

### SCIENCE IN AUTISM TREATMENT

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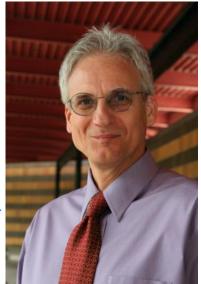
It's Ok to Say "I Don't Know": Advice from ASAT Advisory Board Member Bill Heward, EdD BCBA-D by Josh Pritchard, PhD, BCBA-D

Could you tell the readers how you came to be involved with ASAT? How long have you been on the advisory board?

Catherine Maurice, one of ASAT's founding members, told me about the organization and invited me to participate. I was a member of ASAT's Board of Directors for two years and have been on the advisory board since 2006.

What does ASAT signify to you? Why is it important? How does it relate to your interests and work?

Basic research has revealed some powerful principles about how people learn (e.g., reinforcement, stimulus control), and ap-



plied studies have discovered and refined strategies and techniques (e.g., self-

monitoring, interspersing easy tasks/known items) for putting those principles to work for the benefit of individuals with autism. No matter how potentially powerful these findings, they're of little impact if practitioners and parents are unable to distinguish them from the vast array of unsubstantiated claims clamoring for their attention.

Effective education and treatment of children with disabilities has always been plagued by the promise and popularity of unproven interventions (Heward & Silvestri, 2005). For example, in the '70s and '80s parents and teachers were told that having children with learning disabilities look through colored lenses and walk on balance beams would make them effective readers. The multitude of ineffective (at best) and sometimes even harmful autism treatments promoted today is unmatched in the history of special education. The tremendous range of behavioral deficits, excesses, and idiosyncrasies by which autism spectrum disorders are manifested makes an especially fertile ground for the proliferation of unsubstantiated treatments.

ASAT's mission – to educate parents, professionals, and consumers about autism and its treatment by disseminating scientifically sound information and combating inaccurate or unsubstantiated information – is every bit as important as the discovery and refinement of scientifically valid knowledge. ASAT's leader-ship—an impressive mix of parents, researchers, and practitioners — does an outstanding job separating scientific wheat from ideologically and/or financially driven chaff.

Resources on ASAT's website and articles published in its newsletter inform my thinking and I often share that information with teachers and parents with whom I work. Daniel Mruzek's (2012) discussion of the peer review process, Jim Todd's (2010) examination of the fallacy of facilitated communication, and Tom Zane's (2010) review of Relationship Development Intervention (RDI) are examples of many excellent articles in *Science in Autism Treatment* that help parents and professionals recognize distinctions between scientific evidence and unsubstantiated claims.

#### What kinds of things do you do related to autism?

I read, write, and talk about the relevance and use of applied behavior analysis in the education and treatment of people with autism. I don't read nearly as much as I should, have not written as much I'd like,

(Continued on page 2)

#### Interview with Bill Heward continued...

and almost certainly do too much talking! My most recent writing project was revising a textbook for future special education teachers, which includes a chapter on autism spectrum disorders (Heward, 2013). Most of my autism-related work consists of presentations and workshops for behavior analysts, teachers, and parents. This school year, I'll be presenting a series of five webinars for the Pennsylvania Bureau of Special Education on effective educational practices for students with high-functioning autism.

I especially enjoy and appreciate opportunities to help disseminate ABA internationally. I've given numerous presentations in Asia, Europe, South America, and the Middle East. Next month, I'll be speaking at conferences on ABA and autism treatment in Beijing and Shenzhen, China. Attendees at these events typically include parents, teachers, psychologists, physicians, school administrators, and government policy makers.

In these talks, I typically define ABA (an applied science devoted to understanding and improving human behavior); refute some of the most common misconceptions (e.g., consists only of 1-on-1 discrete trial training); share examples of ABA-derived instructional techniques to teach communication, social, and independence skills; identify characteristics of high-quality education and treatment programs; and suggest resources and organizations where people can learn more about ABA and evidence-based autism treatments. A slide of ASAT's homepage is always included.

## What do you identify as characteristics of high-quality autism programs?

I think the best programs, whether they provide early intensive behavioral intervention or serve school-age students, exhibit the following characteristics:

- Individualized, clearly defined behavior change targets focusing on language, social, and independence skills (and on academic, community, and employment skills as relevant)
- Use of evidence-based teaching practices
- Active programming for generalization and maintenance of newly learned skills to relevant
   settings and situations
- · Direct and frequent measurement of learning
- Data-based decision making (high-quality programs don't just collect data, they use it)
- Structured, frequent opportunities to interact

- with typically developing peers
- Ongoing communication with and involvement by parents and family members
- Teachers and staff who are well-trained in ABA
- Administrators who not only require, but provide support for all of the above

#### Why is ABA so important for children with autism?

When Don Baer, one of the founding fathers of applied behavior analysis, was asked why ABA was the distinctive treatment for autism, he replied that it's because, "ABA is the discipline that has most consistently considered the problem of what behavior changes, made in what order and by what techniques, will confer the maximal benefit to the child" (Baer, 2005, p. 6). Like he did when responding to so many other important questions about teaching and learning, Don's answer hit that one right on the button.

It is the way in which the applied behavior analysts working in the field of autism treatment "consider" problems that has made their findings so relevant. Baer, Wolf, and Risley's (1968, 1987) seven defining dimensions of the science (applied, behavioral, analytic, technological, conceptually systematic, effective, and capable of generalized outcomes) are at the root of ABA's importance for autism treatment. Here are a few other reasons why ABA is ideally suited to help improve the quality of life for children and adults with autism:

- ABA is public everything about ABA is visible, explicit, and straightforward. There's nothing hidden, ephemeral, or mystical about ABA. There are not metaphysical explanations. ABA's transparent nature should be valued by all constituencies: consumers, providers and taxpayers.
- ABA is accountable Therapists and teachers
  whose work is informed by ABA focus on environmental variables that reliably influence learning
  and that can be acted upon. This yields a form of
  accountability and responsibility that is good for
  the public and consumers.
- ABA is self-correcting Direct and frequent measurement is the foundation and most important component of treatment based on ABA. It enables practitioners to detect their successes and, equally important, their failures so that changes

(Continued on page 3)

#### Interview with Bill Heward continued...

- can be made in an effort to change failure to success.
- ABA is optimistic Children with autism are among the teach. ABA provides their teachers and parents a legitimate sense of optimism. First, direct and continuous measurement lets us see small improvements in behavior that would otherwise go unseen (and therefore not reinforced and, as a result, perhaps not repeated). Second, each time a teacher or parent successfully uses a behavioral technique, the more optimistic he or she is about the prospects for future success (positive outcomes are the most common result of behaviorally based interventions). Third, the peer tal disabilities. -reviewed literature in ABA is rich with examples of children, who many had considered ineducable, acquiring life-enriching communication, social, and independence skills.

most difficult of all children to What would you advise a parent of a newly diagnosed child with autism?

> I think any parent of a newly diagnosed child with autism would benefit from reading "Letters to a Lawyer" by Don Baer (2005). It is a collection of affidavits by Baer as an expert witness in court cases in which parents were suing schools or Medicaid agencies to provide ABA services for their children with autism. "Letters to a Lawver" is a plain-English description of the requirements and the potential of ABA as an educational treatment for children with autism and pervasive developmen-

I would also suggest parents read, "The Top 10 Reasons Children with Autism Deserve ABA" by Mary Beth Walsh (2009). Walsh makes the case for the multiple benefits of ABA-

and anecdotes of an engaging child with autism (her son, Ben).

Do you have any advice for professionals who provide education and treatment services for with autism?

Professionals should remember that it's okay to say, "I don't know." Unless you are the parent of a child with autism, you can can never fully know or appreciate what it is like to shoulder the demands and challenges of that responsibility 24/7. But that is no reason for professionals to be defensive or intimidated in their interactions with parents. Welltrained professionals can offer families the knowledge and skills they have without apology, and welcome their input. But parents will sometimes ask questions that you cannot answer or request services you cannot provide. Knowing the limits of your expertise is an important mark of a true professional and an ethical litmus test. So remember that informed intervention with humor it is okay to say, "I don't know the

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## Clinical Corner: How does a behavior consultant who is invested in the child's best outcome encourage parents to actively participate in home-based intervention?

#### **Answered by Alice Walkup, MS, BCBA**

For many parents of children with autism, participation in a home-based behavioral intervention program may seem overwhelming. In addition to managing and advocating for the child's various services, parents may find it difficult to attend to the needs of other family members, their spouses, and their jobs. Participating in their child's home-based program can certainly seem like one more responsibility for which there simply is not enough time. It is important to appreciate that other commonly-endorsed autism therapies, such

The benefits of home-based behavioral intervention programs for children with autism are clear. However, for many families, their participation in such programs can prove to be an overwhelming experience when trying to incorporate it into a myriad of other demands of daily life. In this installment of Clinical Corner, Alice Walkup provides helpful recommendations that behavior consultants can employ to support and encourage parent participation in their child's home-based program.

Nicole Pearson, PsyD, BCBA-D Clinical Corner Coordinator

as occupational or speech therapy, do not usually require the same level of time, energy and parental involvement that an intensive behavioral intervention program does.

#### UNDERSTANDING AND ASSESSING BARRIERS TO PARTICIPATION

When you conduct the intake interview (and likely throughout the consultative relationship), it is important to take note of any potential barriers to the parents' participation. Education level, socioeconomic status, competing responsibilities, other family members in the home, cultural beliefs, and beliefs about autism and autism treatments are just a few factors to consider. It is also important to keep in mind that parents may be unaware that the skills of children with autism (e.g., communication, compliance) do not automatically generalize from therapists to parents. As such, it is important for consultants to gauge the willingness and motivation of family members to be active participants in their child's intervention program (Taylor & Fisher, 2010).

From the outset it is important to explain to parents that they will be a critical part of their child's learning and will be shown how they can help the child practice what they've been taught during therapy sessions. Parents may also hold misconceptions regarding behavioral intervention, such as a belief that behavioral techniques are based exclusively on punishment. Explaining the intervention process at the outset will help eliminate such concerns. A final point to consider is that many parents of children with autism experience their own psychological challenges, such as depression and anxiety. Some research suggests that mothers with depressive characteristics do not acquire as much information and skills during parent training as mothers without depressive characteristics (Gelfand, Teti, Seiner, & Jameson, 1996; Cicchett, Rogosch, & Toth, 2000). Such issues may present challenges for consultants, but once identified can be taken into consideration when individualizing consultation and the scope of the home-based intervention. It may also become clear during the intake process that referral to other services or resources are warranted.

#### SETTING THE STAGE FOR SUCCESS

When working with a new family, there are many strategies you can employ to build a collaborative, open relationship from the outset. These include:

- asking questions that will help you better understand the parents' experiences as they relate
  to supporting their child with autism. Such questions may include asking what other services/
  therapies the child has received (or is still receiving), what supports (community, family and
  individual) are available to the parents, and what they see as their biggest challenges related
  to parenting a child with autism
- being an attentive and compassionate listener
- minimizing "behaviorspeak," including clinical terms and acronyms with which the parent is

(Continued on page 5)

#### **Clinical Corner Continued...**

unfamiliar. When explaining behavioral principles, it may help to use simpler, every-day examples to illustrate the concepts

- · explaining the intervention process and what a typical session may look like
- using language that fosters a cooperative spirit; for example, saying, "we as a team" instead
  of "you" when discussing the home-based intervention

#### **GOAL SELECTION**

When meeting with parents for the first time, encourage them to identify the hopes and fears they have for their child as doing so will help guide intervention planning and goals. It is equally important to identify goals that are most relevant to the family such as eating, sleeping, and community-based goals (Taylor & Fisher, 2010). This conversation should address both short- and long-term goals for the child, such as playing with friends, sitting appropriately in church, or attending college. With this knowledge, the consultant can assist parents in identifying their top three most important goals. One strategy for longer-term goals is to give each a name, such as "Project Friendship" for a socialization goal, as it will serve as a reminder to focus on the big picture. Once these are identified, the shorterterm goals and associated skills to be taught can be more easily defined, and the parents can see how they are supporting the longer-term goal. After selecting initial teaching targets and determining appropriate instructional strategies, the behavioral team will begin implementation. Keep in mind that some parents may challenge your typical approaches to behavior change, such as finding it difficult to tolerate extinction bursts, appreciating the need for direct teaching of desired skills, or using edible reinforcers. This again highlights the critical importance of discussing the intervention process and teaching strategies with parents at the outset. You can also explain their potential roles as teachers and that they will be included in their child's teaching at the appropriate time. Doing so will help foster a more collaborative relationship and help parents better anticipate and understand their roles in the behavioral intervention process.

#### PROMOTING ENDURING PARTICIPATION

Once parents agree to be involved in their child's home-based intervention, many factors can potentially influence their adherence to behavioral programs and their participation. Continued parent participation can be impacted by parental perceptions of themselves as effective in behavior change, confidence in the treatment approach, and by the degree to which the child is accepted in the family and community, among other variables (Moore & Symons, 2011). When engaging parents in the teaching process, the key is setting them up to be successful. Start with a smaller goal that the child has already mastered with the in-home therapists so that parents leave the teaching interaction feeling effective in promoting behavior change in their child. Utilizing best practices for training that incorporate modeling, rehearsal, and feedback will provide parents with valuable opportunities to both observe and practice teaching the targeted skill to their child. Tracking and graphing their progress in addition to the child's, then taking the time to review it with them regularly, is a good strategy to provide encouragement throughout the intervention process.

Parents and consultants should also consider whether or not the funding source for child's inhome services requires parent participation (and to what degree). Currently, some funding sources place a significant emphasis on training the parents to be effective at-home therapists and require behavior consultants to teach parents therapeutic skills to a level of mastery that they can do so. Parents can be asked to implement programs and collect data, and the consultant must report the level of parent involvement to the funding source. In extreme cases, in-home services have actually been terminated due to a lack of parent participation. While it is often more effective to appeal to parents on a more personal level when encouraging their involvement, this requirement and the potential loss of services should be discussed.

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#### **Clinical Corner Continued...**

Behavior consultants providing in-home services are tasked with addressing a child's needs within an existing, and sometimes challenging, family dynamic. The ideal in-home behavioral intervention program would include extensive and high-quality parent participation during therapy sessions; however, this may not always be possible. As such, we must individualize the type and extent of parent involvement on a case-by-case basis and employ our skills as consultants to encourage and maintain active parent participation, where possible. Despite the challenges that may accompany our efforts, it's important to remember that, at the end of the day, we are all working towards the same goal: ensuring the best possible outcomes for the child.

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

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It is my pleasure to report that we have welcomed subscribers from six new countries in 2012! This means a lot to all of us who are committed to disseminating science in autism treatment worldwide. Every subscription means a new group of parents and professionals can access information about autism that has been carefully prepared to assist them in making informed choices to benefit those for whom they care.



## Shout Outs, Accolades, and Appreciations! By Kerry Ann Conde, MS, BCBA

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

- The Southwest Autism Research and Resource Center (SARR) for sharing information about ASAT on its Facebook page and encouraging their fans to sign up for Science in Autism Treatment
- The Manitoba Association for Behavior Analysis for inviting a brief message from our International Liaison to the audience of their Annual Conference in Winnipeg, Canada.
- Barry Donlin for volunteering his time to create a logo for our NYC Marathon runners "TEAM ASAT".
- Verlaine Brunot and his family for generously donating customized t-shirts and sweatshirts for the members of "TEAM ASAT" who had planned to run in the NYC Marathon on November 4th.

If you would like to share information about any initiatives you have undertaken to support ASAT, please write us at <a href="mailto:publicity@asatonline.org">publicity@asatonline.org</a>.



#### **Underwater Basket Weaving Therapy for Autism: Don't Laugh! It Could Happen...** by David Celiberti, PhD, BCBA-D and Denise Lorelli, MS

Yes, sadly it can happen. With 400+ purported treatments for autism, there is no shortage of such whose name begins with an activity, substance, or favorite the time of introduction of effecpastime and ends in the word "therapy." A cursory internet search would reveal such "therapies" as music therapy, art In their guidelines focusing on therapy, play therapy, sand therapy, dolphin therapy, horseback riding therapy, bleach therapy, vitamin therapy, chelation therapy, and helminth worm therapy joining the list of the more established habilitative therapies such as physical therapy, occupa-

tional therapy, and speechlanguage therapy (this is by no means an exhaustive list

of the array of "therapies" that are marketed to consumers). Touted therapies can involve all sorts of things. I recall sitting on a panel at Nova University in the late '90s with another provider touting the benefits of Ilamas and lizards as well.

What concerns us are the assumptions - made by consumers and providers alike - that promoted "therapies" have legitimate therapeutic value, when, in fact, there is often little-to-no scientific evidence to support them. Some might rightfully say that many of these touted methods are "quackery" without such evidence. The focus on such unproven methods or "therapies" may result in financial hardship and caregiver exhaustion, further exacerbating the stress levels of participating families. What is most alarming is that these "therapies" may be detri-

mental because they may separate individuals with autism from interventions that have a demonstrated efficacy, thus delaying tive therapy.

American Academy of Pediatrics. the management of autism spectrum disorders, they state: "Unfortunately, families are often exposed to unsubstantiated. pseudoscientific theories and related clinical practices that are, at best, ineffective and, at worst, compete with validated

#### SOME FAULTY ASSUMPTIONS **REGARDING "THERAPIES"**

 Anything ending in the word "therapy" must have therapeutic value. The word "therapy" is a powerful word and clearly This concern is echoed by the overused; therefore, it would be helpful to begin with a definition.

#### Merriam-Webster

Therapy: noun \'ther-a-pe\ "a remedy, treatment, cure, healing, method of healing, or remedial treat-

Let's take a moment and think about this definition: When a "therapy" provider or proponent uses the word "therapy,"

> he/she is really saying: "Come to me...I will improve/treat/cure your child's autism." The onus

is on the provider/proponent to be able to document that the "therapy" has therapeutic value, in that it treats autism in observable and measurable ways or builds valuable skills that replace core deficits.

2. Providers of said "therapy" are actually therapists. It is not unreasonable for a parent or consumer to assume that the providers of particular "therapies" are bona fide therapists. It is also reasonable for a parent to believe that someone referring to him/herself as a therapist will indeed help the child. However, simply put, if an experience is not a therapy, then the provider is not a therapist. He or she may be benevolent and caring, but not a therapist.

Some disciplines are well established and have codified certification or licensed require-

"What is most alarming is that these 'therapies' may be detrimental because they may separate individuals with autism from interventions that have a demonstrated efficacy, thus delaying the time of introduction of effective therapy."

> treatments or lead to physical, emotional, or financial harm. Time, effort, and financial resources expended on ineffective therapies can create an additional burden on families" (p. 1174).

If a child diagnosed with cancer were prescribed chemotherapy, there is a reasonable expectation that chemotherapy would treat or ameliorate the child's cancer. Parents of individuals with autism have that hope as well when their children are provided with various therapies. While this hope is understandable, it is often placed in a "therapy" for which there is an absence of any legitimate therapeutic value. We hope the following will help both providers and consumers become more careful in how they discuss, present, and participate in various "therapies."

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#### **Underwater Basket Weaving continued...**

ments, ethical codes, and practice guidelines (e.g., psychology, speech-language pathology, occupational therapy). Consumers would know this, as "therapy" providers will hold licenses or certifications. Notwithstanding, consumers can look to see if the provider has the credentials to carry out a particular therapy, and these credentials can be independently verified (please see <a href="http://">http://</a> www.bacb.com/index.php?page=100155 as an example). A chief distinction is that licenses are mandatory and certifications are voluntary. In the case of licensure, state governments legislate and regulate the practice of that discipline. It cannot be overstated that just because a discipline has certified or licensed providers it does not necessarily mean that those providers offer a therapy that works for individuals with autism. This segues into the third assumption.

3. All "therapies," by definition, follow an established protocol grounded in research and collectively

defined best practices. Let's revisit our chemotherapy example. Chemotherapy protocols have a basis in published research in medical journals and are similarly applied across oncologists. In

other words, two different oncologists are likely to follow similar protocols and precise treatments with a patient that presents with similar symptoms and blood work findings. This is not the case with many autism treatments. Most therapies lack scientific support altogether and are often carried out in widely disparate ways across providers often lacking "treatment integrity."

4. If "XYZ therapy" is beneficial for a particular condition, it would benefit individuals with autism as well. Sadly, this kind of overgeneralization has been observed and parents of children with autism are often misled. Suppose underwater basket weaving was demonstrated through published research to improve lung capacity. Touting the benefits of this as a treatment for autism would clearly be a stretch. Therapeutic value in autism must focus on ameliorating core symptoms and deficits associated with autism such as social challenges, improving communication skills, and reducing or eliminating the behavioral challenges associated with autism.

#### **SOME SCENARIOS**

As stated above, when parents invest time and hope into therapy there is, most likely, an assumption that their child's autism will be ameliorated. Parents and providers look for improvement or significant changes in the core deficits related to autism (e.g., socialization, language, and maladaptive or problem behavior). What complicates the picture is that many so-called "therapies" appear to be enjoyable to individuals with autism. When we find pleasure in a particular thing or activity we tend to stick with it, we express our joy about it in some way such as a gesture, smile, or verbalization. This would apply to individuals with autism as well. Some of the activities associated with various "therapies" are just that: enjoyable experiences. However, "therapy" must involve more than positive moments in time; it must promote positive change that endures over time. The following are a few examples of alternative ways to conceptualize "therapies." This is not to say that

"Some of the activities associated with various 'therapies' are just that: enjoyable experiences. However, 'therapy' must involve more than positive moments in time, it must promote positive change that endures over time."

these experiences are bad; they are not, however, scientifically-proven therapeutic interventions.

#### Dog Therapy

Dogs can be very sociable and affectionate pets. A dog may be a common interest that may be shared with others. There are many opportunities for socialization when people gather around a dog. An individual with autism may tolerate a closer proximity of others who approach the dog and may learn to answer predictable questions about his/her pet. In addition, more conversational language may be heard from an individual with autism while interacting with a dog. This example is not intended to minimize the experience of dog services, as it may be applied in other ways (e.g., a dog that prevents a child with autism from bolting); however, it is meant to showcase how easy it is to tout "therapeutic value" when an array of positive experiences may be brought about by the "therapy."

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#### **Underwater Basket Weaving continued...**

Therapeutic Horseback Riding

Horseback riding involves a number of important routines beyond the sheer act of riding a horse. The routine of prepping the horse stays the same each time and the repetitiveness of the large strokes in brushing the horse's body may also be very pleasurable for some. Individuals with ASDs may become very adept at feeding, grooming, and/or saddling a horse, and they may look quite appropriate during these activities. In addition, the individual with autism may appear very competent and content while engaged in horseback riding; however, in the absence of more global benefit to the core deficits of autism, it would be inappropriate to call this a "therapy" for autism.

Sensory Activities such as Swinging

Many individuals appear very calm and content when swinging. It is important to make a distinction between whether the individual with autism *needs* to swing or merely *likes* to swing. In the latter case, swinging may serve as a powerful reinforcer and can be incorporated into the child's schedule as such. Furthermore, an individual may be very motivated by other reinforcers such as chocolate cake, and cake may have a calming effect; however, it would be imprudent to coin the term "chocolate cake therapy."

In many of these examples, what is touted as "therapy" is more accurately described as a potential source of pleasure or an opportunity to practice or develop certain skills. As such, they set the occasion for a leisure experience that the individual with autism may share with others; but they do not, in and of themselves, result in lasting, functional change.

As an autism community, we need to be very careful and selective about which experiences we attach to the word "therapy." Misuse of this term can be misleading, can raise false hope, can sap family resources, and can separate children from treatments with a documented track record of success. If you want to call something therapy it must be scientifically proven to be therapeutic. Otherwise, call it a wonderful recreational experience, a reinforcer, a hobby, etc. Such a shift in how we refer to these experiences is not meant to cheapen their value, but to clarify our expectations with regard to outcomes.

#### Reference:

Myers, S. M, Johnson C. P., & the Council on Children with Disabilities (2007). Management of children with

#### Is a "therapy" a THERAPY?: Questions to Ask

Below are six questions that should always remain at the forefront:

- **1. What is the focus of the therapy?** The therapy must target one or more of the core features of autism in order to be legitimately viewed as an autism therapy (e.g., social skill deficits). In other words, which deficit or excess is, the therapy intended to target?
- **2. What is the therapeutic value?** This therapeutic value must involve demonstration of a positive impact on those targets. Furthermore, there must be a clear connection between the therapy and the subsequent therapeutic outcome not just a temporal association. That is, it must be demonstrated that the improvement is actually due to the "therapy."
- **3.** Is there published research in peer-reviewed journals supporting claims made? Consumers should look for evidence of published findings in peer-reviewed journals rather than anecdotal evidence or testimonials.
- **4. Are therapeutic gains enduring?** The documented benefits must persist over time and generalize across settings.
- **5. Who can provide this?** The "therapist" should have the proper training, experiences, and credentials to carry out said therapy.
- **6.** How is the therapy carried out? Therapy should be adapted to the individual with autism based on the individual's characteristics and needs, not based on therapist preferences (he or she carries out therapy in a certain manner for all recipients).

#### Message from SIAT President Mary McDonald, PhD, BCBA-D

It is hard to believe how quickly the summer has flown by and that we are now in full swing of the fall season. We are just wrapping up our 2012 Sponsorship campaign at this time and would like to thank our many sponsors who support ASAT's mission and share our dedication to science in autism treatment. If you are interested in sponsoring ASAT, please take a look at the Sponsor Page for more information <a href="http://asatonline.org/about\_asat/professional-sponsors">http://asatonline.org/about\_asat/professional-sponsors</a>.

We appreciate all of the support provided by so many of you. ASAT has made a great amount of accomplishments this year, and I would like to highlight just a few to share with you. Our 2013 goals will be reported in the Winter 2013 issue of the newsletter.

Some ASAT Highlights for 2012:

- Wrote a large number of grants this year, and received two small grants from Provident Bank Foundation and BCB Community Bank to assist with our physician awareness program
- Developed a formal externship program to provide opportunities for externs to be a part of ASAT's mission
- Refined our "How You Can Help" section on the website and hope you will consider helping: <a href="http://asatonline.org/about\_asat/hych">http://asatonline.org/about\_asat/hych</a>
- Made a larger effort to address life span issues by adding content to our webpage and newsletter addressing adult topics
- Increased our focus on international interest by adding international content to the newsletter and targeting countries to increase international newsletter subscribers
- Used social media to increase our visibility through increased use of Twitter, Facebook, Youtube, and Fundly

I would like to take this opportunity to thank our volunteer board, externs, and committee volunteers for all of the work they do on behalf of ASAT. They do it because they believe in ASAT and want to further ASAT's mission. I hope that you too will consider supporting ASAT. When selecting possible recipients of your year end donations, I ask that you please give ASAT your fullest consideration. Donations to ASAT help us to continue to do the work that we do. Your donations to ASAT truly make an impact on the field of autism. By contributing to ASAT, you will increase the likelihood that the thousands of families with newly-diagnosed children, as well as the professionals that serve those children, will have timely access to clear, accurate and science-based information about autism and autism treatments. It is very difficult for parents to distinguish between the fad and the proposed cures for autism and we continue to provide information while promoting science. If you would like to support ASAT, please go to: <a href="http://fundly.com/asatonline">http://fundly.com/asatonline</a>.

Sincerely,

Mary E. McDonald ASAT, President of Board of Directors

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# Raise Your Glass: Wicked Wolf Tavern Donated \$1415 to Dine InDeed

The Association for Science in Autism Treatment has partnered with the Boys & Girls Clubs of Hudson County and the Jubilee Center to launch Dine InDeed 2012, a community-wide restaurant event. According to Dr. David Celiberti, ASAT Executive Director and creator of Dine InDeed, "All three organizations are committed to extending meaningful opportunities for children to realize their fullest potential. In my view, there is nothing more incredible than that." The Wicked Wolf Tavern was the very first Hoboken restaurant to participate this year by donating 10% of customers' food bills on Tuesday nights throughout the summer. Celiberti stated that "Wicked Wolf offers their guests a comfortable and friendly environment, exceptional ser-

vice, and an incredible view of Manhattan."

"We are so thankful to the Wicked Wolf Tavern for supporting children within Hoboken," stated Jubilee Center Executive Director. Armstead Johnson. These sentiments were echoed by Gary Greenberg, Executive Director of the Boys & Girls Clubs of Hudson County, "It's very impressive how a neighborhood can join together in support of its nonprofit community, and we're very grateful to be one of the recipients of the generosity of the people of Hoboken. Dine InDeed is really an innovative way of involving the public through our local restaurants and businesses while keeping the nonprofits in mind. It's really a great program; it raises awareness that nonprofits such as the Boys & Girls Club couldn't be successful without devoted community partners like ASAT and the Jubilee Center. It's what helps us increase our capacity to help the children we serve." Monies raised through this fundraising initiative support the initiatives of ASAT and two other local organizations:



Pictured from left to right: Brian Petrucelli (General Manager of the Wicked Wolf Tavern), Nilesh Patel (Director of Operations for the BGCHC), Gary Greenberg, Executive Director of the BGCHC), David Celiberti (ASAT Executive Director), Armstead Johnson (Executive Director of the Jubilee Center), and Alyssa Kuminski (Events Manager of the Wicked Wolf Tavern)

- The mission of the <u>Jubilee Center</u> is to serve the academic and social needs of children and families in Hoboken's public housing community. The Center has provided a safe after school haven for children in grades K-6 for more than a decade and has recently expanded programming to accommodate the needs of the children during the summer.
- The <u>Boys & Girls Clubs of Hudson County</u> helps young people build strong character and realize their full potential as responsible citizens and leaders. They have been serving youth in Jersey City since 1893 and in Hoboken since 1984. They do this by providing a safe environment filled with hope and opportunity, ongoing relationships with caring adults, and life-enhancing programs year round. Sadly, the Hoboken location of the Boys & Girls Club was significantly damaged by Hurricane Sandy.

Anthony Oland, an active member of the Hoboken community said, "Dine InDeed is another example of how the businesses and residents of Hoboken are always willing to help the overall community of our city. Aiding those with autism and the children of our city is such an easily compelling rationale for dining at those restaurants that partner with Dine InDeed." Anthony David's just wrapped up its participation in Dine InDeed. Other restaurants such as D's Soul Full Café, Cugini Kitchen, and Johnny Rockets will participate in the next few weeks, as Dine InDeed will be an ongoing fundraising event. Stay tuned for further updates!

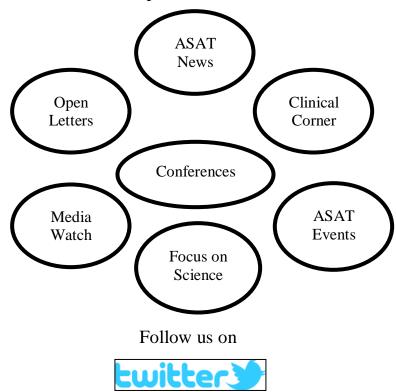
Please visit the Dine InDeed Facebook <u>page</u> to learn more about this effort (and kindly "like" the page as well). If you are a restaurant owner or manager and would like to learn more about Dine InDeed, please email David Celiberti at <u>DCeliberti@asatonline.org</u>.



5,000 fans

## Are you one of them?

With your help, we are reaching out to more and more people every day, united in their commitment to accountability, respect, and science in autism treatment. Individuals with autism deserve nothing less! Join us on <a href="Facebook">Facebook</a> (<a href="www.facebook.com/ASATOnline">www.facebook.com/ASATOnline</a>) to stay connected and get immediate content updates on:



www.twitter.com/ASATonline & www.twitter.com/SIATNewsletter



# First Annual Long Island Behavior Analysis Conference (LI-BAC) Friday, December 7th and Saturday, December 8th 2012

To support the following organizations:

The ELIJA Foundation • New York State Association of Behavior Analysis Association for Science in Autism Treatment

Networking Reception Friday, Dec. 7th 5pm—8pm Full day ABA insurance billing workshop Saturday, December 8th BCBA/SLP CEU's will be available

	ELIJA Members*	Professionals/ Non-Members	Walk-In/Late After November 23 <sup>rd</sup> , 2012			
1 Day (Fri, or Sat)	\$75	\$95	\$110			
Days (Fri & Sat)	\$150	\$175	\$200			
	*to register with ELIJA membership you must be a member 60 days prior.					
Where:	Melville Marriot, Long Island, New York					
	Hotel accommodations available: Please call to make your hotel reservations.					
	ELIJA has reserved a block of rooms from December 6th-December 8th at a rate of \$129 plus tax per night.					
Invited Presenters:	Dr. Bridget A. Taylor, BCBA-D- Alpine Learning Group, New Jersey					
	Dr. Henry S. Roane, BCBA-D- SUNY Upstate Medical University Hospital					
	Dr. Eric V. Larsson, Ph.D., L.P., B.C.B.A					
	Executive Director, (	Clinical Services Lovaas Instit	tute – Midwest			
	Heather Kadey, BCBA-SUNY Upstate Medical University Hospital					
	Judith Ursitti- Autism	Speaks Regional Director of	f State Advocacy Relations			
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#### Long Island Behavior Analyst Group Mission:

We provide ongoing educational support, share resources, provide networking opportunities and the development of unified responses pertaining to local issues that affect the practice of behavior analysts. Members will guide the focus of LIBAG based on the current needs in the field. LIBAG also seeks to expand the awareness and importance of behavior analysis and best practice guidelines in the local Long Island community.

Our hearts go out to all of those affected by Hurricane Sandy and who are still dealing with her aftermath!

Below are pictures of Team ASAT who had been fundraising and preparing for the 2012 NYC Marathon that was cancelled due to the hurricane. We are very grateful to these six runners for supporting ASAT in such a public way! We look forward to next year's marathon!

We hope that those of you in our ASAT community from the northeastern states are able to return to normalcy as soon as possible. You are in our thoughts!



#### Research Review: Teaching Children with Autism to Read for Meaning: Challenges and Possibilities

Randi, J., Newman, T., & Grigorenko, E. L. (2010). Teaching children with autism to read for meaning: Challenges and possibilities. *Journal of Autism and Developmental Disorders*. 40 (7), 890-902.

Reviewed by: Anton Shcherbakov, Rutgers University

#### Why study this topic?

Teaching individuals to read for meaning is challenging – even for typically developing children. For children with autism spectrum disorders (ASDs), this is often even more difficult. Children with ASDs, at all levels on the spectrum, tend to be skilled at word recognition and often develop this skill early and quickly; however, many of these children do not understand the meaning of what they read. Scientists use the term *hyperlexia* to describe this profile of proficient word recognition with limited comprehension. Since comprehension is essential for learning and retaining information, this is clearly an important area for

#### What did the researchers do?

intervention for individuals with ASDs.

The researchers reviewed prior studies on reading comprehension, in children with ASDs and on interventions aimed at improving their comprehension.

#### What did the researchers find?

The researchers in the present study discussed previous findings on components of reading comprehension, which include being sensitive to the structure of the story, making inferences, and monitoring comprehension. Sensitivity to story structure is important to understanding the overall message or theme of the story. Inference-making, which is particularly difficult to teach, involves connecting individual words to the overall meaning of first the sentence and then the broader story. Comprehension monitoring consists of identifying passages that one didn't fully understand and rereading them.

Turning to the specific difficulties individuals with ASDs have, the researchers cite evidence that individuals with ASDs tend to focus on single words or details rather than understanding the broader meaning of a story. This style may strengthen their word recognition but interferes with reading comprehension. Essentially, they often "miss the big picture" because of their "eye for detail." Memory impairments may add to their difficulties with reading comprehension. Although most individuals with ASDs

In this newsletter, the articles summaries are on two different topics, early intervention and reading. Strain and Bovey (2011) conducted an evaluation of the Learning Experiences and Alternative Program for Preschoolers and Their Parents. Randi, Newman, and Grigorenko (2010) discussed previous findings on components of reading comprehension. I hope you enjoy reading them as much as we did summarizing them!

#### Sharon A. Reeve, Ph.D., BCBA-D, SIAT Research Corner Coordinator

have good rote memory (i.e., recalling facts learned by repetition), they usually struggle when the information is complex and requires organization of meaning. Finally, individuals with ASDs have particular difficulties with discerning the intentions and beliefs of characters in the story, as well as the abstract themes and causal chains of events within the story. These difficulties hinder them from grasping the overall story structure and creating meaning.

Next, the researchers reviewed studies on interventions to improve reading comprehension in individuals with ASDs. They found only two such studies. The first study revealed that a strategy called anaphoric cuing may increase reading comprehension. Anaphora are words such as pronouns (e.g., he or she) that refer back to an earlier word or passage. The anaphoric cuing procedure involved underlining the anaphora and asking students to choose what they referred to in the story. The second study indicated that another promising strategy is reciprocal questioning, in which a learner with ASD is paired with a typically developing peer and encouraged to ask and answer questions about a story while reading it.

#### What do the results mean?

Overall, the results of the researchers' review suggest that individuals with ASDs have specific reading difficulties that can be addressed through techniques such as anaphoric cuing and reciprocal questioning. Although neither approach is probably sufficient on its own to teach learners with autism to read for meaning, they provide teachers with a place to start. The review is limited by the small number of available studies and highlights the need for additional research on interventions for reading comprehension.

Research Review: Randomized, Controlled Trial of the LEAP Model of Early Intervention for Young Children with Autism Spectrum Disorders.

Strain, P. S. & Bovey, E. H. II. (2011). Randomized, controlled trial of the LEAP model of early intervention for young children with autism spectrum disorders. *Topics in Early Childhood Special Education*, 20 (10), 1-22.

Reviewed by: Rebecca Schulman, Rutgers University

#### Why study this topic?

Previous research on early intervention for autism spectrum disorders (ASDs) has primarily focused on programs that emphasize discrete trial methods in settings specifically for children with ASDs.

Intervention models that involve inclusion in public school settings, such as Learning Experiences and Alternative Program for Preschoolers and Their Parents (LEAP), have received much less attention. It is essential to assess different types of early intervention programs to ensure that educational resources are being used in the most effective way possible.

#### What did the researchers do?

The researchers aimed to evaluate the effectiveness of LEAP, a manualized inclusion program for preschool children with ASDs. Typically developing peers are taught to facilitate social and communication behaviors of children with ASDs during daily preschool routines. LEAP also involves daily data collection, skill training for families, and a variety of science-based intervention approaches, including errorless learning, time delay, incidental teaching, pivotal response training, and picture exchange communication system.

The current study was a randomized control trial (RCT) to better determine the overall efficacy of enrollment in LEAP. Two hundred and thirty preschool teachers and 294 children with ASDs participated. Classrooms were randomly assigned to either the full LEAP replication or a comparison condition which consisted of LEAP's intervention manuals, videos, and training presentation materials but did not include follow-along training. Intervention lasted for two years. Children were assessed at three time points: before the start of the assigned intervention, after about one year of intervention, and at the conclusion of the second year of participation. At each time point, measures were taken to assess defining characteristics of autism, cognitive ability (IQ), receptive and expressive communication competence, social skill development, and problem behavior. In addition, this study tried to account for limitations of previous RCTs by assessing if treatment was being implemented properly and measuring teacher

satisfaction of the intervention.

#### What did the researchers find?

The results indicate that, although the groups were equivalent on all child and teacher measures prior to intervention, the LEAP group averaged twice the gain in IQ and language development, as well as twice the reduction on a measure of autism symptoms, relative to the comparison group. The LEAP group also showed a greater increase in social behavior and decrease in problem behavior than did the comparison group. Furthermore, after one year, the full replication LEAP classes adhered to proper treatment implementation 53% of the time, which rose to 87% at the end of year two. The comparison classes showed 31% adherence to program implementation at the end of year one, which only rose to 38% after the second year. Lastly, ratings from teachers in the treatment classes showed that they liked the LEAP program and thought that it was responsible for the improvements seen in their students.

#### What do the results mean?

This study was the first RCT of a classroom-based intervention in a public school setting for young children with ASDs. It is also the first RCT to collect data on implementation of the treatment and one of the first to evaluate satisfaction with the intervention in addition to Smith, Groen, and Wynn (2000). Additionally, it was the first RCT to show large developmental improvements in children with ASDs using methods other than discrete trials. One limitation of the current study is that ASDs diagnosis and change in ASDs symptoms were assessed by screening questionnaires rather than by standard diagnostic measures involving direct observation. Despite this limitation, results suggest that children in the intervention group made considerable cognitive, social, language and behavioral gains in relation to the comparison group.

#### References:

Smith, T., Groen, A., & Wynn, J. W. (2000). Randomized trial of intensive early intervention for children with pervasive developmental disorder. *American Journal on Mental Retardation*, 104, 269-285.

# SHOW YOUR VALUES SHOW YOUR BRAND



The Association for Science in Autism Treatment (ASAT) accepts advertising for the ASAT.org website, newsletter and other ASAT publications to offset its operational expenses. Products or services accepted for advertisement by ASAT will be consistent with our mission to disseminate accurate, scientifically-sound information about autism and its treatment and to improve access to effective, science-based treatments for all people with autism, regardless of age, severity of condition, income or place of residence.

If you share our values, take this opportunity to support our mission and share yours to 7,000 SIAT subscribers interested in autism treatment, services, and products.

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#### Does Your Agency Share ASAT's Values?

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

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

ASAT works toward a time...

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

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

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

## What It Means to Be a Sponsor...

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

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

## ...Become a 2012 Sponsor Now!

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

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

If you are interested in becoming a 2012 Sponsor, please visit the sponsor page on our website at <a href="https://www.asatonline.org/about\_asat/sponsors.htm#learn">www.asatonline.org/about\_asat/sponsors.htm#learn</a>.

Thank you for your consideration!

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#### Media Watch Update by Barbara Jamison, Media Watch Coordinator

RECENT ASAT RESPONSES TO MEDIA STORIES IN-CLUDE:

## BBC News "France's autism treatment 'shame'" (May 23, 2012)

BBC News carries the heartrending and sobering story of French children with autism who are subjected to outdated, disproven psychoanalytic treatment. <a href="http://www.asatonline.org/media">http://www.asatonline.org/media</a> watches/81

## Macleans.ca's "The Battle Over the 'Cure' for Autism" (May 28, 2012)

Autism treatment is currently a veritable free-for-all, with many providers completely ignoring existing research and with scores of children not given access to the treatments that have the best available support. <a href="http://www.asatonline.org/media">http://www.asatonline.org/media</a> watches/82

## Boston.com's "Could sensory integration disorder be the primary problem?" (June 5, 2012)

Dr. Claudia Gold relies on anecdotal evidence to suggest that a root cause of developmental and mental health disorders, including autism, may be sensory integration (SI) disorder.

We disagree. <a href="http://www.asatonline.org/media">http://www.asatonline.org/media</a> watches/83

#### Boston.com's "Massachusetts Emergency Workers Learn to Recognize Autism" (June 7, 2012)

What is ALEC? And how can law enforcement be trained to respond safely to individuals with autism? <a href="http://www.asatonline.org/media">http://www.asatonline.org/media</a> watches/84

## USA Today's "Video games boost autistic kids" (June 11, 2012)

Reporter Greg Toppo hints at the use of off-theshelf video games as new treatment for autism, but should they replace "months of intensive therapy?" http://www.asatonline.org/media\_watches/85

#### US News story "Doubt Cast on Usefulness of 'Sensory' Therapies for Autism" (June 26, 2012) Is skepticism of sensory integration therapy for children with autism warranted?

http://www.asatonline.org/media watches/86

## MSNBC's "1 in 3 autistic young adults lack jobs, education" (July 4, 2012)

MSNBC's Lindsey Tanner highlights the plight of many individuals with autism upon completion of their high school education.

http://www.asatonline.org/media watches/87

## The Atlantic.com's "The Economic Impact of Autism on Families" (July 13, 2012)

Now more than ever, in these difficult financial times and uncertain economy, it is imperative that families allocate their resources toward treatments demonstrated to be the most effective for teaching individuals with autism to reach their full potential. <a href="http://www.asatonline.org/media\_watches/88">http://www.asatonline.org/media\_watches/88</a>

## US News story "Many Parents of Kids with Autism Don't Put Faith in Pediatricians" (August 3, 2012)

Why do many parents of children with autism lack confidence in their pediatricians? And what can be done to address this problem?

http://www.asatonline.org/media\_watches/89

## MSN.com's "Pets May Help Kids With Autism Develop Social Skills" (August 15, 2012)

Social skills are an important part of the repertoire of a child on the autism spectrum, but parents and caregivers need to be discerning about use of "pet therapy" as a possible intervention.

www.asatonline.org/media\_watches/90

## Charlotte Observer's "Hyperbaric oxygen therapy is healing many ills" (September 16, 2012)

Opinions of medical professionals can be potent in the marketplace of ideas when it come to autism treatment, but sometimes the experts disagree. How to decide? <a href="http://www.asatonline.org/media\_watches/91">http://www.asatonline.org/media\_watches/91</a>

# The Daytona Beach-Journal's "Surf Event Serves as Therapy for Kids with Autism" (September 20, 2012)

David Massey, reporter for The Daytona Beach-Journal, terms this fun activity a "therapy." http://www.asatonline.org/media\_watches/92

(Continued on page 21)

#### Media Watch continued...

#### ABC's "Aquatic therapy center helps those with autism, open to all" (October 8, 2012)

Most of us would agree that being in warm water does provide a calming effect - regardless of whether one has autism or not – but there is no scientific evidence that aquatic therapy heals the symptoms of autism. <a href="http://www.asatonline.org/media">http://www.asatonline.org/media</a> watches/93

#### Huffington Post's "The Curious Case of Autism and MMS" (October 9, 2012)

ASAT commends news writer Todd Drezner for pulling the plug on bleach therapy as a treatment for autism. http://www.asatonline.org/media\_watches/94

#### **Treatment Summary**

#### Social Communication Emotional Regulation, and Transactional Support (SCERTS) Model

**Description**: The SCERTS Model intends to enhance social communication between the parent and the child with an autism spectrum disorder. Parents or teachers are taught to arrange the environment and create temptations for the child to initiate communication during daily routines.

Research Summary: To date, there are no studies with strong experimental designs evaluating whether or not the SCERTS Model is an effective, comprehensive intervention. In a preliminary outcome study, Wetherby and Woods (2006) reported an increase in children's positive affect and frequency of communication, but did not find reliable changes in children's other communication skills.

**Recommendations:** Important next steps for research on the SCERTS Model are replications by independent investigators and comparisons against established early intensive behavioral treatment models. Professionals should present SCERTS as untested and encourage families who are considering this intervention to evaluate it carefully.

#### Selected References:

Prizant, Barry M. The SCERTS Model: a Comprehensive Educational Approach for Children with Autism Spectrum Disorders. Baltimore, MD: Paul H. Brookes Pub., 2006.

#### Selected Scientific Studies:

Wetherby, A. M., & Woods, J. J. (2006). Early social interaction project for children with Autism spectrum disorders beginning in the second year of life: A Preliminary Study, *Topics in Early Childhood Special Education*, 26, 67-82.

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