQ range for the typical population. In contrast, three children in the comparison group showed reliable IQ gains, but three others showed reliable IQ losses. In addition, 17 students who received intensive behavioral treatment were enrolled in a mainstream classroom, compared to only 10 students from the public school program.

What were the strengths and limitations of the study?
What do the results mean?
Overall, the children receiving intensive behavioral treatment out-performed those children in the special education public school program. The study confirms previous research indicating that early intensive behavioral treatment accelerates overall development. Two new findings are that this treatment can reduce autistic symptoms and that, in the most comprehensive test of the effects of the treatment on families, there was no evidence of a negative impact on the family. The study had two significant limitations: rather than being randomly assigned to a treatment group, parents chose which group their child would participate in, and the groups were small. Nevertheless, the study makes an important addition to research on early intensive behavioral treatment.

Interview with Tom Zane, Ph.D., BCBA-D and Suzanne Letso M.A., BCBA by David Coliberti
As readers of Science in Autism in Autism Treatment are well aware, parents of children with autism are confronted by an overwhelming array of treatment options, most of which are not scientifically validated. I had the opportunity to interview Tom Zane and Suzanne Letso, and asked them about their experiences counteracting pseudoscience in the treatment of autism. Their biographies are provided on page 18.

Thank you both for participating in this interview. Tom, please share with us how you first became concerned about pseudoscience.

T Z: Well, it seems like we have been confronted and challenged by pseudoscience for a long time. Being a behavior analyst, and thus committed to data-based decisions and a scientific approach towards autism treatment, I often saw treatments being implemented which either didn’t make sense or were not working. Upon reviewing the literature about the treatment, often I quickly learned that there was simply nothing published, no solid, valid research evidence showing that the treatment worked, or had actually ever been tested! Another influence on my thinking came from my experiences within a School of Education in which we prepared regular and special education teachers. The faculty members were not behavior analytic, but more traditionally trained and prepared, and I saw how little instruction the teachers-in-training had in analysis, science, and data-based decisions. I won’t say that pseudoscience was actively promoted, but I believe that it was tolerated.

Suzanne, although you are now heavily immersed in the field of autism, your initial career path was different. Please tell us about some of your experiences both in your prior career and as a parent.

SL – Actually, I became concerned about pseudoscience in autism treatment well before I ever heard of behavior analysis and, in fact, the industry in which I worked required a level of scientific validation. I was a marketing executive working in the medical industry prior to my son’s diagnosis of autism. At that time, I was responsible for collaborating with surgeons and other medical professionals working in that area. (Continued on page 6)
Talk About Ethics: What do the BACB Guidelines for Responsible Conduct suggest regarding evidence-based treatment?
Mary Jane Weiss, Ph.D., BCBA-D

One of the hallmark characteristics of Applied Behavior Analysis is its reliance on scientifically-validated treatments. In addition, there are a number of scientific values that permeate the application of ABA intervention for individuals with autism. There is a focus on empiricism, on demonstrating the effectiveness of procedures and on the identification of functional relationships between treatments and effects. Furthermore, ABA focuses on changing socially significant behaviors with procedures that are clearly defined and replicable. Unlike other interventions for individuals with autism, much data exist that supports the effectiveness of ABA in the treatment of individuals with autism. It is important to note that these studies have been published over the course of several decades, by hundreds of researchers worldwide, and many of them have been published in peer reviewed journals. The quality of research available regarding the effectiveness of ABA is vastly superior to that available for any other treatment approach. Studies are rigorous, have controlled for extraneous variables, have been replicated and have demonstrated effects that have generalized and been maintained over time. Many claims are made regarding treatments that are supposedly effective, but only ABA has been scientifically verified as effective to date.

Furthermore, behavior analysts value the provision of effective services. Every effort is made to ensure that the learner’s time is not wasted through the selection and monitoring of operationally-defined targets, systematic collection of data and the careful analysis of those data. In other words, behavior analysts not only utilize procedures that have been demonstrated to be effective, but they also ensure that intervention is effective at the individual level. Data are collected to demonstrate the impact on individual learners. Thus, the commitment to effectiveness occurs at the broad level of implementing empirically-validated treatments and at the local level of analyzing the effectiveness of intervention for the individual learner.

Welcome to Talk About Ethics, which will run as an occasional feature of this newsletter. This column is dedicated to exploring ethical issues related to autism treatment and interventions. Authors will be drawn from a variety of stakeholders: professionals, family members, and self-advocates, united in their commitment to the basic human dignity of individuals with autism as well as their fundamental right to effective intervention.

We are very grateful to Dr. Mary Jane Weiss for this inaugural column which takes a close look at the Conduct Guidelines of the Behavior Analysis Certification Board.

Mary Beth Walsh, Ph.D.
SIAT Talk About Ethics Coordinator

Behavior analysts often struggle with issues related to the effectiveness of treatment. Often in clinical practice, behavior analytic services are offered in combination with interventions that are not empirically validated. Essentially, ABA is often combined with other (non-validated) approaches in an eclectic model of intervention. Such dilution of services often leads to reduced effectiveness. Effectiveness

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Book Review: The Complete Guide to Autism Treatments—Sabrina Freeman, Ph.D.

ISBN# 978-0-9657565-5-6
Reviewed by David Celiberti, Ph.D., BCBA-D

Just when we think we have seen everything, we are reminded that with autism treatments anything and everything is possible, particularly given that many individuals have recognized that autism treatment can be a very lucrative business. The array of treatments for autism is indeed quite diverse and taken together can be absolutely overwhelming. Take a few examples:

- “In packing, children are wrapped tightly for up to an hour in wet sheets that have been refrigerated, with only their heads left free. The treatment is repeated several times a week, and can continue for years.” (See http://www.theautismnews.com/2009/06/26/battle-autism-with-bentonite-clay.)
- “The Autism Code Program™ makes all this possible by opening a door in the blocked wall of autism, allowing the parents to communicate with their children in a way unknown before. Through their work in the program, the parents form communication with their children solely at the level of consciousness without any interaction with the children, and the children respond to the words being articulated within their parents’ inner world.” (See http://autismcode.org.)

Thankfully, there is a new resource available to help parents and other consumers develop the skills needed to differentiate science from pseudoscience and viable options from nonsense.

Dr. Sabrina Freeman is a prolific writer who has published numerous works related to autism and its treatment. Her latest book, The Complete Guide to Autism Treatments, may indeed be her most important contribution to parents of children with autism, as well as to those professionals who work with this clinical population. It is

(Continued on page 14)
Choosing a behavioral service provider can be a challenging task. Fortunately, there are some resources to guide consumers in making sound choices. Consumers should judge behavioral service providers based on the effectiveness of the interventions they use. By definition, applied behavior analysis involves meaningful changes in behavior (Baer, Wolf, & Risley, 1968; Cooper, Heron, & Heward, 2007). Providers of applied behavior analysis, therefore, should only be considered effective when they successfully bring about behavioral change for the learners with whom they are working (i.e., desired skills are acquired, and behaviors of concern are reduced in frequency or intensity).

Formal credentialing of professional behavior analysts (i.e., registration, certification, or licensure) helps consumers identify quality service providers and provides safeguards for consumers by screening potential providers and offering opportunities for recourse if incompetent or unethical practices are encountered. Currently, efforts to establish licensure or registration for behavior analysts are underway in many states. Progress in development of such qualifications—and related requirements—varies from state to state. Subscribers of Science in Autism Treatment will be kept apprised of developments as they unfold.

Behavior analysts are certified by the Behavior Analyst Certification Board, Inc. (BACB). The BACB credentials practitioners at two levels. Board Certified Behavior Analysts® (BCBA) must possess at least a master’s degree, have 225 classroom hours of specific graduate-level coursework, meet supervised experience requirements, and pass the behavior analyst certification examination. Recently, the BACB added the BCBA-D credential to distinguish doctoral level behavior analysts. Board Certified Assistant Behavior Analysts® (BCaBA) must have at least a bachelor’s degree, have 135 classroom hours of specific coursework, meet supervised experience requirements, and pass the assistant behavior analyst certification examination. The BACB specifies it is mandatory that BCaBAs practice under the supervision of a BCBA. All BCaBA certificates (whether BCBA, BCBA-D, or BCaBA) must accumulate continuing education credits to maintain their credentials.

The BACB maintains a Task List, which outlines content areas in which behavior analysts should be well qualified. These content areas are applicable to all behavior analysts, and include:

- Ethical Considerations
- Definition And Characteristics
- Principles, Processes And Concepts
- Behavioral Assessment
- Experimental Evaluation Of Interventions
- Measurement Of Behavior
- Displaying And Interpreting Behavioral Data
- Selecting Intervention Outcomes And Strategies
- Behavior Change Procedures
- Systems Support

More recently, the BACB developed a Task List for Board Certified Behavior Analysts Working with Persons with Autism, to highlight a more specific skill set. This Task List was published in the Fall 2007 Autism Special Interest Group (SIG) of the Association for Behavior Analysis International (ABAII) newsletter, and is reprinted with permission on page 19 of this newsletter.

For details about certification in behavior analysis, access to the registry of certificants by name and state, and the Conduct Guidelines for certified behavior analysts, visit the BACB website at www.bacb.com.

For additional information on identifying quality behavioral providers, consumers are also encouraged to review the Revised Guidelines for Consumers of Applied Behavior Analysis Services to Individuals with Autism and Related Disorders, developed by the Autism SIG. The Autism SIG urges consumers to ask prospective directors or supervisors of ABA services to provide documentation of their qualifications in the form of: a master’s or doctorate degree in ABA or a related field; full membership in ABAI and possibly one of its regional chapters; letters of reference from employment supervisors and/or families for whom they have directed ABA programming for similar individuals with autism (with appropriate safeguards for privacy and confidentiality); any registration, certificate, or license in Applied Behavior Analysis per se (i.e., not psychology, special education, education, or another discipline with no emphasis in behavior analysis); participation in professional meetings and conferences in behavior analysis; and publications of behavior analytic research in professional journals.

The Autism SIG recommends that training and supervision for clinicians who will direct ABA programs for individuals with autism should focus on competency in a number of areas, including designing and implementing individualized skill acquisition programs (especially in skill areas of particular relevance for individuals with autism, such as social interaction, communication, attending, and imitation skills); providing ABA services for individuals with autism who represent a range of ages and skill levels; utilizing a variety of behavior analytic teaching procedures (e.g., discrete trial teaching, task analysis, incidental teaching, activity schedules, script fading procedures, video modeling); conducting functional assessments and developing individualized behavior reduction programs to treat stereotypic and disruptive behaviors; and programming for effective generalization. It is important to note that participating in a few workshops, courses, or brief hands-on experiences do not qualify one to practice Applied Behavior Analysis effectively and ethically.

For further details about these guidelines, visit the Autism SIG website. A PDF of Revised Guidelines for Consumers of Applied Behavior Analysis Services to Individuals with Autism and Related Disorders in their entirety can be found at http://www.abainternational.org/Special_Interest/AutGuidelines.pdf.

References

Robert LaRue, Ph.D., BCBA-D
Associate Director of Behavioral and Research Services
Douglass Developmental Disabilities Center/Rutgers University

Lori Bechner, M.A., BCBA
Clinical Director
Educational Partnership for Instructing Children (EPIC)

Kate Fiske, Ph.D., BCBA-D, SIAT Consumer Corner Coordinator
Interview with Tom Zane and Suzanne Letso continued....

As you both pointed out, varying degrees of respect for science can be found within many diverse fields. Suzanne, in light of your marketing background, are there differences in presentation style between those that support scientifically validated treatment and those that do not?

SL: In a sense it is a very uneven playing field when you compare the promotion of pseudoscientific treatments with the ways in which scientifically-validated treatments are described to the public. In stark contrast, scientists, including the behavior analytic scientist-practitioner, are very careful to describe the limits of their research, and make every effort not to overstate the effects of the treatment under study. Pseudoscientific proponents often describe their treatments in value-laden, emotional terminology and often promise extraordinary outcomes that go well beyond the available evidence.

Unfortunately, it is difficult, if not impossible, to disarm autism-specific pseudoscience in a time, place, and culture that routinely embraces pseudoscientific claims in other areas of day-to-day life. Perhaps we would have a greater chance of minimizing the appeal of pseudoscientific interventions for high stakes disabilities such as autism if we can first convince others that there is benefit to utilizing a scientific approach in general. Unfortunately the 20-second sound bite rules the marketing world and our perceptions of what is “good for us” is often shaped by messages that are at best unclear and not founded in good science. Do 4 out of 5 dentists really recommend a particular brand of gum? If only 5 dentists were asked, or if each dentist had a stake in the gum company then the statistic would be less believable than if an independent market research firm conducted a nationwide survey of all dentists. Statistics can deceive as well as inform yet it is virtually impossible for each of us to assess the credibility of every claim for every sales pitch we are bombarded with each day. However, being able to differentiate between the relatively innocuous and critical issues that warrant further investigate is as important a skill to develop as learning how to evaluate the overall quality of the evidence when we do decide to look beyond marketing claims and headlines. The inquiring mind that wants to know – and to raise questions – is far more likely to be receptive to information about what works and what doesn’t when their child can’t talk, won’t look at them, and is falling further and further behind with each passing day.

Suzanne, these are excellent observations. Tom, what lessons should advocates of scientifically-validated treatments learn from the resilience of pseudoscientific treatments?

TZ: This is a good question. First, we need to realize that many people have different opinions and definitions of what constitutes “scientifically-validated.” A colleague and I are currently reviewing the criteria for evidence, as promulgated by various organizations around the country. There is quite a disparity that exists, ranging from the reliance on “clinical judgments” to levels of statistical significance. So, first, we who advocate scientifically-validated treatments need to understand that we don’t have the monopoly on how that is defined. Second, we need to be able to argue persuasively for why our definition of empirical evidence matters the most. Last, I would say that the major focal point for our efforts in this area has to be parents. They are the ones who make the decisions as to what treatments to select for their children. They hold the power. We need to effectively communicate with parents as to what criteria should guide their treatment decision-making and that using such criteria may enhance the outcomes for their children.

In your view, what strategies seem to be the most effective? What strategies seem less effective?

TZ: Primarily, take data on the effect of these treatments. Data should show that they are not working in most cases. Attempt to establish, a priori, criteria for when a treatment will be withdrawn due to ineffectiveness. We need to confront this on a child-by-child basis. In addition, as I noted above, we need to effectively communicate with parents to ‘sell’ our view of evidence and criteria for effectiveness. If parents were to accept our vision of this world, then we would see a reduction in use of these wild treatments.

With respect to less effective strategies, assuming that we have all the right answers and that professionals and parents should simply listen to us, is one bad idea. Another bad strategy is not recognizing the possibility of a method working for a particular child. We need to be able to make the argument that, although extensive research may show a lack of effectiveness, a particular method might work for an individual child, for at least a brief period of time. By making this recognition, we won’t come across as close-minded and inflexible.

Those are excellent points. What are some suggestions you would make to behavior analysts working on multi-disciplinary teams in public school settings where there may not be a shared commitment to science-based treatment?

(Continued on page 16)
Treatment Summary: Vision Therapy and Specialized Lenses by Tristram Smith, PhD

**Vision Therapy**

**Description:** The use of professionally supervised eye exercises to correct problems with vision. Some also apply this term to the use of special eyeglass lenses in isolation or in conjunction with eye exercises. Some practitioners may recommend lenses with prisms (sometimes called Kaplan lenses), while others may recommend filtered or tinted lenses (sometimes called Irlen lenses).

**Examples:** Eye Exercises to enhance visual attention, Rapid Eye Therapy, Irlen lenses. Ambient lenses, or Yoked Prisms, eyeglasses that are prescribed and are considered to be effective in improving visual attention.

**Research Summary:** Eye exercises may be useful for treating certain vision problems such as strabismus (difficulty coordinating the movements of the two eyes) or converging insufficiency (difficulty turning eyes inward). However, there is no known association between such problems and autism spectrum disorders. Although one uncontrolled study suggested that vision therapy might be effective for children with autism spectrum disorders (Kaplan, Edelson, & Seip, 1998), this intervention has not been evaluated for individuals with autism spectrum disorders in studies with strong experimental designs (Rawstron, Burley, & Eldeer, 2005). According to a joint statement from the American Academy of Pediatrics, American Association for Pediatric Ophthalmology and Strabismus, and American Academy of Ophthalmology (1998), “No scientific evidence exists for the efficacy of eye exercises (‘vision therapy’) or the use of special tinted lenses in the remediation of . . . complex pediatric neurological conditions” such as autism spectrum disorders.

**Recommendations:** Researchers may wish to conduct studies with strong scientific designs to evaluate Vision Therapy. Professionals should present Vision Therapy as an untested and encourage families who are considering this intervention to evaluate it carefully.

**Selected References:**


**Iridology**

**Description:** The diagnosis of medical problems by closely inspecting patterns and colors in the iris (part of the eye). Practitioners believe that sections of the iris correspond to parts of the body and reveal whether those body parts are healthy or diseased. Based on the diagnosis, herbs or homeopathic treatments are often prescribed.

**Research Summary:** Studies indicate that inspection of the iris is not a valid way to diagnose disease. Also, there is no evidence that individuals with autism spectrum disorders have abnormalities in the iris. Therefore, iridology is an inappropriate intervention for autism spectrum disorders.

**Recommendations:** Iridology is not a useful intervention for individuals with autism.

**Selected References:**

Book Review Continued…..

also noteworthy that Dr. Freeman is the parent of a 21 year-old daughter with autism, and holds a Ph.D. in Sociology from Stanford University, where she specialized in small group research. As will be detailed below, Dr. Freeman shares her perspectives as a mom, which further contributes to the authenticity of this book, and may appeal to parents who may be more amenable to the cautionary words of one who walks in their shoes.

The book is comprehensive, thoroughly researched, and well organized. Throughout, Dr. Freeman communicates a critically important message: individuals with autism deserve access to science-based treatment and their time, their potential, and the overall resources of their families should not be wasted. This message is wholly consistent with the mission of ASAT; therefore, it seemed very fitting to highlight Dr. Freeman’s book in this issue of Science in Autism Treatment.

The Complete Guide to Autism Treatments is divided into two primary sections. Section I is organized around topics related to the various treatments for autism, of which there are several dozen. Section II highlights basic concepts about science, hypothesis testing, and research methodology. Section I begins with a review of behavior-analytic treatments for autism across home and school settings, as well as within the area of early intervention. The various offshoots of applied behavior analysis are also summarized and evaluated (e.g., intensive behavioral treatments, pivotal response training, positive behavior support, verbal behavior therapy, and fluency training). Then there is a fairly comprehensive subsection related to the myriad of non-behavioral treatments, including those that occur in school, as well as those that are child-initiated or parent-facilitated. These subsections are followed by biomedical therapies, speech and language therapies, and, ultimately, a final section for miscellaneous therapies not better categorized in the above subsections. Each of these subsections is divided, and in some cases divided further, in an effort to capture the more frequently-touted treatments for autism.

It is frankly unfortunate that such an extensive taxonomy is needed simply to categorize all that which is available to consumers, particularly given that the vast majority of treatments proposed for autism lack adequate scientific support. Consumer advocates who think that exposure to many diverse treatment options is a good thing are likely not considering the agonizing decisions parents must make about how best to help their child with autism, or the second-guessing and guilt that may come from worrying that one is not doing enough, or the extraordinary financial burdens that come from paying for numerous treatments out of pocket. Individuals with autism deserve a clearer path to effective intervention.

Parents of children with autism, particularly those with newly diagnosed children, face a dizzying array of options that can be absolutely overwhelming. Do parents of children from any other clinical population have to face these matters to the extent that we see in autism? Quite simply, no. Parents of children with autism deserve all of the information needed to consider possible treatments carefully and to make the most informed decision for their child. Fortunately, this book will be of tremendous help in that regard, for Dr. Freeman’s review and description of the available research is presented in a careful, thorough and straightforward manner.

Each of these treatment subsections is organized around responses to a series of 8-9 questions. These questions are applied to each treatment discussed. (see table on opposite page)

Section II, titled “How do we know what works and what doesn’t?” focuses on the scientific method, hypothesis testing, and research methodology. At times, the content may seem somewhat dense, but that speaks more to the complex nature of scientific inquiry than to Dr. Freeman’s writing style. These more technical sections are preceded by a number of caveats empowering parents to question the “experts” whom they will undoubtedly encounter over the course of their child’s treatment. There is considerable attention paid to the

(Continued on page 9)
Book Review continued...

Questions applied to the treatments highlighted in Dr. Freeman’s book

<table>
<thead>
<tr>
<th>“What is ___?”</th>
<th>Dr. Freeman defines the treatment, highlights its purpose or intent with respect to autism, and describes its rationale and theoretical underpinnings. The proponent’s more significant hypotheses about autism’s etiology and treatment are often described as well.</th>
</tr>
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<tr>
<td>“What evidence do the practitioners have that this really works?”</td>
<td>Dr. Freeman summarizes and evaluates peer-reviewed research and other possible sources of support (e.g., anecdotal evidence). She reports the results of database searches and is often quite explicit about numbers of articles that fall into categories (e.g., non-published studies, pamphlets, published in peer-reviewed journals, published in non peer-reviewed journals).</td>
</tr>
<tr>
<td>“What does this therapy actually look like?”</td>
<td>Dr. Freeman describes, often in great detail, the actual procedures associated with the treatment. This information is essential, as many consumers know little about the therapies to which they are subjecting their children. These descriptions are written in an objective, non-partial manner which, when read in isolation, would not necessarily reveal the author’s stance on a particular treatment. Information about side effects and/or adverse effects is provided when warranted.</td>
</tr>
<tr>
<td>“What else do I think?”</td>
<td>Dr. Freeman speaks to broader issues that bear relevance when judging the merits of the particular intervention. She reveals her impressions of the treatment in a very forthright and compelling manner.</td>
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<tr>
<td>“Would I try it on my child?”</td>
<td>In contrast to the objective and factual tone of her responses to the questions above, here Dr. Freeman offers a more personal take on the treatment: a take that is honest and at times, blunt. Clearly, every child with autism is different, and thus, treatment decisions need to be made in consideration of those differences. Even if readers disagree with Dr. Freeman’s stance, they will appreciate the candor and thoughtfulness of her position as a fellow parent.</td>
</tr>
<tr>
<td>“What kind of study would I like researchers to do?”</td>
<td>Perhaps the most insightful arguments can be found in these responses. Dr. Freeman argues that it is not sufficient that treatment proponents simply churn out publishable research, but rather that they design research that carefully addresses questions pertinent to that particular treatment. These may include, but not be limited to, better definition of the independent variable, use of tighter research designs, selection of more appropriate dependent variables, and a clearer demonstration of the relationship between the manipulation of the independent variable and the dependent variables. These particular sections clearly demonstrate Dr. Freeman’s command of the existing research and what is needed to move forward.</td>
</tr>
<tr>
<td>“Who else recommends for or against _____ as a method for the treatment of autism?”</td>
<td>Dr. Freeman highlights recommendations from professional membership organizations such as the American Academy of Pediatrics and the American Speech-Language-Hearing Association, from state and federal government entities, and from other organizations such as Quackwatch. It is important to point out that position papers from organizations represent a consensus among leading scientists and clinicians based on a thorough review of evidence and experience. These recommendations should be an important factor in decision making and I applaud Dr. Freeman for reporting them throughout her book.</td>
</tr>
<tr>
<td>“So you’re still on the horns of a dilemma?”</td>
<td>Dr. Freeman provides further information for those still struggling with their decision for any number of reasons.</td>
</tr>
<tr>
<td>“What’s the bottom line?”</td>
<td>Dr. Freeman offers a “bottom line.” Essentially, based on the scientific research to date, she clearly states when there is either no evidence, not enough evidence, or sufficient evidence to conclude that a particular intervention is effective. What is both striking and incredibly sad, is that for many widely-used treatments for autism, there is NO evidence.</td>
</tr>
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This book has many notable strengths. The format of nine recurring questions within Section I provides a predictable framework for the reader. In fact, Dr. Freeman’s careful analysis of the state of the research underlying specific ABA treatments is offered in the same spirit and with the same diligence as the non-behavior analytic treatments. This is critically important, given that the abundance of research in ABA may mistakenly give the impression that all that falls under the umbrella of ABA is well supported empirically. This could not be further from the truth. Although some behavior analysts who are proponents of Positive Behavior Support, Verbal Behavior Therapy, Fluency Training, and Pivotal Response Training may disagree with many of Dr. Freeman’s specific assertions, the quality of her analyses and the clarity of her concerns contribute to a much less divisive dialogue then we have seen in other books to date.

Proponents of the various treatments would benefit from careful consideration of the suggestions offered in the “What kind of study would I like researchers to do?” section. Far too often, a single study is put forth as validation of an entire treatment and all of its theoretical and conceptual underpinnings. For instance, as Dr. Freeman discusses in her book, a published research study that uses an art-based activity to integrate children with autism with their typically developing peers in no way validates art therapy as a treatment for autism. The type of research that is desperately needed is a well-designed study in which a clearly-developed treatment protocol for art therapy is implemented, and dependent variables are selected that measure core manifestations of autism. Sensory integration is another treatment for which research is sorely needed. In particular, Dr. Freeman recommends that commonly accepted, standardized measures should be used and administered by qualified people who do not know the group assignments of participants. The reader will find that Dr. Freeman has individualized her recommendations based on each treatment’s existing research history. Execution of these research agendas may enable a number of treatments to live up to their promises.

Perhaps of greatest significance is

(Continued on page 12)
From the Archives continued...

persistent of these ineffective treatments are those that are based upon outdated psychodynamic theories, wherein autism is seen as an emotional wound. In the past, this putative emotional fragility was treated largely through psychoanalysis; today it is addressed through play therapy. This model continues to be offered by those who see their role as understanding and reassuring a frightened child.

- The tendency of many in the professional community to ignore or even denigrate treatments that do have good, supportive data. Indeed, the very notion of data, outcome measures or objective validation simply does not figure in much of the published literature on autism intervention. Rather, the norm has been for many authorities to posit a speculative cause for autism, and propose an equally speculative remediation of the condition, based largely upon personal belief, or "clinical intuition."

Looking Back
What gave rise to these trends? Probably a multitude of factors, too complex to analyze at any length here. However, we can at least identify some of the major formative influences on treatment politics.

- From the moment autism was identified in the 1940s, erroneous assumptions about its etiology have flourished. Children with autism are often beautiful, with no obvious physical impairment or distinguishing features. This unremarkable physical appearance is but one of the factors providing a fallback ground for the idea of autism as an emotional wound – something stemming from a psychological trauma rather than a physiological or genetic difference. Universities and medical schools provide little training in how to evaluate the effectiveness of proposed autism treatments; hence, there is a troubling scientific illiteracy on the part of the people from whom we most often seek such guidance. In fact, until recently, medical attention was focused largely on endlessly redefining the symptoms of autism, rather than on any effective treatment.

- In the absence of accurate, objective information about effective autism interventions, our educational system has failed to meet the profoundly complicated learning needs of our children. Many educators have low expectations for children with autism, in part because they have had little training in how to overcome inappropriate behaviors common to many children with autism, such as crying, screaming, self injury and aggression. As these behaviors can radically interfere with learning, learning does not take place.

- The need to base treatments for autism upon a solid foundation of scientific research, and not on anecdotes, is not that obvious to the public. In the culture at large, there are many negative assumptions about the very nature of science. Some people tend to equate science with all that is cold, dangerous and controlling. This problem is exacerbated by the inability of many scientists to translate their discoveries into the vernacular. Instead, many rely upon an impersonal, mechanistic jargon to convey their findings about human beings. In contrast, treatments cloaked in a language of quick fixes, nurturing love or instinct have strong emotional appeal. In some quarters, there is strong resistance to the very notion of treatment itself. Rather than seeing autism as a disability - one that strips a human being of many possibilities and promises - some regard it as a variation of the human condition, one to be embraced and celebrated, not eradicated. These advocates decry any attempts at treatment – or especially cure - as oppression, rejection, or discrimination.

There are serious problems creating turmoil within the field of behavior analysis, a field scientifically validated as effective in the treatment of individuals with autism. These include the misapplication of behavioral science by unskilled or unethical practitioners; the absence of nationally accepted standards of competency; and the claims of a few individuals to be the only competent professionals.

And finally, there is the seductive rhetoric of an ideology that keeps trumpeting such appealing concepts as open-mindedness, choice, an eclectic approach, and options. Unfortunately, open-mindedness without healthy skepticism, choice that is not informed choice, and options embraced for the sake of option alone only prolong the sad history of failed treatments.

Disastrous Consequences
But whatever the causes, the resultant dismissal of treatments backed by science has disastrous consequences for our children’s already fragile future. When children who are not developing functional language are denied effective treatment, there is a double tragedy: their potential for growth and learning is thwarted; and they often become the subjects (or objects) of repeated, ineffective experiments as parents pursue all possible flickers of hope.

Continue These Trends?
All these political ideologies have survived, however, largely because both professionals and parents have allowed their survival. It is a natural human tendency to follow personalities, especially charismatic ones, rather than dry, scientific literature. We tend to seek warm and compelling stories, rather than cold statistics. We are very willing to accept the expertise of people who base their recommendations upon anecdote and opinion, their “thirty years in the field,” their clinical judgment; and we are often bored with people who talk about

The National Autism Center has some important news – the announcement of the National Standards Report!
Watch this to find out more: www.nationalautismcenter.org/ecard/2009_NSR/index.html

The National Autism Center is a nonprofit organization dedicated to responding to the rising need for reliable information about Autism Spectrum Disorders. The Center provides comprehensive resources for families and communities.
social worker, speech therapist, etc.). Once this assessment process is completed, an Individualized Family Service Plan (IFSP) meeting is held in which recommendations for treatment are made. Families will very rarely get a recommendation for the 25 hours of behavioral intervention that the National Resource Council deems appropriate for educating children with autism. The team from Early Intervention will make the recommendation for number of hours and type of treatment. They may not even make a recommendation for behavioral intervention in the form of Applied Behavior Analysis (ABA). Once the Early Intervention team makes their recommendation for number of hours ABA program with a qualified consultant or case manager directing the program (minimally coming to the home 2 to 4 times per month to provide supervision) is more likely to render quicker positive results than a program that consists of less than 25 hours a week with lesser qualified supervision and therapists. Supervision (often in the form of “clinics” i.e. team meetings) should focus on working with the child and providing on-going training for therapists and family. To obtain a private program as described, you can contact one of several agencies that provide outreach services, or a private individual who provides consulting services. Finding these service providers often occurs through the grapevine—although some local advocacy organizations may provide lists of providing agencies. The Behavior Analyst Certification Board (www.bacb.com) also has a certificant registry which may provide a good starting point.

Finally and less utilized, parents can go through parent training to become teachers themselves. Parent training has long been established as a key element to effective behavioral interventions for children with autism, but unfortunately, this option is not always suggested by those who diagnose children with autism. Further,

(Continued on page 14)


Why research this topic?
Project TEACCH (Treatment and Education of Autistic and related Communication handicapped Children) was the first public school program for children with autism and remains one of the most popular intervention models for these children. TEACCH emphasizes structured teaching and clear visual organization of classrooms and activities. A key component of TEACCH is the use of individual work systems, which organize tasks into separate bins, provide “jigs” to guide children in completing these tasks, and set up a place to put the tasks when they are done. Work systems are intended to increase independence while reducing the need for prompts from a teacher. However, the efficacy of TEACCH work systems had never been scientifically tested until this study.

What did the researchers do?
Three students with autism participated. Each student was initially in a baseline phase (no work system). The baseline phase was followed by an intervention phase in which the work system was introduced. After the intervention phase, each child returned to the baseline phase, and then the intervention was re-introduced. This procedure allowed for a careful test of whether the work system changed each child’s behavior. The researchers measured each child’s on-task behavior, work completion, and number of play items used. They conducted a follow-up assessment of these behaviors one month after the end of the last intervention phase to see whether the effects of intervention were still evident.

What did the researchers find?
For all three children in the study, independent work and play activities increased when work systems were introduced and decreased when work systems were taken away. Thus, the work systems improved children’s independent engagement in tasks. In addition, work systems decreased the amount of prompting from staff members.

What are the strengths and limitations of the study?
What do the results mean?
This study used a strong scientific design to provide the first scientific evidence that TEACCH work systems are effective. Replications by other investigators will be necessary to determine whether similarly favorable results can be achieved for other children with autism and other classroom staff. Also, it was unclear in the study whether the number of prompts from teachers decreased because children really needed fewer prompts or simply because teachers were aware that the work systems were being evaluated. It was also unclear which of the many components of the work systems contributed to children’s improvements. Additional studies will be needed to address these issues, but the present study provides promising initial evidence for the effectiveness of TEACCH work systems.

Check out ASAT’s description of TEACCH on our Web site: http://www.asatonline.org/intervention/treatments/teacch.htm
that the author is writing from the dual perspectives of professional and parent. When speaking as a parent, her commitment to science is unwavering and, appropriately so; she is unapologetic in honestly sharing her perspectives as an informed mother. This is greatly needed at a time when many individuals fear being perceived as close-minded or unwilling to recognize the contributions of other disciplines. Her professional perspective only adds further credence to her stance regarding treatment options.

There are wonderful insights throughout the book which will make this resource useful to those who will tend to read this book a few sections at a time. For instance, there is a very interesting discussion at the beginning of the book about participation in research with the caveat that precious time and resources should never be wasted on low-quality research, for not all research is created equally.

There are a few minor concerns. Many readers may have benefitted from an introduction to some of the content in Section II at the very beginning of the book. To her credit, Dr. Freeman makes the suggestion to review this content first. I suspect this introduction would have laid a foundation for readers to synthesize the tremendous amount of information in Section I. Organizationally, I believe that the judicious use of tables and charts would have facilitated comparisons across treatments. Clearly, many parents are surrounded by those who support their informed decision making and their commitment to science-based treatment. Unfortunately, there are many other parents who find their efforts punished or derailed by those with competing agendas.

Therefore, this comprehensive resource would have been further strengthened by specific and concrete strategies for both managing the behavior of others involved in treatment decisions, and for resisting and responding to pressures exerted by others to “just try” a particular treatment (e.g., the mother-in-law who argues that the gluten-free diet is harmless, so why would one not want to try it).

In summary, I believe The Complete Guide to Autism Treatments is a much needed contribution to the field of autism. The diligence and comprehensiveness of the various treatment reviews make this book an important “go-to” resource for parents and professionals alike.

Undoubtedly this is a resource that the reader can expect to pick up time and time again.

For more information about The Complete Guide to Autism Treatments, as well as other books written by Dr. Freeman, please visit www.skfbooks.com.

From the Archives continued...

data, numbers, controlling for variables, and the like.

A New Path
But after the debacle of the Bettelheim era, where one man’s opinion reigned virtually unchallenged for so long, and created so much harm and hurt, it is clear we need to challenge every one of these experts with at least as much skepticism as we bring to the purchase of a used car, let alone to life-altering decisions for our children. We need to add critical thinking to compassion, or we will continuously follow every self-confident savior and every sad dead end.

So where does that leave us - we parents, educators, and people affected by autism – who wish to make decisions based upon both tenderness and tough thinking? It leaves us in need of reliable guidance, founded on facts, not fame.

ASAT
It is that pressing need that has given rise to ASAT’s mission: to disseminate scientifically sound information about autism and treatments for autism. And recognizing that treatments will only be as effective as the people providing the treatments, ASAT will support the development of professional credentialing, standards of education and treatment, and resources to help consumers secure the most effective treatments for individuals with autism.

Facts, Not Fads
As a guiding principle, ASAT intends to evaluate claims about treatment from the perspective of sound, scientific reasoning. ASAT is locked into no one treatment for autism, but we will not hesitate to let people know which treatments are supported by solid scientific research, and which are not—be they from medical, behavioral or educational science. We are seeking to move public awareness away from personalities and fads, to the true hope that scientific research has produced, and will continue to produce, for all of our children.

By Whose Authority?
How will ASAT provide such guidance? Not through any personal opinion or (Continued on page 17)
Interview with Joe Forgione continued...

skills such as resume preparation, mock interviews, public speaking, how to dress and groom, how to use a PC, etc. We then placed the kids in summer jobs where they obtained practical, on-the-job experience. Currently, I chair the Finance and Audit Committee of the All Stars board, serve on other board committees, and work one-on-one mentoring young people.

That is an incredible program and I know you are being very modest. Is it indeed the case that a school is named after you?

Yes, the Development School for Youth is named after me. Friends and colleagues personally donated to fund the program. Unbeknownst to me, the All Stars approached Merrill Lynch executives who coordinated the fundraising with other friends and colleagues.

That is such an incredible story. Being a native New Yorker myself, I am well aware of how important it is for inner city youth to make connections with caring adults, to identify their personal strengths and passions, and to be given the resources to pursue their dreams.

Let’s turn our attention to ASAT. How did you first learn about us? What led you to get involved?

I was introduced to ASAT by a friend and colleague whose wife was a co-founder of the organization. They told me about their two children and their quest to seek effective treatment for autism. I initially donated to ASAT and was subsequently asked if I would join the board. I connected with ASAT because I could relate my rare autoimmune disease and my family's sacrifice with the pain of the children who suffer from autism and the pain felt by their parents.

I was fortunate to have devoted, loving parents who were tireless in their quest to seek a cure, or at least pain relief, for my suffering. An organization like ASAT, with so many wonderful, caring people, and its goals of educating parents and battling harmful, unscientific research, would have been most beneficial to my parents, who had limited resources and education. There was no ASAT-like organization for my parents when I was younger, but for the thousands and thousands of parents learning of a child’s autism diagnosis, I can appreciate the important role that ASAT can play in guiding them to the best possible treatment decisions for their child. Again, this ties back to my desire to help children and adolescents access meaningful, high quality educational experiences.

I see the parallels that run through your volunteer experiences, as well as your own personal experience with a chronic illness. Why do you remain involved with ASAT after all these years?

Quite simply, there is more work to be done! Although progress has been achieved, partly due to the efforts of organizations like ASAT, many of the old issues continue to exist. Individuals and their families are overwhelmed by the plethora of treatment options; there is a lack of a shared commitment to science; many doctors need education and accurate information; and the media continues to sensationalize pseudo-scientific treatments.

ASAT needs to continue to bring valuable insights to parents and afford them guidance and tools to make the best possible treatment decisions for their children. Furthermore, solid scientific research needs to be disseminated and acknowledged. I am glad to be a part of this.

Non-profit organizations such as ASAT benefit tremendously from the participation of members of the community, like you, with strong business credentials and experiences. As you know, our country is facing some tough economic conditions. Do you have any insights on how non-profit organizations can remain viable during these times?

I tend to work with non-profit organizations that utilize, or desire to utilize, a business model while not relying on a bureaucratic and unreliable government. A strong board of directors which blends content experts and business people is essential for success. Ideally, at least half the board should be active in raising funds. A board has several critical initiatives, but in order to remain viable, none are more important than fundraising.

In difficult economic times, like today, the non-profits that perform well already have a long track record with a broad, but not necessarily wealthy, base. They also target donors with an array of interests in the population served.

Considering all that still needs to be accomplished, especially in this very difficult economic environment, ASAT, and many worthy organizations like it, need support now more than ever. Whatever an individual can contribute will be greatly valued and appreciated by the children and their families.

Thank you, Joe. I appreciate this opportunity to learn more about your experiences and background. On behalf of ASAT, we are grateful for your service, appreciative of your business smarts, and inspired by your story!
Talk About Ethics: Evidence-Based Treatment continued...

may be reduced in these contexts simply because there is less time allocated to and available for ABA instruction. In addition, there may be inconsistencies between approaches or interactions between treatments with differing philosophies and methods.

Furthermore, many families pursue a wide variety of alternative interventions. Challenges are multiple and progress is slow, even with very effective and excellent intervention. This leads parents to consider adding additional or ancillary treatments. Parents often feel that no stone should be left unturned and pursue interventions that may ultimately be shown to have merit, but which currently lack empirical verification. This is understandable, given what is at stake. But it also may lead to a reduced overall impact of intervention.

Behavior analysts can help parents to evaluate the impact of such interventions by suggesting a way to objectively assess their effect on targeted skills or behaviors. In many cases this may involve some type of single case design. In this way, the potential contribution of an ancillary therapy can be systematically evaluated, and decisions about continuing or extending the treatment can be based on objective information.

Behavior analysts struggle to work collaboratively with consumers and other professionals while maintaining their adherence to the values of scientifically-validated treatment and implementation of effective intervention. It is often difficult for behavior analysts to discern how they should conduct themselves in these contexts. Many behavior analysts struggle with fears of offending or alienating consumers/clients. Behavior analysts approach these dilemmas differently, and often report doubt regarding their choice of action.

The Guidelines for Responsible Conduct developed by the Behavior Analyst Certification Board contain several relevant directives. Section 1.0 (Responsible Conduct of a Behavior Analyst) states that the behavior analyst “must maintain the high standards of the professional organization.” Specifically, Section 1.01 (Reliance on Scientific Knowledge) states that, “behavior analysts rely on scientifically and professionally derived knowledge when making scientific or professional judgments in human service provision, or when engaging in scholarly or professional endeavors.”

The implications of this guideline are that behavior analysts base their recommendations regarding intervention on the available data surrounding the effectiveness of specific procedures. We implement procedures that have been demonstrated to be effective. In addition, we are obligated to inform consumers about the available data regarding the effectiveness of procedures (or lack thereof). In practical terms, this means that we implement ABA strategies that have been documented to be effective. In addition, it means that we inform parents and school personnel about the available data regarding behavioral and non-behavioral approaches to treatment.

Section 2.09 of the Guidelines (Treatment Efficacy) states several relevant points.

Section 2.09(a) states that, “The behavior analyst always has the responsibility to recommend scientifically-supported, most effective treatment procedures. Effective treatment procedures have been validated as having both long-term and short-term benefits to clients and society.”

Section 2.09 (b) states that, “Clients have a right to effective treatment (i.e., based on the research literature and adapted to the individual client).” This guideline takes our commitment to effective treatment a step further, making access to effective treatment an entitlement for all clients.

Section 2.09(c) states, “Behavior analysts are responsible for review and appraisal of likely effects of all alternative treatments, including those provided by other disciplines.” This may be the most instructive guideline, as it challenges us to use our science to also evaluate the effectiveness of other interventions. We are responsible for ensuring the appropriate and effective implementation of all interventions. In that regard, we should offer our expertise in defining behaviors, analyzing behaviors, evaluating data, and making individualized data-based decisions regarding the effectiveness of (behavioral and non-behavioral) procedures. Behavior analysts who assume these roles and do so in a collaborative, nonjudgmental manner will better serve their clients and likely be more effective in inspiring other professionals to embrace greater accountability and rigor.

Mary Jane Weiss, Ph.D., BCBA-D
Clinical Director
Douglass Developmental Disabilities Center Rutgers University

Clinical Corner: Early Detection and Intervention continued...

there are limited training opportunities available for parents other than the standard training offered by Early Intervention. Training opportunities will vary depending on where you live. For example, there has been a recent increased emphasis on training in the New Jersey area. The Institute for Child Development through Hackensack University Medical Center has paired up with the Alpine Learning Group to provide short-term intensive parent training to families of newly diagnosed children. This training is dedicated to teaching parents to recognize learning opportunities in their every day environment, which maximizes their child’s learning. In addition to teaching parents how to be good teachers, the training also helps educate parents on how to gain access to the services that their child would benefit from (e.g., Early Intervention, contacting school district, etc).

Overall, 25+ hours a week of ABA therapy, with a qualified team leader/consultant and therapists that begins as close to the point of diagnosis as possible, along with parent training, is the ideal treatment package for a newly diagnosed child with autism. Parents with children with autism continue to impress me each day with their level of dedication, so it’s not surprising that with the economic strains and treatment accessibility issues, many still become the best teachers and advocates for their children.
Autism Science Foundation Releases First Request for Scientific Proposals

(September 23, 2009—New York, NY)—The Autism Science Foundation, a not-for-profit organization founded in April 2009 and dedicated to supporting and funding autism research, today announced that it had issued its first request for scientific proposals. ASF is inviting applications for a Doctoral Training Award for graduate and medical students interested in pursuing careers in basic and clinical scientific research relevant to autism spectrum disorders.

The proposed training must be scientifically linked to autism. Autism Science Foundation will consider for training purposes all areas of related basic and clinical research including but not limited to: human behavior across the lifespan (language, learning, communication, social function, epilepsy, sleep, repetitive disorders), neurobiology (anatomy, development, neuroimaging), neuropathology, human genetics/genomics, pharmacology, immunology, molecular and cellular mechanisms, and studies employing model organisms and systems.

Autism Science Foundation will make a number of Doctoral Training Awards determined by its available financial resources. The term of the award will be a period of one year and will include a maximum $25,000 stipend plus $5000 for travel and research materials/supplies. Applications are due by November 16, 2009.

Applicants must be currently enrolled in a program leading to a research doctorate such as a Ph.D. or Sc.D., a combined degree such as an M.D./Ph.D., in an academic department at an accredited university or health/medical institution, or an M.D. at an accredited university medical school. Each student must also have a mentor to oversee his/her work and provide appropriate training. The mentor must hold a tenured or tenure-track faculty appointment (or equivalent) at an accredited institution of higher education or health/medical/research institution, and must be an established and active investigator in some aspect of autism research.

“We are thrilled to be soliciting grant applications after only five months of fundraising and operations” said Autism Science Foundation President Alison Singer. “Outstanding research is the greatest gift we can offer our families and we intend to make every dollar count.”

The Autism Science Foundation is a 501(c)(3) public charity. Its mission is to support autism research by providing funding and other assistance to scientists and organizations conducting, facilitating, publicizing and disseminating autism research. The organization also provides information about autism to the general public and serves to increase awareness of autism spectrum disorders and the needs of individuals and families affected by autism.

Grant applications will be reviewed by members of ASF’s Scientific Advisory Board (SAB) and other highly qualified reviewers. Current SAB members include Dr. Emanuel DiCicco-Bloom (UMDNJ-Robert Wood Johnson Medical School; past program chair of the International Society for Autism Research); Dr. Ami Klin (Yale Child Study Center); Dr. Sharon Humiston (University of Rochester); Dr. Harold Koplewicz (NYU Child Study Center); Dr. Eric London (New York Institute for Basic Research and co-founder of NAA); Dr. Catherine Lord (University of Michigan); and Dr. Matthew State (Yale Medical School).

To learn more about the Autism Science Foundation’s grant program, visit www.autismsciencefoundation.org/

Message from ASAT President continued...

- We updated the treatment summaries and resources on www.asatonline.org for biomedical, behavioral and non-behavioral treatments, as well as the items related to the autism-vaccine link.
- We resumed publication of Science in Autism Treatment. This quarterly newsletter includes featured articles, research reviews, interviews, book reviews, a Clinical Corner, a Consumer Corner, a Talk about Ethics column, Conference Announcements, and Media Watch updates.
- Through a variety of marketing strategies, we nearly tripled the number of Science in Autism Treatment subscribers in one year.
- ASAT’s Media Watch has responded via letters to accurate and inaccurate media portrayals of autism treatment.
- Numerous board members have presented and participated in a variety of autism-focused regional and national conferences.
- 20 organizations participated in the 2009 Real Science, Real Hope Sponsorship Initiative.
- We established an ASAT Facebook page.
- ASAT is now listed on the websites of several organizations to promote awareness of science in autism treatment.
- Our new ASAT logo has been created and integrated throughout website, newsletter, and other print materials.
- ASAT has advertised in an array of professional and parent publications.

Our accomplishments to date and our goals for the future would not be possible without the tireless efforts of a cadre of parents and professionals. Please find the list of the Board of Directors on page 8, Advisory Board members on page 12, and Committee members on page 13.

On our first page, you will also find our SIAT Newsletter staff. It is wonderful to have so many individuals committed to our newsletter’s success. Science in Autism Treatment exemplifies ASAT’s mission to disseminate accurate, scientifically sound information about autism and autism intervention. It also strives to improve access to effective, science-based treatments for all people with autism, regardless of age, severity of condition, income or place of residence.

In keeping with that mission, we are committed to maintaining and updating our website (asatonline.org) and to distributing this quarterly newsletter free of charge. During these tough economic times, we would not want consumers to be unable to access our information due to financial constraints.

Having said that, I would like to end this letter with an appeal. The ongoing success of ASAT is predicated on the financial support of generous donors. Although we strive to keep our costs low, have no paid staff, and rely exclusively on volunteers, donations enable us to carry out our initiatives and disseminate information about science and autism treatment.

In the next few weeks, we will be soliciting donations from our subscribers. If you support our mission and believe in the promotion of science and the need for the type of information that we provide, and we hope you do, please give ASAT your full consideration. These are tough times, but as you know, the number of children being diagnosed on the autism spectrum is rising dramatically and we believe there is a greater need now than ever for ASAT to make a positive impact.

Best,

David
Interview with Tom Zane and Suzanne Letso continued....

TZ: First and foremost, be a team player, in that you always show respect and thoughtful consideration. However, second, always go to the literature and the research. Try to educate the team about the importance of science-based treatment. Talk about how science guides clinical practice in other professions, such as medicine. When specific treatments are discussed, report on the extent of the literature. For example, Relationship Development Intervention (RDI) has only one published so-called study attempting to assess effectiveness, and that was done by the developer of the treatment. When facts like these are pointed out, often the argument is won. Another strategy that has been successful for me was to encourage administration to adopt an organization-wide policy that reflects a commitment to evidenced-based practice. What this means is that the organization is committed to using only those treatments that have empirical evidence of effectiveness, defining what will constitute evidence, and developing a procedure for someone to propose the use of a treatment that may or may not have evidence. Institutionalizing such a policy has gone a long way in filtering out possiblefad treatments.

SL: Selecting goals and objectives that will have social validity within the school setting, as well as those that are most likely to be successful, quickly can go a long way to help other professionals see that what we do works and can enhance the quality of life for the student, family, and school community.

Given the significant impact that pseudoscience has had on distracting consumers from treatments that have significant scientific support such as applied behavior analysis, what should organizations, such as the Association for Behavior Analysis International (ABAI), do differently to address this issue?

TZ: First, ABAI should continue to promote science in autism treatment and never waver from that commitment. Second, we need to talk more about how science-based treatments promote the dignity and welfare of the clients we serve—that is, by implementing evidenced-based treatments, clients and consumers are more likely to make progress and be more independent. Third, ABAI should respond to reports of pseudoscientific and faddish treatments. ABAI needs to disseminate information regarding the lack (if in fact there is a lack) of evidence to support particular treatments that are popular in autism. ABAI needs to become a rapid responder to wild claims that are promoted in the press and in our society.

SL: ABAI, ASAT, and other national or local agencies should all take a leadership role in the dissemination of accurate information about pseudoscientific treatments at every opportunity. Issuing position statements and producing scholarly comparison of treatment effects are important contributions. However, translating this information into the everyday language of the general population is also vitally important if we want the general

(Continued on page 17)

Clinical Corner: Functional Analysis

What is meant by “functional analysis”? When should this be done, and who should do it?

Answered by Robert LaRue, Ph.D., BCBA-D

Prior to a discussion about functional analysis, it is important to make the distinction between functional analysis and functional assessment. Functional assessment represents a variety of techniques and strategies used to gather information that can be used to maximize the effectiveness and efficiency of behavioral support. The purpose of a functional assessment is to determine the factors that cause or maintain problem behavior. There are three broad categories of functional assessment. One component involves the use of indirect measures, such as interviews and rating scales. The second component is referred to as descriptive assessment, which involves observing behavior and collecting data regarding the events that precede problem behavior (antecedents) and the events that follow problem behavior (consequences). The third component is functional analysis. Functional analysis represents the most sophisticated and precise functional assessment procedure. Functional analyses are used to identify the environmental contexts in which aberrant behavior is likely and unlikely to occur. Similar to a descriptive analysis, functional analyses evaluate the antecedents and consequences that maintain problem behavior. Unlike descriptive analyses, functional analyses involve making systematic changes to the environment to evaluate the effects of different conditions on the target behavior(s). In a functional analysis, the student is exposed to situations that may or may not cause problem behavior.

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Memorial for Dr. Edward Carr

It was with great sadness that we reported about the death of Dr. Edward (Ted) Carr and his wife in our last issue of Science in Autism Treatment. This was accompanied by the touching tributes of 5 individuals who knew him well. Ted was a friend, colleague, teacher, and mentor to hundreds of professionals and students around the globe. His pioneering work in the areas of severe problem behavior and positive behavior support informs the work of every person currently working in the field of autism intervention.

To honor the work and life of this incredible man, the State University of New York, Stony Brook Psychology Department is planning a memorial on Sunday, November 8th from 2-5 pm in the Student Activities Center Auditorium on the campus in Stony Brook. Several of Ted’s collaborators from around the country as well as former students and local colleagues will pay tribute to Ted and his work. Since Ted touched so many lives, all are welcome to attend and registration is free. If you would like to attend, please complete the following form:

http://www.tinyurl.com/tcarr

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Their misconduct involves weapons or dangerous to self or others. From a clinical standpoint, functional analyses should be conducted when the student’s behavior impedes learning of self or others, presents a danger to self or others, or the behavior results in suspension or interim placement in alternative setting approaching 10 total days. Functional analysis is a specific procedure for conducting these functional assessments. There are no specific guidelines for when practitioners should use functional analyses rather than other types of assessment. However, functional analyses have the most empirical support for their use. Typically, the use of functional analysis procedures is determined by the skill level of the practitioner, the resources available to the practitioner, and the setting itself.

Conducting functional analyses does require a high level of expertise to be done effectively. Functional analyses should be conducted by individuals with experience using the procedures (or while supervised by someone with experience). Many (though not all) people who have board certification in behavior analysis (BCBA), have experience conducting functional analyses. However, it is important to note that many practitioners without their certification have extensive experience in conducting such analyses. Consumers should ask practitioners about their level of experience and comfort prior to starting these analyses.

From the Archives continued…

belief of ours, but through the help of an exemplary Board of Directors and Advisory Board drawn from both the biological and behavioral sciences—men and women whose strongest credential is not their popularity, but their adherence to the highest standards of scientific integrity. ASAT claims no authority other than what reason and science have supported. We have no illusions about the fallibility of human opinion. But one thing we do know is that children and adults with autism, and the people who love them, can be helped. We know autism is treatable, but only when people get the information and help they need.

Science for People
And finally, it is important to note that ASAT will use the tools of science to achieve our mission, but we are not working for science as an end. The end, for all of us, lies not in the mere furthering of human knowledge or human technology. The goal, the motive, the dream, is to allow our children, our students, our friends who have autism, every opportunity to lead full and independent lives, to grow in ways of their own choosing, to exercise their own choices and to achieve their own goals in life. It is science that guides us, but love and hope that inspire us.

This article originally appeared in an issue of “Science in Autism Treatment”, the newsletter of the Association for Science in Autism Treatment (ASAT). It may not be republished or reprinted without advance permission from ASAT. For reprint permission please contact info@asatonline.org

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Interview with Tom Zane and Suzanne Letso continued....

population to understand the information we share with them. It isn’t always easy to describe what we do without putting our listeners to sleep.

Moving forward, what are the three most important things needed to attenuate the influence of pseudoscience?

TZ: First, we need to model pro-science, pro-evidence behavior. We need to use evidenced-based treatment in our work and to publicize science and the importance of its use in autism treatment. Second, we need to police our field and minimize or eradicate the use of pseudoscience treatments by behavior analysts! As frightening as that seems, it is the case that some behavior analysts actually are certified both as behavior analysts and as practitioners of other therapeutic models that are not deemed effective through controlled research. We behavior analysts have to consistently promote our adherence to science and scientific methodology. And, third, we need to continually explore, through our science, treatments that are effective. The more treatments that are demonstrated to be effective, the less need there will be by some people to rely on unproven treatments.

Thank you very much for sharing your experiences and insights with us. As you know, the issues you raise are central to ASAT’s mission and initiatives and we appreciate all your efforts.

Dr. Thomas Zane is an Associate Professor in the School of Education, and the Founder and Director of the Center for Applied Behavior Analysis at The Sage Colleges in Troy, New York. Dr. Zane earned his Bachelor’s and Master’s degree in psychology at Western Michigan University and his doctorate in Applied Behavior Analysis at Virginia University. He has served as a Post-Doctorate Research Associate at the University of Massachusetts, Professor at Mount Holyoke College, and Johns Hopkins University Department of Psychiatry. He is a licensed psychologist in New York and Massachusetts. Dr. Zane has published in various journals and books, presented at regional, national, and international conferences, and been an invited lecturer in Ireland and the Republic of China. His research interests include teacher training, staff development, and evidenced-based practice in autism. As part of his duties at Sage and the Center for Applied Behavior Analysis, he offers a Master’s of Science Degree in Applied Behavior Analysis and Autism, a distance-learning graduate program.

Suzanne Letso is the co-founder and CEO of the Connecticut Center for Child Development, Inc. (CCCD) in Milford, Connecticut. Mrs. Letso currently serves as a Scientific Advisory Council member for the Organization for Autism Research, member of the Board of Directors for the Association of Professional Behavior Analysts, as Chairperson for the Connecticut Association for Behavior Analysis Public Policy and Legislative Action Committee, and is Vice President of the Board of Directors for Marrakech, Inc. She has participated in the establishment of a number of other service organizations and autism-related initiatives over the last 15 years. Mrs. Letso holds a B.A. in Elementary Education from Southern Connecticut State University, a M.A. in Leadership from Duquesne University, and is a Board Certified Behavior Analyst. Prior to her work related to behavior analysis, Mrs. Letso worked as a marketing executive for international medical product manufacturers, where she was involved in new product, business, and venture capital start-up initiatives. In addition, she has been involved in organizational assessment and development of for-profit enterprises in other fields. Mrs. Letso is the parent of a 19 year old son with autism.
BEHAVIOR ANALYST CERTIFICATION BOARD® TASK LIST FOR BCBAs® WORKING WITH PERSONS WITH AUTISM®

CONTENT AREA A: COMMUNICATE THE HISTORY AND CULTURE OF AUTISM TO THE AUTISM COMMUNITY, CONSUMERS AND THE PUBLIC
A-1 Discuss key historical events with the autism community, consumers, and the public.
A-2 Discuss current and local cultural conditions influencing treatment choices for autism.
A-3 Explain myths, fads, and controversies to consumers and the public.
A-4 Discuss movements, legislation, and legal issues with consumers and the public.

CONTENT AREA B: ASSESS, DESIGN, AND IMPLEMENT INTERVENTIONS TAILORED TO CHARACTERISTICS OF AUTISM AND INDIVIDUALS WITH AUTISM
B-1 Understand general considerations.
B-2 Understand diagnostic practices and their implications; communicate to consumers and others.
B-3 Identify associated characteristics and conditions.

CONTENT AREA C: EXTRACT RELEVANT INFORMATION FROM VARIOUS SOURCES FOR PLANNING INTERVENTIONS AND COMMUNICATING WITH CONSUMERS
C-1 Research the relevance, reliability, validity, and proper use of various assessment instruments.
C-2 Understand limitations of norm-referenced measures for drawing inferences about behavior and planning intervention.
C-3 Extract relevant information from the following assessments to establish behavior analytic and collaborative intervention priorities:
  • communication skills assessments
  • mental health assessments
  • vocational skills assessments
  • adaptive skills assessments
  • motor skills assessments
  • academic skills assessments
  • cognitive skills assessments
  • developmental skills assessments
  • behavior problem checklists and other instruments
  • social skills assessments
  • medical and quasi-medical assessments
C-4 Research best scientific evidence regarding validity and necessity of medical and "biomedical" tests, limitations of inferences that can be drawn from them.

CONTENT AREA D: EXPLAIN DIAGNOSTIC PROCEDURES
D-1 Communicate status of current research on etiology.
D-2 Summarize diagnostic criteria - current and evolving.
D-3 Extract relevant information from diagnostic tools to establish behavior analytic and collaborative intervention priorities.
D-4 Distinguish among diagnostic categories.
D-5 Identify common co-morbid conditions.
D-6 Summarize information regarding epidemiology for consumers, public, etc.
D-7 Explain clinical, legal, educational, and research implications.
D-8 Refer consumers to professionals who can diagnose.
D-9 Use screening tools.

CONTENT AREA E: DEVELOP SYSTEMS AND SUPPORT
E-1 Work with families.
E-2 Manage funding and resources.
E-3 Maintain public and professional relations.

CONTENT AREA F: IMPLEMENT CURRICULA
F-1 Use existing curricula.
F-2 Customize curricula.
F-3 Develop a scope and sequence across domains.

CONTENT AREA G: NON-BEHAVIOR ANALYTIC INTERVENTIONS
G-1 Differentiate behavior analytic from non-behavior analytic interventions.
G-2 Research best available scientific evidence on non-behavior analytic interventions.
G-3 Critically evaluate the evidence regarding effectiveness, efficacy, and side effects of a nonbehavior analytic intervention (including documented or potential interference with behavior analytic intervention).
G-4 Educate consumers about risks and benefits of alternative interventions and combinations of interventions.
G-5 Educate other professionals and organizations (e.g., school districts, government, insurance companies) about risks and benefits of alternative interventions and combinations of interventions.

CONTENT AREA H: IMPLEMENT SAFE AND EFFECTIVE EMERGENCY PROCEDURES
H-1 Understand the philosophy and behavior analytic considerations when considering the use of emergency procedures (e.g., risks and benefits).
H-2 Develop and use emergency procedures.
H-3 Use physical and non-physical emergency management techniques.

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CALL TO ACTION: Legislative Alert

We would like to share this recent letter with our subscribers:

Hello! I’m writing you today to alert the Association for Science on Autism Treatment of some very unscientific treatment being proposed for funding in Massachusetts legislation. In senate bill 223, all regular and special education teacher candidates will be exposed to augmentative and alternative communication (AAC) techniques. I agree that this is a great idea in principle, and was prepared to fully support it. Unfortunately, I read the bill, and on line 30 noticed that facilitated communication is listed as one of these techniques. If you value science-based treatment for autism, please write to the Joint Committee on Education and let them know that you will only support the bill if the unscientific and contraindicated treatment (facilitated communication) were struck from it. They need to hear from all of us ASAP, please write to:

Rep. Martha Walz—Rep.MartyWalz@hou.state.ma.us
Sen. Robert A. O’Leary—Robert.O’Leary@state.ma.us
Joint Committee on Education
State House, Room 473G
Boston, MA 02133

Editors note: we’re providing the following links to provide you with information regarding the contents of this letter:

To read the language of Senate Bill 223: http://tinyurl.com/MASB223
To read a news story regarding the bill: http://tinyurl.com/SB223asat
To read ASAT’s summary of FC: http://tinyurl.com/ASAT-fc
Click the names of the following organizations to read their position on Facilitated Communication:

American Academy of Pediatrics
Association for Behavior Analysis International
American Psychological Association
American Speech-Language Hearing Association

Message from Josh continued...

small lightning icon next to each new feature. These new features include a book review, the “Talk About Ethics” column, research reviews, a treatment summary, “From the Archives” column, and our attempt at a cartoon (see above).

We also want to report that we currently distribute the newsletter to 3000 subscribers in over 90 different countries. Even better — the number of subscribers is growing daily! Please feel free to forward our newsletter to anyone that you think might be interested in science and autism treatment. Encourage them to sign up at www.asatonline.org/signup (see page 17 for details).

Stay tuned for the Winter Issue of Science in Autism Treatment.

Best,

Josh