



Table of Contents

Is There Science: Examining Respen-A [1](#)
 Message from David..... [1](#)
 SIAT Team [1](#)
 ASAT Advisory Board [2](#)
 From the Archives [3](#)
 ASAT Board of Directors..... [3](#)
 Treatment Summary: Verbal Behavior [4](#)
 Adventures in Driving..... [5](#)
 Shout Outs and Accolades..... [6](#)
 Clinical Corner: Infants and Educational Issues.... [7](#)
 Letter from Josh [9](#)
 ASAT Committee Members [9](#)
 Consumer Corner: Supported Employment [10](#)
 Consumer Corner: Life-Journey through Autism .. [11](#)
 Clinical Corner : Educating for Inclusion [12](#)
 ASAT's Facebook update [15](#)
 ASAT Scores a Touchdown! R4AA [16](#)
 R4AA Business Sponsors and Volunteers..... [18](#)
 Local Businesses Support ASAT [19](#)
 Acoustic for Autism [20](#)
 ASAT Donor Wall..... [20](#)
 Media Watch Update [21](#)
 Research Review: Post-High School Services..... [22](#)
 Research Review: Psycho-Educational Model.... [23](#)
 Research Review: Synthesis of EIBI [23](#)
 ASAT Advertising Policy [24](#)
 ASAT Sponsorship [25](#)
 Cartoon: Ice Cream and Violent Crimes [27](#)

Caveat Emptor! Blood Pressure Drug Marketed as a “Homeopathic Topical Treatment” by Daniel W. Mruzek, Ph.D., BCBA-D

The marketing of a drug called Respen-A™ provides an opportunity to illustrate how we can watch for the “red flags” of unsubstantiated autism treatments.

The marketers of the drug are Elaine DeLack, RN and Kurt N. Woeller, D.O. Their business, Neuro-Med, is connected to another business called MedDev that is housed in the Gateway Centre business complex in Stanwood, WA. The marketers also maintain a Respen-A™ website (see <http://www.respen-a.com/>). They strongly suggest positive results with Respen-A™, a drug administered to persons with autism through a transdermal patch. On their Respen-A™ “Frequently Asked Questions” webpage, the marketers state: “Many parents are reporting in the

first month of using the Respen-A™, increased concentration, better eye contact, more socialization, less irritability, decreased anxiety, and some children who were unable to speak are now trying to verbally communicate once again” (see <http://www.respen-a.com/respen-a-faq.html>).

According to the marketers, the active ingredient in Respen-A™ is reserpine. The National Center for Biotechnology Information (2011) reports that reserpine is in a class of medications called rauwolfia alkaloids. It works by reducing the activity of the nervous system, causing the heartbeat to slow and the blood vessels to relax. Reserpine is used to treat high blood pressure, as

(Continued on page 2)

What Autism Awareness Should be About by ASAT President, David Celiberti, Ph.D., BCBA



Autism Awareness Month has come to a close. The blue puzzle pieces will soon disappear from Facebook pages and billboards, the media will focus their attention to other topics of interest, and we will return to business as usual. And business as usual is not OK.

When I first entered the field over twenty years ago, autism was considered a rare condition. When people asked what I did for a living, they often misheard me and thought I worked with “artistic” children. Today, autism

(Continued on page 26)

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Is there Science continued...

(Continued from page 1)

well as severe agitation in persons with mental health disorders.

The Respen-A™ marketers hypothesize autism is caused by a “cocktail” of drugs given to mothers who use epidurals for pain management during birthing. To support this assertion, they note the positive correlation between the use of epidurals in the United States and the increased prevalence of autism. Regular readers of *Science in Autism Treatment* know that a correlation between two events does not mean that one *causes* the other. Consider the positive correlation one might find in a particular community park between the number of ice cream cones sold and the number of children who have playground accidents. As ice cream sales rise, the number of accidents rises as well; however, does ice cream cause accidents? This is doubtful. Rather, both variables are affected by other variables (e.g., temperature; on warm days, more children are in the park, increasing *both* ice cream sales and opportunities for accidents). Similarly, epidurals and

the diagnosis of autism have both increased in recent years; however, has one caused the other? It would seem much more likely that change in health care practices in recent years may account for increased access to epidurals for mothers *and* much greater attention given to the early identification of autism in children.

The marketers further propose that Respen-A™ helps to correct resultant neurological problems leading to autism in children by decreasing the presence of serotonin in the autistic brain. Parents need a prescription for the drug, and the Respen-A™ marketers provide a list on their website of five pharmacies that can fill this prescription. A 28-day supply of Respen-A™ costs \$82.00. A daily calcium

supplement must accompany the drug due to calcium depletion as a possible side-effect.

What proof do the marketers offer regarding the effectiveness of their drug? They offer up a “Respen-A™ Video Testimonial Series” with comparisons of a boy’s behavior, including communication skills, on and off the drug. Hawkers of unsubstantiated treatments often rely on testimonials as a standard tactic for suggesting beneficial results with their product. Indeed, testimonials can provide the illusion of efficacy by providing a biased but compelling example of purported positive outcomes. But, testimonials are a far cry from scientific evidence published in peer-reviewed journals.

The Respen-A™ marketers include a table with a bar graph representing “Average Change in ATEC Score After One-Month on Respen-A” on their website. (The ATEC is a brief autism symptoms checklist that can be completed by parents.) “Pre” and “post” comparisons *look* compelling; however, it appears that these data are collected through on-line submissions by parents and participating physicians, not through a scientifically acceptable method. No information is given with regard to sample size or the use of any standard scientific procedures to establish the validity of the data (e.g., treatment and/or placebo control groups, double-blind procedures).

To further promote their product, the marketers make use of Respen-A™ blog and “Respen-A™ in the News” links. A review of their posted “news” items reveals the following: 1) a mention on the *Spectrum Magazine* Facebook page; 2) an “advertorial” (i.e., an advertisement written in the form of an editorial) on the *Spectrum Magazine* website; 3) a single blog post by a parent trying the drug with her son; and 4) a “news release” apparently authored by one of the marketers announcing her presentation at a Autism One/Generation Rescue conference.

What is the state of the science with regard to the use of reserpine in treating autism? Our review of the scientific literature revealed one study published several decades ago in a peer-reviewed journal (Lehman, 1957). Using the administration of a simple rating scale, Lehman found positive effects on the behavior of 9 children described as having autism; however, it should be noted that this study did not employ important procedures for scientific control

(Continued on page 3)

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Is there Science continued...

(e.g., double-blind ratings, control group). Also, it is worth noting that these authors report concerns about possible toxicity and side-effects (e.g., withdrawal symptoms) related to an improper dosage of reserpine. No other peer-reviewed studies have been identified in the last 54 years!

What can we do to evaluate the science behind hyped marketing schemes, such as the one promoting Respen-A™? First, recognize common signs of baloney, including reliance upon testimonials and contrived “news” to create the “feel” of documented treatment effectiveness. Second, recognize that just because a treatment is described as “homeopathic”, it is not necessarily safe. In this instance, the active ingredient, reserpine, is a psychoactive drug that has serious potential side-effects, including dizziness, dry mouth, loss of appetite and several others. Third, ask providers- and marketers- direct questions about the state of the science behind their claims and politely request direct answers. Marketers should present their autism treatment products without contrived hype and ill-defined data. And, they should present the state of their science clearly and accurately. Persons with autism and their families deserve nothing less.

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From the Archives



Our day-to-day interactions with family and friends are based on anecdotes and personal experience. We often try new products or foods simply because of a personal recommendation. Why should these decisions be held to different standards when searching for a treatment for a child with autism?

Many families often question their decision to rely on evidence-based programs for their child with autism. In this issue of “From the Archives” Jeri Logemann gives us a refresher course on exactly what “Evidence-Based Practice” is, and why is it important!

ASAT’s Guiding Values

ASAT is **committed to science** as the most **objective**, time-tested and reliable approach to discerning between safe, effective autism treatments and those that are harmful or ineffective. ASAT supports **all** scientifically-sound research on the prevention, treatment and cure of autism, as well as **all** treatments for autism that are shown to be effective through solid scientific research, **regardless of discipline or domain.**

A copy of this article can be found on our website.

[What is Evidence-Based Practice and Why Should We Care?](#)

By **Jeri A. Logemann**
 (Originally appeared in Spring 2000 SIAT)

Sara Gershfeld, MA, BCBA
 SIAT *From the Archives* Coordinator

Treatment Summary: Verbal Behavior

Description: *Verbal behavior* is a term coined by B.F. Skinner to describe a behavioral approach to understanding how typically developing individuals develop and maintain communication skills. The approach emphasizes that communication is a behavior that follows the same laws and principles as other forms of behavior. In his book, *Verbal Behavior*, Skinner introduced and described new terms to refer to language processes from a behavioral perspective. For example, a *mand* is a type of verbal behavior that is reinforced by a particular consequence (e.g., making a request and then the request is granted). A *tact* is a type of verbal behavior that occurs in the presence of a particular stimulus (e.g., saying the name of an object in response to being shown the object).

Although Skinner did not discuss interventions to promote language development for children with autism spectrum disorders, many professionals within the field of applied behavior analysis have applied Skinner's concepts to develop teaching procedures for these children and have called their procedures *Verbal Behavior* or *Applied Verbal Behavior*. Verbal Behavior programs emphasize teaching children with autism spectrum disorders to use mands to request items that they are highly motivated to obtain. Such programs also provide instruction on other types of verbal behavior as well as nonverbal behavior such as self-help skills. In so doing, they rely on teaching methods developed by other ABA programs independently of Skinner's *Verbal Behavior*. These methods include structured teaching approaches such as discrete trial training and procedures for motivating learners such as mixing difficult and easy tasks within a session. Verbal Behavior programs strongly recommend teaching children to use sign language before vocal speech or other communication systems such as the Picture Exchange Communication System (PECS).

Research Summary: Teaching procedures based on Skinner's analysis of verbal behavior have been developed to increase vocalizations in previously nonverbal children, but studies on the efficacy of these procedures have yielded inconclusive findings. Several small studies support the use of Verbal Behavior procedures to teach mands (verbally, through sign language, or with picture symbols); however, the preference for sign language over other augmentative and alternative communication systems such as PECS is not supported by research (Tincani, 2004). Whether Verbal Behavior procedures are a new development within the broader field of ABA, or simply a new name for tools and strategies that have historically been present in the field, is a matter of some debate and controversy. In any case, although some evidence supports teaching procedures based on Skinner's conceptual analysis of language, much more research is needed to evaluate overall outcomes that might be achieved from a comprehensive Verbal Behavior curriculum.

Recommendations: Teaching procedures derived from Skinner's analysis of verbal behavior may be effective for teaching some communication skills to children with autism. Additional research, however, is greatly needed to test whether these procedures are effective for teaching complex, flexible, and generalized verbal repertoires to individuals with autism. Additional research is also needed to determine the differences, if any, between teaching procedures based on Skinner's analysis of verbal behavior (e.g., mand training) and already established teaching procedures (e.g., incidental teaching). Research is also needed to test the effectiveness of the comprehensive use of curricula based on Skinner's analysis of verbal behavior.

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Adventures in Driving by Lora Perry, Executive Director, ABA Services, Providence of Maine

There's nothing like teaching your adolescent to drive to make you a better driver (at least according to the Department of Motor Vehicles' standards.) It's amazing what we, as "seasoned" experienced drivers, forget or fail to do. For example, have you noticed how far away the white stop line and stop sign are from a reasonable location to actually stop and evaluate vehicle and pedestrian traffic? The instructor at Advantage Driving School taught my son, Jason, to come to a full stop, or a "stop, bobble." (She defined "bobble" as the momentum still in force when the car stops while your body keeps moving before bouncing gently back.) After coming to a stop bobble she instructed Jason to "count one, two. Then creep." Seasoned drivers learn that it isn't until one "creeps" that he can actually see what's going on and make informed safety judgments. Who stops way back at the stop line? (Answer: people who don't want to flunk the on-the-road test.)



Then there are the secondary road speed limits. If you respond promptly to secondary road speed limits in most cases, you are causing a major hazard. Who actually slows from 45 miles per hour to 35 mph, right where the signs are? Seasoned drivers "go with the flow," easing into the speed limit over a smooth and controlled period of time. Those who slow abruptly risk being rear-ended. Most of us seasoned drivers can do several things at the same time. We can keep some car momentum up while concurrently scanning over our shoulder, yielding (Yield: Let the other guy go first, if there is another guy) and then merging with the privileged drivers that don't have to worry about yielding.

In fact, we seasoned drivers can talk on the cell, adjust the radio, scan the Garmin and drink Five Hour Energy at the same time. Adolescent, student drivers, not so much; especially an adolescent who has an autism spectrum

disorder (ASD). This, I can attest to as the mother of not one, but two of them. They happen to be fraternal twins, and they became the first two clients of Providence of Maine when Jason and Joshua were seven years old. Jason, now 17, earned his Learner's Permit in July, and well, life hasn't been the same since. I don't have typically developing kids, but I do recall learning to drive. My experience, while not effortless, was nothing like Jason's. My friends and I joked "Red means stop, green means go, and yellow means floor it."

Kids with autism can be very concrete thinkers. For example, when Jason came back from his interview at Bowdoin College for an internship as a chef last week, we had this exchange:

"Jay! How did it go?"
"Great!"
"What did they say?"
"Questions."

Or, when I see Jason after school, I'll ask "So, what did you do in Culinary today?"

He says, "A recipe."

Very literal thinkers, kids with ASDs can be. So when the speed limit sign says 35 mph after a 45 mph section, Jason is quick to comply.

Another interesting thing I've learned with Jason is how much of driving depends on non-verbal communication and environmental subtlety. Think about it: there's the head math we do at a four-way intersection about who got there first, second, or third, and therefore in what order everyone is "entitled" to go. First In/First Out. If a driver violates that etiquette, the 7th grader still deep within us mutters "You cut!"

Sometimes it's not clear who got there first or second. When this is the case seasoned drivers rely upon eye contact, a smile, and a beneficent wave. "You go." "No, you go. I insist." "Ok, thank you. Hope you have a fabulous day!" At least that's how it's done in Maine. Jason has had to practice the fine motor skills associated with "the wave" and learn when to do it. The thing about teaching an adolescent with ASD to drive is you need to teach nearly everything. We helped Jay get his learner's permit as soon as he was eligible because we plan to do a ton of driving with him to have that teaching time. (Another Fun Driving Fact: In Maine a Learner can remain on his permit for 18 months, and you can file for an extension. According to GEICO, our auto insurance won't go up until Jason gets his full license or into an accident,

Learning to Drive continued...

whichever comes first.) Jason's pretty good at staying between the lines ("No honey, not the two yellow lines, the yellow line and the white line"), and rather artful at finding all the safe places in Midcoast Maine to pull over and let everyone else by so he can follow each and every speed limit sign and stop just before all the stop lines without inciting too much road rage from the seasoned drivers. Two weeks ago a pick-up truck pulled out of the Dairy Queen to cross Jason's path, which in itself was not unusual. What was unusual for Jay—his first time—is the pick-up had a trailer behind it. That required a whole other level of judgment, timing, and evasive action.

Despite his driving quirks, there are some things Jason can do like no one I've ever seen. He can focus. He's in the car to learn to drive safely, and learn to drive safely is what he will do. As near as I can tell, there isn't a lot of funny stuff going on in his head about all the "silly rules" and what he'll do with the car the first time he's in it without his mother or father. Jason is also what we call a "mapper." He's always been one. Take Jason anywhere, and he will memorize the road signs and the streets, and be able to find his way from point A to point B without fail. He just has a "sense" about direction; and, near as we can tell, almost a photographic memory.

It is that near-photographic memory, combined with Jason's kinesthetic learning style, that are our most powerful tools in teaching Jason to be a safe driver. Once he learns it, whatever "it" is, he owns it. He's good at it. He doesn't look back. You should try his Corn and Cashew Nut Curry.

As the parents of two kids with autism who are now (be still, my heart) young adults, my husband, Steve, and I are committed to doing everything we can to help them be as independent and self sufficient as possible, just like all you other parents out there! Our journey is just a little less conventional.

Starting with this issue of *Science in Autism Treatment*, we would like to recognize individuals and organizations who have gone the extra mile to share information about ASAT and its resources. In the last few months, there have been a few noteworthy examples.

Specifically, we would like to thank....

- Audrey Meissner and the New Haven Learning Centre for including a brief overview of ASAT and a link to our website in their January newsletter which reaches 1,100 subscribers in the Toronto area. [Click Here to view](#)
- Paul McDonnell for sharing a slide show about ASAT when discussing science-based, early intervention with government officials in Saskatoon in March 2011. This included representatives of the Department of Health for Saskatchewan, Department of Education, the University of Saskatchewan, the University of Regina, the Community Colleges, and the Saskatchewan Institute of Applied Science and Technology. Several parents involved in an array of groups such as Autism Today were also in attendance.
- Debra Berry Malmberg from CSUN for recommending ASAT as a resource on the CSUN Common Reading Program [Click Here to view](#)
- Vicki Knapp and NYSABA for sharing information about ASAT with their membership through email and their Facebook page.
- The John Hopkins University School of Medicine, Kennedy Fellows Association, and Kennedy Krieger Institute for allowing us to provide ASAT brochures and other materials at the Spectrum of Developmental Disabilities XXXIII: "Autism: School Age and Beyond" course, held March 28-30, 2011. [Click Here to view](#)
- The American Academy of Pediatrics and the National Center for Medical Home Implementation for providing a brief description and link to ASAT on their website. [Click here to View](#)
- Denise Grosberg for organizing a fundraiser on behalf of ASAT at the Yogurtland in Pasadena, California.

If you would like to share information about any initiatives you have undertaken to support ASAT, please write us at publicity@asatonline.org

Shout Outs, Accolades, and Appreciation!

By Kerry Ann Conde, M.S., BCBA



**Clinical Corner: Working with 18-month olds
I am a behavior analyst working with an 18-month old recently diagnosed with autism. Do you have any suggestions on how to work with such a young client?**

Answered by Peggy Halliday, M.Ed., BCBA, Virginia Institute of Autism and Tristram Smith, Ph.D., University of Rochester Medical Center

By now most of us have become familiar with the importance of early intervention because of the favorable results of outcome studies and efforts to promote awareness, such as the CDC Act Early Campaign (“Learn the signs. Act early.”). It is therefore both exciting and challenging to be given the opportunity to work with a very young child who has been given an autism diagnosis, or labeled “at risk” for an Autism Spectrum Disorder. The excitement comes from the expectation that we can be particularly effective by starting early. The challenges lie in working with a child who is in many ways still an infant with an infant’s unique needs.

Research on intervention for toddlers with autism is still at a somewhat early stage, but two comprehensive interventions have shown promise: early intensive behavioral intervention (EIBI) and the Early Start Denver Model (ESDM). EIBI was originally designed for slightly older children (beginning at two to three years old). However, it has been implemented successfully with a younger age group by making some adjustments that take into account the child’s developmental level.

Early Start Denver Model was developed for toddler-aged children, but is still new, having been tested carefully at only two research sites. ESDM is an "eclectic" autism intervention that combines ABA-based with non-ABA-based approaches. The manual specifies that ESDM "has clear ties" to ABA approaches such as Pivotal Response Training (PRT), incidental teaching, and milieu teaching. Other approaches are described as “developmental,” meaning that the focus is on providing intervention in the context of social interactions that are similar to those in which most other children first learn to interact and communicate. Descriptions of ESDM emphasize that in this model a wide range of intervention approaches is constantly available to children. We eagerly await further replication of this intervention and future research to help us understand its most effective elements.

Regardless of the age of the client, it makes sense to rely on the same tactics needed to create any good behavioral program (e.g., Fovel, 2002). First, it is necessary to assess a baseline of skills across the full array of domains such as social interaction, play, communication, and self-help skills. This will enable you to specify appropriate goals and corresponding curriculum. From there you can develop

I will be taking the reins of Clinical Corner coordinator from Lori Bechner who has served in this role for the past two years, and on behalf of David, Josh, and the rest of the ASAT Board of Directors, we extend our thanks for her contributions to SIAT.

In this installment of Clinical Corner, we address two important topics related to educating learners with autism – developing effective early intervention programs and preparing students for group instruction. The positive outcomes associated with behaviorally-based early intervention services has led to more families seeking intervention for their newly diagnosed children. In the first response, Peggy Halliday and Dr. Tristram Smith offer helpful suggestions for how best to design and implement age-appropriate goals and programs for toddlers receiving these services. Our second Clinical Corner response on page 12 focuses on preparing learners with autism for inclusion, more specifically, to transition from one-to-one instruction to group-based instruction. In her response, Renita Paranjape recommends strategies for teachers to implement to help ease this transition for their students and also to create a successful group learning environment for everyone. **Nicole Pearson, M.A.**

teaching strategies that will give the child frequent learning opportunities and will promote the generalization of skills across situations and people. And last, you will want to continuously evaluate progress. A good program is committed to collecting objective data, analyzing it and using it to make data-based decisions.

As with any other child, it is good practice to begin by administering an assessment to determine the child’s baseline skills and deficits. One assessment tool that is often used in ABA intervention programs is the Verbal Behavior Milestones Assessment and Placement Program (VB-MAPP) because it contains measurable milestones balanced across multiple skill areas such as social behavior and play, motor imitation, and spontaneous vocal behavior. It divides skills across three developmental ages, 0-18 months, 18-30 months, and 30-48 months. This is helpful in setting reasonable, age-appropriate goals. Once you have set the goals, you will be ready to create age-appropriate programs based on both discrete trial instruction and incidental, naturalistic teaching. Most authorities recommend that the child is offered enough teaching time to have frequent learning opportunities (20-25 hours a week, not 40, as in some ABA programs for older children, given the child’s young age).

Parent participation and support is especially critical when working with a toddler. Parents may be reeling from the shock of the diagnosis and are also often frustrated because they may be uncertain about how to play with their child. A typically developing infant teaches her parents how to play with her by reinforcing their behavior. For example, a mom says “Peek a boo!” to her infant and the baby smiles and giggles, so the mom does it again. A baby on the autism spectrum may not have the same interest in social interactions and sometimes parents give up this type of play when their child continues to be unresponsive. In addition, the toddler may show frustration at his inability to communicate well (not at all unusual for any 1 ½ to 2-

(Continued on page 8)

Clinical Corner continued...

year old, hence the nickname “terrible twos” for tantrum prone 2-year olds). Parents, in their desire to make their child happy, may, with the best of intentions, fall into a pattern of inadvertently reinforcing the child’s tantrums by giving their toddler whatever pacifies her.

A high priority, then, when beginning to work with a young child, is to help the child learn a functional way to communicate, whether by pointing, signing, handing a picture, or making a verbal approximation. Teaching parents and caregivers not to give in to the tantrum but rather to respond only to appropriate communication, is critical. At the same time, it can be enjoyable to teach parents how to relax and have fun with their toddlers through play. Parents and interventionists become partners in discovering ways to gain the child’s attention, and then make the most of it. Working together to find out what the child likes, and using those activities and objects in creative ways will enable you to teach the skills you have identified in your goals.

Another important priority is for parents to speak to the toddler in ways commensurate with his or her level of receptive language. Succinct statements made in context and repeated across similar situations to promote predictability may go a long way in advancing comprehension.

Adaptations for the child’s young age in ABA programs include scheduling around naps, and postponing instruction on pre-academic skills such as counting. Specific teaching depends, of course, on a particular child’s baseline functioning. Early learning skills which are the building blocks for more advanced skills may include such tasks as requesting, simple labeling, responding when name is called, simple direction following, exploring toys, motor imitation, and vocal behavior. Working on interaction and play skills in order to develop social relationships is essential. Reinforcement is one of the most critical elements of therapy. A goal is for the child to be having so much fun that he has no idea how hard he is working. This means short periods of work are interspersed with short periods of reinforcement. Reinforcement can come in many forms such as movement like bouncing or swinging, playing with bubbles, singing a song, or silly things like pretending to sneeze. Incidental teaching should incorporate the practice of embedding instruction on target skills into preferred activities all throughout the day. Doing the same preferred activity over and over for just enough of a reward to be reinforcing is a great way to get in lots of practice. For ex-

ample, a child who loves to swing may sit in the swing and say “Go!” in order for the swing to be let go. The child may practice “Go!” 15 times before losing interest in the swing.

When people think of early intensive ABA, they often get an image of a child sitting at a table doing “drills.” While some seatwork may be helpful even for toddlers, sitting on the floor, playing in beanbags, on swings, outside on the grass, taking walks and exploring, and crawling through “forts” should also be part of the picture. Other activities might include performing finger plays to “Itsy Bitsy Spider” or filling in the last word to a line of a nursery rhyme. If the child is fortunate enough to have older or same-age siblings or close neighbors, you might borrow them for part of every session. While toddlers are too young to be expected to play elaborate make-believe games together, they often enjoy activities such as playing alongside each other and imitating each other’s actions. Also, older siblings and neighbors can demonstrate play and communication skills. They can be excellent teachers! As with teaching older clients, you will rely on the data to help you evaluate the program. If the data tell you something isn’t working, try something else. Starting early gives you the time to really get to know your young clients and learn and grow with them.

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Letter from Josh Pritchard, M.S., BCBA

Hello SIAT Subscribers! As you will see, our Spring issue is packed to the brim with content! Although this is a good thing, it necessitates a short letter on my part. This may also be a good thing for the reader. I have contributed to and edited an array of newsletters and publications and this is the first one written entirely by volunteers with which I have had to work so hard to keep it *below* page length. As a co-editor, I must confess – this is a great problem to have. It means we have a lot to share with our readers!

I am extremely grateful for all of the people who contribute to Science in Autism Treatment. David and I feel that all of our hard work is worthwhile knowing that we have a strong team working alongside us. As you know, I typically talk about international travels, and how autism is impacted in other countries, but today, I'm trying to keep it short – so I just want to talk a little bit about our future, and then let you dig into the great pieces found in this issue.



Recently, ASAT's board has evaluated what we can do to enhance our service to the science of autism treatment through our newsletter. Specifically, we believe it is imperative that we include *more* information about autism treatment for older consumers. We are committed to making sure this occurs for all future issues of Science in Autism Treatment, and invite you to support this by sharing any questions or suggestions you may have about this topic. Our goal is to ensure that Consumer Corner, Clinical Corner, and all other features of our newsletter address lifespan topics. In fact, you should notice this commitment has taken effect in this issue with Lora Perry's article about teaching her son to drive, Jennifer Hieminga's review of the Alpine Learning Group's manual about supported employment and volunteerism, Denise Grosberg's review of the Organization of Autism Research's booklet: Life Journey through Autism, and Toni Anne Giunta's research review on Post-High School Service Use. This is just the beginning!

In David's letter, he makes the point that awareness of autism is a good goal, but support for science-based treatment is critical. As our population of children with autism ages, awareness and recognition of the needs of older consumers becomes important. Additionally, the scientific literature base for treatment and services from which they could best benefit becomes increasingly important. It is our goal to make sure that we provide information for science-based treatment for the entire range of those who are impacted by autism, including young and aging adults.

ASAT Committee Members

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

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Supported Employment & Supported Volunteerism Training Manual

Working in the Community: A Guide for Employers of Individuals with Autism Spectrum Disorders

Reviewed by Jennifer Hieminga, M.Ed, BCBA, New Haven Learning Centre for Children

As many of us who have worked with adults with autism know, it can be difficult to engage and encourage local businesses to provide supported employment or supported volunteerism opportunities for our adults. The Alpine Learning Group, with support from The Daniel Jordan Fiddle Foundation, has formulated a user-friendly, functional and detailed manual that will help professionals in the field of autism engage the employers in a way that will make the relationship between the employer and the employee more productive, effective, and meaningful.

This manual is designed to enhance the experience of employees with autism by educating their employers and co-workers at their job sites. It is also an excellent resource with which to approach potential employers in order to help them understand autism and to inform them of what they may expect if they decide to employ a person with autism spectrum disorders. It is written in user-friendly, simplistic terms, making it easy for a person who has little or no prior background in autism or applied behavior analysis to grasp the content.

The manual highlights important facts about autism and common challenges that many individuals with autism encounter. The four main areas of difficulty listed include:

- Communication challenges (e.g., employee may use alternative forms of communication such as pictures)
- Receptive language difficulties (e.g., employee may require simple direction)
- Social skills deficits (e.g., employee may not initiate a greeting or provide eye contact)
- Potential challenging behaviors (e.g., due to difficulty communicating the employee may express themselves in other less appropriate ways).

Worth noting is the authors' use of specific examples related to the work environment, clearly illustrating what it is like to work with a person with autism.

To highlight how an individual with autism learns best, a brief description of Learning Theory (i.e., Antecedent, Behaviour, Consequences), as well as strategies such as prompting, prompt fading and task analyses, are provided. In addition, the employer is made aware of common

As you have noted throughout this issue, SIAT has increased its efforts to address adult issues. Of particular concern to many individuals with autism and their caregivers is the transition from adolescence to adulthood and the individual's integration into new, adult settings. The transition to adulthood, and more specifically, to vocational settings, can understandably stir up apprehension for individuals with autism and their caregivers. To share resources that may help ease concern, Denise Grosberg has written a review of The Organization for Autism Research's booklet, *Life Journey Through Autism: A Guide for Transition to Adulthood*, and Jennifer Hieminga has reviewed the Alpine Learning Group's manual, *Supported Employment & Supported Volunteerism Training Manual Working in the Community: A Guide for Employers of Individuals with Autism Spectrum Disorders*.

Kate Fiske Massey, Ph.D., BCBA-D



strategies that can be used to enhance job performance such as picture and textual schedules, the use of reinforcement systems, data collection, natural supports and extra practice outside of the work setting. It is noted that these strategies can be implemented with the use of a job coach. Further detail regarding the role of a job coach is provided (e.g., they act as a shadow, identify and implement teaching strategies), assuring the employer that their role will be to help successfully integrate their new employee into the workplace, as well as to help co-workers interact with and understand individuals with autism.

Jobs well suited for individuals with autism, such as those which are consistent, repetitive, do not require a lot of social interaction, and those which involve more visual components (e.g., matching, filing, sorting), are noted in this manual. This information enables the employer to better understand, and, in turn, better match jobs to the person with autism's needs, strengths and preferences—a process referred to as “job carving.”

The manual provides practical strategies to promote positive interactions between employees with autism and their co-workers by answering commonly-asked questions, such as:

- How to interact with their colleague
- What to do if their colleague makes an error
- What to do if their colleague exhibits maladaptive behavior
- How to provide praise and encouragement

The manual can be downloaded by going to Alpine Learning Group's website at www.alpinelearninggroup.org/resources/default.asp, or by contacting erichard@alpinelearninggroup.org.

Consumer Corner: Life Journey Through Autism: A Guide for Transition to Adulthood by Denise Grosberg, M.A., Claremont Graduate University

Significant life transitions are often greeted with both excitement and concern. For most caregivers of children and young adults with autism spectrum disorders (ASDs), periods of transition raise significant questions about the future. Increased levels of independence, choice, responsibility, and personal control are just a few of the new experiences individuals with autism face when they enter adulthood. Despite the fact that this can be quite a challenging time for young adults with autism and their families, learning about options, resources, and strategies can lead to a more successful transition to adulthood.

To aid caregivers in preparation for this important stage of development, The Organization for Autism Research (OAR) has published a booklet entitled, *Life Journey Through Autism: A Guide for Transition to Adulthood*. This guide provides an overview of the transition-to-adulthood process, with an emphasis on the following:

- The importance of early planning for adulthood. OAR recommends that this planning begin no later than when the child with autism is 16 years old and, in some instances, may begin as early as 14 years or younger.
- Establishing a knowledge base in the laws and policies that will influence the educational and vocational trajectory of adults with autism. The Guide provides a clear and practical outline of these policies.
- The creation of a transition plan through collaboration between the transitioning individual, their family and friends, interested community members, the schools' professional staff, and representatives from adult service systems in the transition to adulthood services. The Guide outlines key steps that can contribute to a successful, strengths-based approach to long-term transition planning, important questions for parents to think about in approaching the transition planning process, and characteristics of an effective transition plan.
- For some individuals with autism, the transition into adulthood may signal entry into the workforce or postsecondary education. Therefore, the Guide includes strategies and references that can help individuals with autism and their families make more informed employment and school placement decisions.

- Fostering community-based instruction in the development of life skills associated with a more independent adulthood. Examples of such skills include living arrangements, personal care, time management, finance management, hobbies and recreation, sexuality and relationships, daily living skills, and healthy habits.
- The importance of legal and financial planning for the future, including determining future guardianship, so that adults with autism are supported and cared for throughout their life. Although a difficult topic for many caregivers to consider, it is a crucial one that caregivers of individuals with autism must understand and prepare for.

Additionally, the guide lists a number of print resources, websites, and multimedia with which parents can gather additional in-depth information on content areas that are specific to their needs. Sample worksheets are included at the end of the Guide to help parents and individuals with autism identify goals for the future and make decisions regarding vocational, educational, and financial concerns.

Ultimately, the key themes communicated to parents in *Life Journey Through Autism: A Guide for Transition to Adulthood* are preparation and practice for the future. Caregivers can enhance the likelihood of successful transitions for individuals with autism by increasing their knowledge of available options and taking active steps in planning for the future. Caregivers should keep in mind that this guide is not intended to be used as a stand-alone reference tool, but rather to provide a candid snapshot of the variety of issues families need to consider and prepare for when their child reaches adolescence. The importance of recognizing that every child with autism will eventually become an adult and face specific challenges associated with that transition cannot be underestimated. Whether a parent has a child of 3 or 33, this guide is an essential reference tool that every caregiver of an individual with autism should have.

If you would like to download this guide from their website, please visit the OAR website at:

www.researchautism.org/resources/reading/index.asp



Clinical Corner: Educating for Inclusion

I am a special education teacher preparing students with autism for fuller inclusion. How can I set up my small groups to target skills that will serve my students well in the classroom?

Answered by Renita Paranjape, M.Ed., BCBA, Clinical Supervisor-School Support System, Kinark Child and Family Services

Preparing students for group instruction in inclusion classrooms requires careful consideration of the responses required in that setting as well as the strengths and needs of the child with autism. What follows are some considerations that may ease the transition of students from one-to-one instruction to group-based instruction within inclusion classrooms.

Investigate the next setting

Take time to visit and observe group instruction in the inclusion classroom. There are a few questions to keep in mind when observing the inclusion setting, including:

- What is the content of the group instruction?
- How large are the groups?
- How does the teacher engage the students (e.g., visual stimuli, choral responding)?
- How long are the group activities?
- How often are students required to respond during group?
- Are there reinforcement systems in place within the group lessons?
- What are the teacher's general behavioural and learning expectations of the students during group instruction?

Once you have a clear idea of what transpires during group instruction, attempt to replicate, as closely as possible, the activities observed in the inclusion environment during small-group lessons.

Setting up the group

Here are some pointers for setting up group instruction:

1. Group children according to their skill level so that those who require skill building in more foundational skills are grouped together, while the students with more advanced skills are placed together.
2. Alternatively, you may want to consider mixing students by skill level, so that students with more advanced skills can serve as a model for students who require models of responses during the lesson.
3. All students should have a clear view of the teacher

- and the instructional material, with distracting items kept to a minimum.
4. One adult should be the "teacher," delivering all instructions in front of the group and providing the reinforcers to the students.
 5. Position other adults behind the group to serve as "prompters" of responses. These adults should stand, not sit, behind the students, fading their proximity to the students as independence increases. These adults should only prompt if necessary, and the students should be expected to follow the instructions provided by the teacher who is leading the group.
 6. Have available the student's individualized motivation system in view of the student. The teacher leading the lesson should provide the reinforcers to the students based on the student's individualized program.
 7. The other adult or "prompter" can also record data on the responses of the learners during group instruction.
 8. The teacher of the group and the prompters should communicate regularly before and after the group lessons to identify roles and student goals. Discussion should not occur during the lesson.

Readiness skills for small group instruction

The following are a few examples of what learners may benefit from in order to participate in group instruction, but they are not necessarily prerequisites. Some of these goals require group instruction in order for the goals to be taught, whereas other goals can be introduced in smaller groups or in one-to-one instruction.

1. **Attending to the teacher with peers present.** In most ABA programs, attending is one of the first foundational skills that is taught. This is accomplished either by teaching students to provide eye contact or teaching them to orient toward the communicative partner. Once this skill is established, the next step for group instruction would be to teach attending even when there are peers present and when the teacher is standing and moving around the classroom.
2. **Tolerating the presence of peers.** Since small-group instruction requires the presence of other students, it is important to assess whether the student can sit alongside a peer without being distracted.

(Continued on page 13)

Clinical Corner continued...

3. **Sitting for longer periods of time without frequent breaks.** Group instruction will require the student to sit for longer periods of time. Collect baseline data on how long the student will sit appropriately before accessing a reinforcer; then systematically increase that time so that the student can sit for longer periods of time to earn access to a bigger reinforcer (e.g., recess).
4. **Remaining on task for longer periods of time.** This may seem similar to number 3 above, but it is not only important to consider *how long* your students can sit appropriately, but also *how long your students will work efficiently* before becoming off task and or requiring breaks. In small group settings, students are typically required to complete independent seat work for upwards of 15 minutes or more. As a readiness skill, assess how long your students can remain on task and systematically increase how long they are required to work independently.
5. **Preparing the student for thinner schedules of reinforcement.** Consider your students' current schedule of reinforcement and develop a plan to thin that schedule. This would apply primarily to appropriate behaviour, such as attending and sitting appropriately, as correct responses in group would likely be reinforced on a continuous schedule initially.
6. **Responding to name and following distal instructions.** Can your students respond to their names from varying distances and in different contexts? Can they follow directions given from afar? In addition to being able respond to their name in a classroom setting, students must also learn to *not* respond in certain situations. Distinguishing between, and responding to, instructions such as "everybody," "[student's name]" and "[other student's name]" are key foundational skills for small-group instruction.
7. **Following complex instructions.** Your students should not only be able to complete one-step directions (e.g., "Get a pencil"), and two-step directions ("Get a pencil and write your name"), but they should also be taught to follow even more complex directions (e.g., "Get a pencil, turn to page 5 of your workbook, and write your name at the top").
8. **Waiting for attention and instructions.** When a student makes the transition from one-to-one instruction to a group setting, the teacher's focus is no longer solely on one student, but he or she is balancing his/her attention from one student to another. It is important to teach the student how to occupy his or her time without engaging in stereotypic, or other challenging behaviour, as the teacher's attention is diverted.
9. **Hand raising.** Hand raising is a skill that requires attending, performing a gross motor action, inhibition of responding until cued by teacher, and discrimination of instructions. Initially, students can learn to raise their hands to access a preferred item with an embedded prompt in the instruction (e.g., "Raise your hand if you want candy!"). The instructions can then become increasingly more complex and students can learn to raise their hands to answer questions, to refrain from raising their hands when they are not able to answer a particular question, to request an item they might need for a task, and to volunteer to participate in an activity.
10. **Observational Learning.** One of the benefits of small-group instruction is the abundance of opportunities to learn appropriate responses by attending to the responses of other members of the group. Often times, students with autism need explicit instruction in attending to the responses of others, in differentiating whether those responses were appropriate based on teacher feedback, and in being able to repeat those correct responses when directed by the teacher.
11. **Choral Responding.** Another key response of small-group instruction is being able to say responses aloud and in unison with other students. For example, the teacher may say, "Everyone tell me what is two times two," and all of the students would be expected to say, "Four". This skill can first be introduced in one-to-one instruction.

Effective teaching strategies to include in small group instruction

The research in small-group instruction has identified specific strategies that have been found to be particularly effective for learners to acquire skills in a group setting (e.g., Heward & Wood, 1989; Kamps et. al, 1991).

1. **Creating many opportunities for learners to respond:** Given that the density of instructions will likely be less in a group situation than in a one-to-one teaching interaction, it is important to create as many opportunities as possible for your students to practice responding, and, in turn, acquire skills. Ensure that there are many instructions delivered for each student.

(Continued on page 14)

Clinical Corner continued...

2. **Frequent rotation of materials:** This is a necessary strategy to help alleviate boredom with the content of the curriculum; and it also helps to promote generalization of responding across various stimuli.
3. **Interspersing known targets with unknown targets:** This strategy creates a momentum for responding fluently, provides the opportunity for reinforcement to occur, and also ensures that mastered targets are maintained.
4. **Choral responding:** Having your students respond in unison is a useful strategy, and is important to target, because it occurs frequently in most general education settings. It is beneficial for learners, as it allows them to have more opportunities to respond, as well as allows them to be cued by their fellow classmates rather than their teacher.
5. **Random responding:** Random responding refers to presenting instructions in an unpredictable format so that students are not aware of when they might be called upon. This method can improve attention and motivation, as students will not be able to predict when it is their turn to respond.
6. **Repeating peer responses:** Requesting that students repeat the correct responses of their classmates can help further observational learning skills by requiring students to attend to and assimilate the responses of others.
7. **Student-to-student interaction:** Another effective teaching strategy is to promote interaction among students. Specifically, students can learn to listen and repeat each other's responses to general curriculum-related questions, ask peers to clarify if an instruction was missed, or ask peers for items needed for a task.

Small-group instruction can be a highly effective way to prepare students for less restrictive settings. With appropriate environmental manipulations, as well as effective teaching strategies, students who participate in group instruction can acquire skills needed for fuller inclusion.

For more information about effective strategies for teaching children with autism in small groups, please refer to the following articles:

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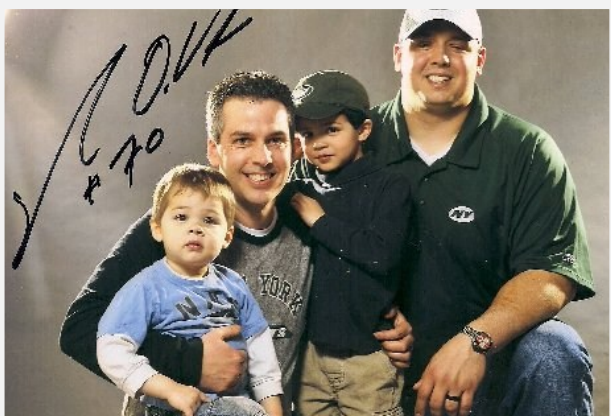
ASAT Scores a Touchdown with Rock'n 4 Autism Awareness Hoboken Benefit Concert By: Ruth Donlin, M.S. and David Celliberti, Ph.D., BCBA-D

Science in Autism Treatment

Last July, ASAT hosted its first Rock'n 4 Autism Awareness benefit concert in Lancaster, PA. The excitement of bringing families together in the community led David Celliberti (President of ASAT) to propose co-hosting a Rock'n 4 Autism Awareness concert in Hoboken, NJ with Hoboken-based, HOPES CAP, Inc., a Community Action Agency committed to providing services to the underserved.

Yvette Ypelaar, the Family & Community Partnership Manager, and John Tamasi, the Family & Community Partnership Specialist at HOPES Head Start/Early Childhood Program joined ASAT to build this event from the ground up, along with other key volunteers. It was a wonderful experience collaborating with a well-respected local organization to bring this event to fruition.

We were fortunate to have Jessie DeVito and her husband Mike DeVito from the New York Jets assist us and volunteer their time to this important event. Mike grew up



a die-hard Jets fan and the Jets picked him up as an undrafted free agent in 2007. Not a stranger to a little hard work, Mike has been voted Iron Jet by his teammates for the last 3 of his 4 years with the team.

Mike was also awarded the Kyle Clifton Award by the coaches for being the "good guy" on the team for 2010-2011 season. We can attest to both honors personally. Mike not only attended the entire event, but devoted at least two days to pound the pavement and help us solicit sponsorships for the event. For a defense guy he amassed a lot of yards in support of autism awareness. Mike also donated a signed football and jersey for the silent auction, and he generously agreed to take photographs with fans. Jessie was an integral part of our event planning team and was involved in all stages, working tirelessly to make this event the success it was! Thanks again Jessie and Mike!

Another highlight was a slide show about Karina and her family's journey since she was diagnosed with autism. Her parents Larry and Kathy provide monthly donation jars that benefit ASAT at their Dairy Queen stores in

Maine, and they drove down from Maine to attend this amazing concert event. They have been an inspiration to us and so many in their communities. When I asked Jessie Martin how Karina motivated her to get involved with ASAT, she said, "When Karina was brought home from Russia, she exhibited the typical behaviors of a child with autism. Years later, because of information available through ASAT and her family's commitment to science-based interventions, this little girl is thriving and growing. She is a brand new person. How could I not get involved with an organization that helped to change her life?"

This type of collaboration that reaches across states is a testament to the power in numbers. The event held on April 9th at the Rue School Gym in Hoboken included a variety of activities with something for everyone, with an emphasis on promoting autism education. Knowledgeable parents and professionals were available for questions, and they provided information bags about best practices to all families affected by autism. Dena Russell commented, "I was extremely happy to be a part of ASAT's Rock'n for Autism Awareness fundraiser! It was an amazing event - for

an amazing cause - put on by amazing individuals! As a mother of twin boys on the Autism Spectrum, I feel very lucky that ASAT is looking out for the best interest for our children



ASAT Scores a Touchdown continued...

by providing us with accurate information regarding the diagnosis and treatment of autism!"

So many people came together to bring this to fruition: Candice Stern, a graphic designer, donated her time and services to help us. Thanks to Balbo's and Pizza Republic for the delicious pizza, to Kings Supermarket for donating snacks and drinks and the wonderful Rita's Italian Ice . We were fortunate to have the Travelin' Tumblers and their great bouncy house. But without a doubt what kept the event "Rock'n " was the family-friendly rock band Fuzzy Lemons, who really made the event so exciting and fun. The kids had a blast dancing and singing to the catchy tunes and enthusiastic performance. The Fuzzy Lemons truly understand how to entertain children and families while sending positive messages to everyone.



Rock'n 4 Autism Awareness Hoboken brought two great organizations together, including the generous, valuable, and caring volunteers from both HOPES and ASAT! We had many people show up and just offer to help in any way they could. We greatly appreciate your donated time and effort; it was a terrific collaboration. The event was a great success. We raised over \$15,000 and had almost 300 attendees. We are grateful to the 83 local businesses that supported this event and to everyone else whose support made this event a success!

There are so many people to thank, that we had to devote an entire page to it (see [page 18](#) for all the volunteers and business sponsors). More information about the businesses that donated over \$200 can be found at www.facebook.com/R4AA.Hoboken.



All in all, it was a wonderful event and we are already planning for next year.

We raised over \$15,000 and had almost 300 attendees. We are grateful to the 83 local businesses that supported this event and to everyone else whose support made this event a success!



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Science in Autism Treatment

Volume 8, Winter 2011

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**“Volunteers don't get paid, not because they're worthless,
but because they're priceless.”**

~Sherry Anderson

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We were grateful to have State Farm's Good NeighBear visit our event and bring joy to so many!



DQ's Autism Information Table with ASAT poster.



From Brrrr to Grrrr, ASAT is supported by local community businesses



For customers who make a donation to ASAT, DQ owners Kathy and Larry Hannon offer their customers sizeable coupons!



ASAT's customized donation jars prominently displayed with ASAT business cards.



Yogurtland raises money for ASAT with donation jars at their Pasadena, CA location!

Support the Association for Science in Autism Treatment by purchasing the “Acoustic for Autism” CD, of which ASAT is one of the beneficiaries along with other science-based autism organizations. Acoustic for Autism is a collaboration between childhood friends Louis Gendron and Michael Cusanelli. After 20 years, Louis and Michael reconnected and discovered the many things they still had in common, including careers in the entertainment industry, a continued passion for music, and the way autism had touched both of their families. Acoustic for Autism features compelling, independent music specifically chosen to convey themes of love, compassion, hope and healing. The goal of Acoustic for Autism is to increase awareness, acceptance, and understanding for those with autism and to help raise funds for organizations that are making a direct, positive impact for families and their children today.



Purchase your CD today: <http://acousticforautism.org/about/>

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ASAT

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

Media Watch Update by Barbara Jamison, ASAT Board Member and MW Lead

The media is often one of the first points of contact that the public consumers have with autism treatment. Unfortunately, it has not always been a great resource to get the best treatment. In fact, the media are often motivated by news stories that are likely to be sensational. Science is rarely sensational, it tends to move too slowly and tediously for the media. While this is good for those receiving the treatment, it does not help those who are trying to find out about treatment options.

Below are just samples of the most recent Media Watch responses to both accurate and inaccurate portrayals of autism intervention in the media (Click dates to read full replies):

ASAT Responds to Fort Worth Star-Telegram's "Applied Behavior Analysis Is Autism Treatment of Choice" ([December 10, 2010](#))

What the experts say about the preferred treatment for autism is no surprise to us. But why is ABA considered to be the "treatment of choice?" ASAT explains in response to Fort Worth Star-Telegram's recent article

ASAT Responds to Contra Costa Times Story "Swinging the Outcome" ([December 28, 2010](#))

Journalist Melanie Sacks claims that there is "research" behind swing therapy, but ASAT points out that none exists for this purported treatment, and further clarifies the detriment to families misled by false promises of non science-based intervention.

ASAT Responds to Star-Ledger Article "Apple iPad, iPod Touch Might Help People with Autism Take Steps toward Independence" ([January 19, 2011](#))

An important goal for individuals with autism is independence. Now, popular technology may be instrumental in helping to achieve this goal.

ASAT Responds to ASAT Responds to Globe and Mail's "Medical Fraud Revealed in Discredited Vaccine-Autism Study" ([January 25, 2011](#))

The scientific evidence is in; the posited vaccine-autism link has been refuted. Andrew Wakefield not only practiced "junk science," but also perpetrated a cruel fraud on his victims: children and parents. ASAT applauds Andre Picard for "Medical fraud revealed in discredited vaccine-autism study."

ASAT Responds to ASAT Responds to Salon.com's "Correcting Our Record" ([February 23, 2011](#))

Dead wrong: Salon.com's 2005 "Deadly Immunity" article, which claimed a relationship between a vaccine preservative and the incidence of autism. But Salon's Editor-in-Chief Kerry Lauerman now does the right thing by admitting to the error and publishing a correction.

ASAT Responds to ASAT Responds to Chicago Tribune's "When the Evidence Is Conclusive" ([February 27, 2011](#))

Topping the "Suggested Reading" list: "Deadly Choices" by Paul Offit. Tribune journalist Trine Tsouderos reviews recent books by Offit and Seth Mnookin, once again bringing a clear perspective to the vaccine issue. ASAT gives a "thumbs up" to the Tribune in their response.

ASAT Responds to ASAT Responds to NIU's "Science or Bunk: How to Tell the Difference" ([March 28, 2011](#))

Learn what NIU's Physics Department professor Suzanne Willis has to say about the seven warning signs of bogus science. ASAT responds to "Science or Bunk: How to tell the difference."

ASAT Responds to ASAT Responds to Mansfield Journal's "Shelby Coach Steps Down to Help Son Battle Autism" ([March 30, 2011](#))

A father's quest to help his son with autism leads him to DAN doctors and the Son-Rise program; however, he dismisses Applied Behavior Analysis as "Pavlovian." ASAT reveals the lack of science behind these alternative therapies and answers the claim against ABA.

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



Research Review: Post-High School Service Use Among Young Adults With an Autism Spectrum Disorder

Shattuck, P. T., Wagner, M., Narendorf, S., Sterzing, P., & Hensley, M. (2011). Post-high school service use among young adults with an autism spectrum disorder. *Archives of Pediatrics and Adolescent Medicine*, 165(2), 141-146.

Reviewed by: ToniAnne Giunta, Caldwell College

These articles summaries are on very different topics, but all equally important. The first summary describes a survey indicating a major decline in services for young adults with an Autism Spectrum Disorder (ASD) post-high school. The second evaluated the effectiveness of three interventions used with individuals with autism, applied behavior analysis (ABA), which is aimed to improve socially important behavior by using interventions based on the principles of learning, Treatment and Education and Autistic and related Communication-handicapped Children (TEACCH), which is designed to accommodate learning styles through visual cues and distraction-free work stations, and the Denver Model which emphasizes social communication during playful interactions. The third summary is an analysis of 13 studies comparing outcomes of those who received Early Intensive Behavioral Intervention (EIBI) to those who did not. **Sharon A. Reeve, Ph.D., BCBA-D, SIAT Research Corner Coordinator**

Why review this topic?

With the prevalence of autism increasing, policy makers are working to improve services for children with autism spectrum disorders (ASD), including education of early warning signs and covering the cost for early intervention. There has been little effort, however, in planning for supports as children transition into adulthood. Special education enrollment of adolescent children with ASDs, aged 12 to 17 years, has increased from 15,480 in 1998 to 99,803 in 2007. The National Institute of Mental Health reported that availability of special education services is usually terminated at the conclusion of high school. Nationally representative data on prevalence and characteristics associated with services for young adults with ASDs are lacking. Such information is needed for several reasons: (a) to improve current services, (b) to improve access to services, (c) to recognize underserved populations, and (d) to help clinicians and family members better prepare adolescents with ASDs for adulthood.

What did the researchers do?

The researchers attempted to produce a nationally representative estimate of rates of services (i.e., psychological or mental health services/counseling, medical evaluation and assessment, speech or language therapy/communication services, case management) in young adults with ASDs during the years after high school. Characteristics that were associated with services were also examined. Data were retrieved from the National Longitudinal Transition Study 2 (NLTS2), conducted by SRI International for the US Department of Education. 920 young adults with an ASD enrolled in special education settings participated in NLTS2, with a subset of 410 young adults examined in the present study. The young adults' parents/guardians were surveyed via a computer-assisted telephone interview, in which questions were asked about their children receiving any of the aforementioned services. Other characteristics examined in the survey included need and severity indicators, socioeconomic status, ethnicity and race, diagnosis of attention-deficit/hyperactivity disorder, and a functional mental skills scale (an example of a functional mental skill could be how well the youth tells times without help).

What did the researchers find?

For the 410 young adults in the years following high school, 35.0% received mental health services, 23.5% received medical services, 9.1% received speech therapy, and 41.9% received case management. In contrast, NLTS2 results reported that in adolescents still in high school, 46.2% have mental health services, 46.9% have medical services, 74.6% have speech therapy, and 63.6% have a case manager. Approximately 39.1% of exiting high school students did not receive any services. The odds of not receiving any services were 3.31 times higher in African American young adults and 5.96 times higher in families with incomes of \$25,000 or less, compared to Caucasian young

adults and families with incomes greater than \$75,000, respectively. No case management was 5.88 times higher in families with incomes of \$25,000 or less, compared to families with incomes greater than \$75,000. Those with higher functional mental statuses had higher odds of no services and lower odds of case management and medical services. Need indicators and presence of attention-deficit/hyperactivity disorder did not correlate with the outcomes.

What are the strengths and limitations of the study?

It is expected that the number of adolescents with ASD transitioning into adulthood will increase in the future. Further research on improved services for these individuals is needed, and the present study provided an important first step in achieving this goal. The size and diversity of the group of individuals being assessed was representative of the national population, making the findings highly generalizable. This representative group made it possible to examine variables based on demographic factors (e.g., race, socioeconomic status). The data presented also represent the most recent findings in young adults with ASDs. The findings, however, have some limitations. Only students enrolled in the special education autism category as per the Individuals with Disabilities Education Act were examined. Students did not have to have an autism diagnosis as per the *Diagnostic and Statistical Manual of Mental Disorders* (Fourth Edition) to participate in the research. Epidemiological research, however, has found that 99% of children in the autism special education category also meet the *DSM-IV* criteria. Additionally, policy-making differs from state to state, and the study did not take location into consideration. Perhaps the greatest limitation was the use of self-report as the data collection procedure. Such subjective reporting measures, which rely mainly on respondents' personal knowledge and recollection, may lead to inaccurate prevalence estimates. Direct examination of the youths' functional levels and services would have yielded more accurate information. Finally, the list of services examined was not inclusive of all possible services that could have been in use at the time of the survey (e.g., applied behavior analysis services or other type of educational/vocational services).

What do the results mean?

According to these results there is a decline in services (i.e., mental health services, medical evaluation and assessment, speech therapy, case management) in exiting high school students with autism spectrum disorders. Additionally, there is a need to examine patterns of service disengagement in regards to race and socioeconomic status. The researchers point out that access barriers, service delivery models, and policies to promote access must be examined in these underserved populations, and it is recommended that this can be done via revisions of the Interagency Autism Coordinating Committee.

Research Review: Outcome of Comprehensive Psycho-educational Interventions for Young Children with Autism

Eikeseth, S. (2009). Outcome of comprehensive psycho-educational interventions for young children with autism. *Research in Developmental Disabilities, 30 (1)*, 158-178. Reviewed by Kathleen Moran

Why study this topic?

With the causes of autism currently unknown, psycho-educational treatments are the primary interventions for individuals with autism. However, while many psycho-educational interventions have become popular, systematic evaluations are needed to determine the extent to which they have scientific support.

What did the researchers do?

The researchers in this study conducted a search of the scientific literature to find articles evaluating comprehensive psycho-educational interventions in children under the age of six. Twenty-six studies were reviewed and rated according to their scientific strength as well as the significance of the results that were seen in the individual studies. Twenty-one of the studies evaluated applied behavior analytic (ABA) treatment; 3 studies evaluated TEACCH and 2 studies evaluated the Denver Model developed at the Colorado Health Sciences Project. ABA treatments aim to improve socially important behavior by using interventions that are based upon principles of learning theory and that have been evaluated in experiments. TEACCH ((Treatment and Education of Autistic and related Communication-handicapped Children) is

designed to accommodate the learning styles characteristic of children with autism through strategies such as presenting visual cues and setting up distraction-free work stations. The Denver Model is a developmental therapy that emphasizes promoting social communication during ongoing playful interactions between a therapist or parent and a child with autism. The quality of the science was broken down into 4 levels based on scientific rigor, from Level 1 (strong research design with random assignment of participants to a treatment group and a control group, monitoring of the quality of treatment, and comprehensive outcome assessments) to Insufficient Scientific Value (studies with significant scientific flaws, such as not using a comparison or control group). The magnitude of improvements was also broken down into 4 levels, with Level 1 referring to studies that showed significant differences between the treatment group and control group in both IQ and adaptive functioning, and Level 4 studies observing improvements only between pre and post intervention.

What did the researchers find?

While only 1 of the twenty-six studies achieved a scientific quality score of 1, and only 4 others

achieved a rating of 2, all 5 of these studies were on ABA interventions. Additionally, ABA studies received all four Level 1 scores for the significance of results, as well as three of the studies receiving Level 2 ratings. This indicates that children receiving ABA improved significantly in IQ, adaptive functioning, and language skills, as compared to the control groups in their respective studies. It can also be noted that studies on TEACCH and the Denver model only achieved Levels 3 or ISV in this review with regard to scientific quality. Based on these results, the author classified ABA as a “well established” intervention, according to guidelines set forth by Chambliss and colleagues. The TEACCH approach and the Colorado Health Science model did not meet criteria as “well established” or “probably efficacious” by these same standards.

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

The author concluded that ABA can be considered an effective psycho-educational intervention for children with autism spectrum disorders. He highlighted a need for additional high quality empirical research on other treatments and outcomes.

Research Review: Comprehensive Synthesis of Early Intensive Behavioral Interventions for Young Children with Autism Based on the UCLA Young Autism Project Model

Reichow, B., & Wolery, M. (2009). Comprehensive synthesis of early intensive behavioral interventions for young children with autism based on the UCLA young autism project model. *Journal of Autism and Developmental Disorders, 39*, 23-41. Reviewed by Kathleen Moran

Why this topic?

Early intensive behavioral intervention (EIBI) begins in the preschool years and involves up to 40 hours per week of applied behavior analytic (ABA) intervention for 2 years or more. This review provided a comprehensive synthesis of studies evaluating EIBI.

What did the researchers do?

Thirteen EIBI studies were analyzed, including a total of 373 children diagnosed with autism, autism spectrum disorder (ASD), pervasive developmental disorder (PDD), or pervasive developmental disorder – not otherwise specified (PDD-NOS). Of the participants, 251 received EIBI and 121 were in non-EIBI comparison groups. Treatment was provided for an average of 30 hours a week and lasted an average of 12-48 months. Treatment primarily took place in the home and included training staff and parents.

What did the researcher find?

Overall, the data indicate that EIBI is an effective treatment for children with autism. Results show academic placement, diagnostic reclassification, and fewer or less severe autistic symptoms after intervention. The average child in EIBI made larger gains in IQ than

about 75% of children who did not receive EIBI. In the 9 studies that assessed classroom placement, approximately 65% of participants receiving EIBI were placed in a regular education classroom. In 10 of the 13 studies, participants displayed less severe autistic symptoms after intervention. In 7 of the 13 studies, 31 of 172 participants receiving EIBI met criteria for diagnostic reclassification. The review also indicated that more hours of treatment may lead to more positive outcomes, particularly gains in IQ.

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

The evidence suggests that EIBI is effective for the treatment of autism spectrum disorders. However, the authors noted that, because of limitations in the available studies, many gaps in knowledge remain. These limitations include the small number of children in the studies, narrow criteria for selecting children to include in the studies, and non-random assignment of children to EIBI or non-EIBI groups. One large limitation is that few studies have compared the effectiveness of EIBI to other empirically validated treatments, and such comparisons should be targeted for future research.

ASAT Advertising Policy and Protocols

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.

All advertisers must sign the ASAT Advertising Application. ASAT maintains the right to refuse any proposed advertisement that is incompatible with its mission, as determined through a case-by-case review by the ASAT Board of Directors, prior to placement of advertisement in ASAT publications.

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For each possible ASAT advertiser, an authorized person will be required to sign off that his/her organization is in support of the following tenets:

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2. Service providers have a responsibility to rely on treatments that have been shown to be safe and effective in scientifically rigorous, peer-reviewed research studies.
3. Service providers should take steps necessary to help consumers differentiate between scientifically-validated treatments and treatments that lack validation.
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5. Objective data should be used when making clinical decisions.

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

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

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

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

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

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

.....Become a 2011 Sponsor Now!

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

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

If you are interested in becoming a 2011 sponsor, please visit the sponsor page on our website at www.asatonline.org/about_asat/sponsors.htm#learn.

Thank you for your consideration!

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ASAT Needs Your Help in 2011

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

Help us make a difference!

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

is no longer the rare diagnosis that impacts *someone else's* child. Our extended families, our neighbors, and our co-workers are now all touched by autism. With 1 in 110 children receiving a diagnosis, the sheer number of individuals with autism heightens awareness in and of itself.

For many conditions, awareness is key because awareness promotes detection, and with detection comes a relatively clear path towards treatment. Take, for example, Lyme disease and many forms of cancer. Better prognoses are attached to early detection. Within a few short weeks of detection and diagnosis, patients typically receive science-based treatment. If their conditions are not detected early, then access to such treatments is delayed and their conditions will likely worsen.

In the world of autism, detection is not the “be all and end all.” We do not just have a detection issue in autism, but also (and perhaps more importantly) we have an intervention issue. It is my hope that the conversation about autism awareness will be broadened to focus upon the obstacles that separate individuals with autism from effective, science-based intervention and that those that separate their families, caregivers, and teachers from accurate information about autism intervention.

I leave you with 10 ideas about what “autism awareness” should be about.

1. **"Autism Awareness" should recognize the need to differentiate effective treatments that are scientifically validated from the plethora of "therapies" and "cures" lacking scientific support.** Autism treatment has become a multi-million dollar industry with 400+ alleged treatments and thus, science sadly placed on the back burner. This means that heart wrenching testimonials, surveys that are pawned off as scientific research, and outrageous claims abound, making it challenging for parents to determine the best course of action for their child. The aggressive marketing of these "therapies" and "cures" is absolutely overwhelming for parents who are desperate for accurate information to help their children realize their fullest potential. For most other medical conditions, a provider that disregards proven intervention and uses a fringe treatment may actually be sued for malpractice. Such safeguards do not yet exist for autism. *Please see our treatment summaries for information about the presence or absence of scientific support for scores of autism treatments at <http://asatonline.org/intervention/autismtreatments.htm>*
2. **"Autism Awareness" must recognize the responsibility that we have as a society to make sound choices.** I use the term “society” given the myriad stakeholders who make critically important decisions for persons with autism - not just parents, but siblings, teachers, treatment providers, administrators, program coordinators, and tax payers. Decision-making power comes with tremendous responsibility. There are far too many individuals with
- autism who are not receiving effective treatment, are receiving ineffective treatment, or are subjected to treatments that are, in fact, dangerous. Every minute of ineffective intervention is one less minute spent accessing effective intervention. Every dollar spent on an intervention that does not work depletes resources available for intervention that does work. *Please see the questions that appear at the end of this article to promote more careful decision making at <http://www.researchautism.org/uploads/roadless.pdf>*
3. **"Autism Awareness" must recognize that available information (and information providers) varies greatly in accuracy.** As we know, not all information on the Internet is reliable and accurate. Often Internet information is deemed equivalent in relevance, importance, and validity to research published in peer-reviewed scientific journals. In fact, it is not.
4. **"Autism Awareness" must include careful and responsible reporting by journalists who fully embrace their role as "public educators" and are committed to the dissemination of accurate information.** There are dozens of "miracle cures" and “breakthroughs” for autism that receive widespread media attention, even if they have not been proven effective. Unfortunately, treatments actually shown to be effective typically receive the least amount of media attention. It is hard to imagine that things will improve dramatically for the autism community in the absence of more accurate representations of autism treatment in the media. *You will find examples of accurate and inaccurate reporting here http://asatonline.org/media_watches. ASAT is also undertaking some proactive steps to enhance accuracy in media reporting.*
5. **"Autism Awareness" should recognize the critical need for newly diagnosed children to access effective treatment as soon as possible.** We know that early intervention can make a huge difference. We also know that we have a limited window of time to prepare children for the least restrictive setting once they enter public school. The fact that resources allocated early can save a tremendous amount of resources over an individual's lifespan does not always enter the conversation when evaluating costs and benefits. That must change.
6. **"Autism Awareness" should also instill hope for a better tomorrow for those individuals who are not part of the "best outcome" group.** With the right treatment, individuals with autism can lead happy and fulfilling lives. Research indicates that interventions such as applied behavior analysis (ABA) can effectively help children and adults with autism realize their fullest potential. The conversation about “cure” often delegitimizes and derails important conversations about how we can help individuals with autism live and work independently, develop meaningful relationships, reduce challenging behaviors that may limit opportunities, access faith communities, and enjoy the array of recreational pursuits

(Continued on page 27)

that are available within their communities. Those are important conversations to be had.

- 7. **"Autism Awareness" must mandate accountability from all treatment providers.** Accountability involves a shared commitment to data collection, objectively defined targets, and respect for the scientific method. It is every provider's responsibility to objectively measure outcomes regardless of their discipline. No one should get a pass on accountability. No one is immune from defining their target and objectively measuring progress. No one should be permitted to boast claims that they cannot demonstrate through data. In fact, one could argue that providers using interventions that lack scientific support have an ethical obligation to share this fact with their consumers and to exercise even greater caution in predicting and measuring outcomes. Far too often, applications of interventions that lack any scientific support are carried out in a manner divorced from any semblance of objective measurement. That should not be tolerated.
- 8. **"Autism Awareness" must involve recognition that an abundance of clinical research already exists.** Too often, the plethora of peer-reviewed research that could guide and inform treatment efforts is disregarded or ignored altogether. If treatment providers and consumers are interested in published research on diverse topics such as improving conversation skills, promoting academic skills, eliminating pica, or developing tolerance for dental procedures, they can find it. Thousands of researchers have worked hard at publishing their findings in peer reviewed journals and their findings are often overshadowed by a media that practices sensationalism to provide consumers with information about the "next big thing" in autism treatment.

- 9. **"Autism Awareness" should help us identify and overcome the barriers that face our families everyday.** Not every child with autism is invited to birthday parties. Not every faith community welcomes families of children with autism. Not every school provides meaningful contact between students with autism and their typically developing peers. Not every community provides recreational opportunities for individuals with autism. The absence of these opportunities is both a function of misinformation about autism and lack of awareness about the successful efforts of others who have overcome such barriers. With 1 in 110 children being diagnosed, every facet of society would benefit from evaluating what they are doing, what they are not doing, and what they could be doing differently
- 10. **"Autism Awareness" should be about the reality that the hundreds of thousands of children with autism will soon become hundreds of thousands of young adults with autism.** We are facing a crisis in the field with a scarcity of services for adults with autism and the absence of a clear strategy for closing the gap between the ever increasing need and an unprepared supply of resources. It was recently brought to our attention that our website and newsletter did not represent lifespan issues. Starting with this issue of *Science in Autism Treatment* and moving forward, we are committing to broadening our scope so we are part of an important dialogue about adults with autism.

We all play a role in bettering the lives of individuals with autism and helping their families and supporters become skilled and savvy consumers. Embrace that role with an eye toward identifying what additional steps you can take to become a contributor to important conversations and an even bigger part of the solution.

David Celiberti

Ice cream sales go up in the summer months...

...so do violent crimes!

Does the spike in ice cream sales CAUSE an increase in violent crimes?



Happily, for Ice Cream Aficionados the world over, Correlation and Causation are two different things!

