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SPRING 2010

FROM THE LOCAL, STATE, AND NATIONAL NEWS SCENE

VOL. 2 NO. 4

Understanding and Accessing Clinical Treatment Services

Making the Right Decision When Choosing a Psychologist

By Lynda Geller, PhD, Director
Institute for Cognitive Diversity
Bank Street College and Asperger
Center for Education and Training

What are the key elements in making the right decision about selecting a psychologist? There are many kinds of professionals who may play different roles in addressing the issues associated with having Asperger Syndrome. How do individuals and families determine what type of professional is needed and how to determine if that person can capably deliver needed treatment?

Diagnosis and Evaluation

Diagnosis of Asperger Syndrome is typically conducted by a psychiatrist, a neurologist, or a psychologist. The result of such diagnosis may range from, “you have Asperger Syndrome,” and little in the way of treatment guidance to a de-



tailed treatment plan and referrals to appropriate professionals. This article will review some of the considerations for obtaining the treatment necessary to improve skills and handle problems associated with this diagnosis.

Interventions Psychologists May Provide

Psychologists have a wide variety of training backgrounds and approaches. The most common orientations are cognitive

behavioral, behavioral, psychodynamic, psychoanalytic, and eclectic, that is using a little of each. The age and treatment need should be primary considerations when choosing a therapist to do individual work. Typically cognitive behavior therapy (CBT) is one of the most effective approaches for children and adults with AS as it addresses the relationship between thoughts and feelings and helps clients change thoughts and behaviors that are not productive. Psychoanalysis and psychodynamic approaches may occasionally be useful for adolescents and adults with AS if they want to explore what led them to develop their current psychological characteristics and how they interact with important others. However, these approaches may have limited usefulness if basic skills still need intervention, as is so frequently the case with children and adults on the spectrum. Behavioral therapists tend to examine the antecedents and consequences of behaviors

see Psychologist on page 24

An Autism Spectrum News Interview with Charles N. Cartwright, MD Director of the Autism Center at the YAI Network

By David H. Minot, BA
Associate Director
Autism Spectrum News

Receiving the highest quality clinical treatment services is something every person diagnosed with an autism spectrum disorder (ASD) deserves. In this interview, Dr. Charles N. Cartwright, Director of the YAI Autism Center at the YA Network in New York City, provides an overview of the vital programs and services provided by the YAI Autism Center and the YAI [LINK](#) information and referral program. Dr. Cartwright also offers helpful advice to families with young, adolescent and adult children on the autism spectrum to ensure that they receive the most effective treatments. We are grateful to Dr. Cartwright for sharing his knowledge and spirited optimism on clinical treatments and working toward an improved

quality of life for people of all ages with ASD and their families.

Q: What is the YAI Autism Center and what services are provided for people with ASDs?

A: The YAI Autism Center provides families with young, adolescent and adult children access to high level clinical assessment and treatment services. Families are able to benefit from our expertise in identifying early signs of being on the autism spectrum; and then access vital treatments such as speech, occupational and behavioral therapies, as well as treatments of co-existing emotional, behavioral, and neurological issues (such as seizure disorders). We're also moving beyond clinical services to offer specialized socialization and arts programs. We're bringing together talented professionals from across the YAI Network to create new and innovative programs for people of all ages with ASD.

In order to improve access to our autism services, we work very closely with YAI [LINK](#) (1-866-2-YAI-LINK or link@yai.org), the intake, information and referral service at the YAI Network that provides current, relevant information on services and programs in the New York City metropolitan region for people with developmental disabilities and their families. Families who are looking for information on how to obtain autism services for their children should call YAI [LINK](#) as a first step; they will be asked about their concerns, given information about the services they might need and helped through the process of scheduling appointments.

Q: I am impressed with the range of programs that the YAI Network can provide to people of all ages with autism and their families.

A: We take a “lifespan approach” to all our services within the YAI Network. We begin with early detection and interventions

at a young age, and then continue to offer services that maximize potential and enable people to be as independent and productive as possible throughout their lives. Among the YAI Network's more than 450 community-based programs are early intervention and preschools for children from birth to age 5 through clinical assessment and treatment for children and adolescents, family support, health care, adult day programs, employment training and placement, residential and recreation programs. We serve the needs of people with autism spectrum disorders at each stage of their lives.

We also know that autism does not only affect an individual. It affects a whole family — all the people who are involved in that person's life. We provide support and information for families so they have the tools they need to advocate for themselves and their children. Often, we provide interventions to help families cope with the high level of stress

see Cartwright Interview on page 8

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Autism Spectrum News Theme and Deadline Calendar

Summer 2010 Issue:

"Helping Families Cope With Stress"

Deadline: June 15, 2010

Fall 2010 Issue:

"Addressing the Growing Needs of Adults"

Deadline: September 15, 2010

Winter 2011 Issue:

"Mental Health Treatments for Autism"

Deadline: December 15, 2010

Spring 2011 Issue:

"Navigating the Legal System"

Deadline: March 15, 2011

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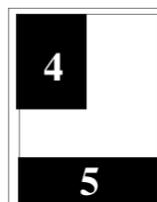
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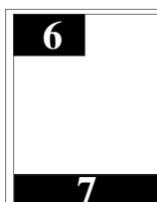
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From The Publisher

Choosing the Right Path Towards Clinical Treatment Best Practices

By Ira H. Minot, LMSW
 Founder and Executive Director
 Mental Health News Education, Inc.

The theme of this issue of *Autism Spectrum News* is "Understanding and Accessing Clinical Treatment Services." This topic is something that all parents must struggle with when their child receives an autism diagnosis. It is at this moment when the journey of learning and discovery about the many different treatment options available begins.

Many parents probably have heard of autism and may know someone with a child on the spectrum, but it is likely that they don't have an understanding of what types of clinical treatment options are available for their child. More importantly, parents of a newly diagnosed child with an autism spectrum disorder may be aware of the great amount of misleading, ineffective, and often dangerous treatment options that should be avoided. A quick internet search reveals both the proven clinical treatment best practice options and "snake oil" treatments offering false promises and preying on vulnerable parents who are willing to try anything to help their child. With so many conflicting options, how is a parent supposed to make the right choices to ensure the best quality treatment in this environment of deception and misinformation?

If you are reading this, you already know the answer - you must seek out only trusted resources of proven science-based information to guide you and your child down the path of success and effective treatment. *Autism Spectrum News* is an example of a resource dedicated to providing trusted information about proven clinical treatment best practices for autism spectrum disorders. The articles found in each issue of *Autism Spectrum News* are written by experts from trusted organizations that provide quality safe and effective treatment services to young, adolescent, and adult children with autism spectrum disorders. In addition, our Editorial Board that is made up of leaders in autism treatment services,



Ira H. Minot, LMSW

scientific research, and advocacy review all content in each issue of *Autism Spectrum News* to make sure it is trusted, safe, and proven effective in the treatment of autism spectrum disorders. Please share this invaluable resource with other new parents of a child with autism so that they too can understand and have access to the trusted information and education they need to ensure that their child receives the highest quality and most effective clinical treatment services available.

Continuing on our interview series with experts in autism, *Autism Spectrum News* had the opportunity to sit down with Dr. Charles Cartwright, MD, Director of the Autism Center at the YAI Network. Dr. Cartwright has a tremendous amount of experience in clinical treatment and offers helpful advice to families with young, adolescent and adult children on the autism spectrum to ensure that they receive the most effective clinical treatments. Dr. Cartwright concludes the interview with a message of hope that, "It is never too late to learn and grow and develop. People of all ages can improve given the proper type of biological and behavioral treatments.

New treatments and interventions are currently being tested and many of these show promise. There are lifelong opportunities for your child, adolescent or adult with an ASD to participate in effective interventions.

On page 13, Dana Levy, PsyD and Elizabeth Roberts, PsyD, of the NYU Child Study Center profile two evidenced-based, parent-implemented behavioral intervention programs that address both the need for early intervention and methods for reducing non-compliant and other maladaptive behaviors that interfere with learning. "When parents are successful at learning and can offer the required degree of intensity of therapy, these approaches may offer a more cost-effective and naturalistic method of teaching skills and reducing problem behaviors than those that rely on service delivery by professionals. For these families, ESI and PCIT are two potentially valuable ways to help their children."

On page 14, Dr. Thomas Zane, PhD, BCBA, Director of The Center for Applied Behavior Analysis at The Sage Colleges focuses on evaluating the effectiveness of autism treatments and understanding what allows a research study to give valid and believable results to deem a treatment to be considered evidence-based. "Just because a research study has been conducted and shows positive changes in some aspects of autism does not necessarily mean that the treatment was responsible for those changes. Since autism is said by some to be a 'fad magnet,' parents and other consumers must critique any research study that purports to show a positive effect of a treatment and try to determine if the positive changes could be due to other explanations, or could only be due to the treatment."

Peggy Halliday, MEd, BCBA and David Celiberti, PhD, BCBA-D on page 15 offer some invaluable advice and helpful resources that may help when approaching a family member who has a child that may be showing signs of autism. "As is the case with many concerned family members, you may worry that such a discussion may not be well received. If autism is a possibility, you would not want to delay screening and

referral for possible evaluation and services, because this may waste valuable time during which intervention can be most beneficial for your grandson."

In addition to the articles mentioned, there are many others that address the latest advances in autism science by experts in the field of autism that we hope will inform and inspire you. Let me conclude by telling you about our exciting roundup of themes in the upcoming quarterly calendar of *Autism Spectrum News*. Our summer issue theme will be "Helping Families Cope With Stress." Our deadline for articles and advertising for this important issue is June 15th.

Our calendar continues with our fall issue which will focus on "Addressing the Growing Needs of Adults." Next winter we will take an in-depth look at "Mental Health Treatments for Autism" and next spring our theme will be "Navigating the Legal System."

We would like to invite everyone to participate in these exciting upcoming issues. Our goal is to continue our format of providing evidence-based news, information, education, advocacy, and resources on a variety of topics of importance to the autism community. As a nonprofit organization, we ship thousands of free copies of each issue of *Autism Spectrum News* to our growing family of autism and mental health organizations. For those who may not have the opportunity to pick up copies of each issue at our delivery locations, we post each entire issue for free on our website: www.mhnews-autism.org. On our website you can subscribe to receive your own personal hardcopy that will be mailed to your home or office address. You can also order our group subscription and receive 50 copies of each issue for your clients and staff.

We look forward to hearing from you. Please e-mail us at dminot@mhnews.org and tell us what topics are important to you, so that we can address them in future issues of *Autism Spectrum News*.

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Have a Wonderful Spring Season!

Letter to the Editor

Dear Editor,

I want to say that I have been very impressed with the quality and scope of *Autism Spectrum News*. However, I do have a specific issue to discuss.

The issue concerns the second sentence of the otherwise excellent article, "The Neurobiology of Sensory-Perceptual Symptoms in Autism" by David Grodberg in the Winter 2010 Issue

of *Autism Spectrum News*. When Dr. Grodberg implies that a significant proportion of individuals diagnosed with autism have "high pain thresholds," he tends to perpetuate a mistaken idea about pain in autism.

Several recent studies (see below) have strongly indicated that, while individuals with autism often show unusual or reduced expressed reaction to pain, they do not have reduced sensitivity to

pain. This has important clinical and research implications. Most importantly, special attention and extra care should be employed to ensure that individuals with autism do not suffer needlessly.

Cited Studies

Tordjman S, Anderson GM, Botbol M, Brailly-Tabard S, Perez-Diaz F, et al. Pain reactivity and plasma beta-

endorphin in children and adolescents with autistic disorder. *PLoS One*. 2009 4 (8):e5289

Nader R, Oberlander TF, Chambers CT, Craig KD. Expression of pain in children with autism. *Clinical Journal of Pain*. 2004 20(2):88-97.

George M. Anderson, PhD

AUTISM SPECTRUM NEWS DESK

Vaccine Court Denies All Three “Thimerosal Causes Autism” Test Cases

By Alison Singer, President
Autism Science Foundation

On March 12, the U.S. Court of Federal Claims (i.e. Vaccine Court) issued its decision regarding whether thimerosal-containing vaccines can cause autism. The decision, handed down by three Special Masters, was a resounding “No!”

In the King case, the Special Master wrote: “This case is not a close case. The overall weight of the evidence is overwhelmingly contrary to the petitioners’ causation theories...based upon all the evidence that I have reviewed, I find that it is extremely unlikely that Jordan’s autism was in any way causally connected to his thimerosal-containing vaccines. In short, this is a case in which the evidence is so one-sided that any nuances in the interpretation of the causation case law would make no difference to the outcome of the case.”

And in the Dwyer case the Special Master wrote: “Petitioners propose effects from mercury in [vaccines] that do not resemble mercury’s known effects in the brain, either behaviorally or at the cellular level. To prevail, they must show that the exquisitely small amounts of mercury in [vaccines] that reach the brain can produce devastating effects that far larger amounts experienced prenatally or postnatally from other sources do not.”

In the Dwyer case, the Special Master also dismissed claims that some groups of children are unusually susceptible to the effects of mercury, writing, “the only evidence that these children are unusually sensitive is the fact of their [autism] itself.”

This whole process began back in 2002 when the Special Masters from the Vaccine Court created an omnibus proceeding for handling the claims alleging that vaccines were associated with autism. The March ruling focused on whether

thimerosal-containing vaccines could cause autism. Last August, the court ruled that thimerosal in combination with MMR vaccine could not cause autism.

There are two key points to keep in mind with regard to these proceedings. First, the special masters are not scientists and they did not answer a scientific question with their rulings. The science had been in for some time now in and it’s quite clear. Vaccines do not cause autism. Multiple studies have been conducted (www.autismsciencefoundation.org/autismandvaccines.html) investigating whether or not thimerosal, at the level contained in vaccines, causes autism and looking at hundreds of thousands of children on several different continents by several different investigators and in different populations of children. Children who received thimerosal in vaccines, compared to those who received lesser quantities of thimerosal in vaccines or no thimerosal in vaccines, all had the same risk of autism.

And frankly, the amount of mercury one is exposed to in the environment or even breast milk, compared to what is contained in vaccines, would argue against vaccines being causative.

Secondly, a review of the history of vaccine court indicates that this court hasn’t always come down on the side of the science. The standard of evidence bar is purposely set very low in vaccine court. The court was designed to compensate victims of vaccine injury, which of course is very real. The standard of evidence is biologic plausibility, rather than scientific evidence. In other words, you don’t have to prove that thimerosal actually causes autism, only that it might. One of the goals of the legislation creating the vaccine court in 1986 was to be generous with compensation because there are people who have very real, very serious adverse reactions to vaccines who deserve

see *Vaccine Court* on page 27

Pfizer Launches New Autism Research Group

By Robert H. Ring, PhD, Senior Director
Head, Autism Research Unit
Pfizer Global Research & Development

The creation of Pfizer’s Autism Research Unit represents a groundbreaking investment into one of the largest unmet and fastest growing medical needs in the neuroscience disease area. Formed in early 2009, the Pfizer Autism Research Unit is the first formal discovery group of its kind in the pharmaceutical industry.

The goal of the Pfizer Autism Research Unit is to improve the quality of life for patients with Autism Spectrum Disorders (ASD) through the discovery and development of innovative medicines that treat the core deficits of the disorder and associated symptoms.

Supporting this goal, the Autism Research Unit has developed near- and long-term strategies for building a viable portfolio of clinical candidates that leverage recent advances in human genetics and synaptic neurobiology. Pfizer also plans to examine the application of the company’s R&D efforts in psychoses and neurodegenerative disorders, and will investigate potential therapeutic relevance of other Pfizer compounds in development, as well as marketed Pfizer medicines.

Since its launch, Autism Research Unit has built a portfolio of a number of early discovery programs.

The Team

The Research Unit is comprised of a multidisciplinary team of 16 scientists

with relevant expertise in genetics, neurobiology, and behavioral pharmacology.

Pfizer’s work in autism extends beyond the Research Unit to include a team of medicinal chemists, computational biologists, translational medicine experts and clinicians.

Many of those involved in the Pfizer Autism Research Unit have a passion for the research that also originates in personal stories, with several members of the team having family members on the Autism Spectrum.

A Focus on External Partnerships and Relationships

External engagement is a core strategy underlying the Autism Unit’s approach to discovery, with a focus on building collaborative partnerships with external ex-

perts from academic research centers, non-profit foundations, and governmental agencies to advance the basic and translational understanding of disease pathophysiology in ASD.

Pfizer is also taking a leadership role in helping to form precompetitive consortia with other pharmaceutical companies to explore ways of increasing the field’s probability of success in bringing new medicines to this patient population through a variety of partnership models.

Pfizer wants to establish itself as a partner with the Autism Community to help advance basic research and accelerate the translation of discoveries into needed medicines. External Partnerships and Relationships include the University of Pennsylvania and the University of California at San Francisco.

National Autism Center Publishes Autism Manuals for Educators

By The National Autism Center

Educators across the country, eager for reliable, research-based information about effective interventions for the ever-increasing number of students with Autism Spectrum Disorders (ASD) in their school districts, are turning to the National Autism Center for guidance.

The Center, a nonprofit organization

dedicated to supporting effective, evidence-based treatment approaches for individuals with ASD, recently wrote and published a comprehensive manual titled, *Evidence-Based Practice and Autism in the Schools*. The 181-page manual includes important findings from the Center’s newly released National Standards Report, the most extensive analysis of treatments for children and adolescents with ASD ever published.

Thanks to philanthropic support, the National Autism Center distributed the first 3,000 copies for free to special educators in school districts throughout the country. Since this initial distribution, the Center has been inundated with requests for additional manuals. Visitors to the Center’s website from 50 states and more than 20 countries have downloaded thousands of free copies of the manual, which is now also available for purchase.

The manual assists educators in the selection and implementation of the most effective research-supported treatments for ASD. In addition to providing important information about newly published research findings, it offers guidance on how to integrate professional judgment, family values, and preferences into treatment selection in order to build capacity

see *Autism Manual* on page 30

Understanding and Addressing the Needs of Spanish-Speaking Families

By **Marco R. Damiani, MA**
 Director of Clinical and Family Services
 YAI/National Institute for
 People with Disabilities

Autism diagnoses among children of Latino descent have risen more than 90 percent since 2002, according to a Centers for Disease Control and Prevention study released in December 2009.

While the reasons for this are multifaceted, Dr. Charles Cartwright, Director of the YAI Autism Center, identifies several factors that have contributed to this startling increase.

"There is now a broader definition of autism spectrum disorders, which results in more children getting the diagnosis," Dr. Cartwright said. "Parents are also becoming more aware of the signs and asking more questions when going to the doctor and parents are more motivated to receive the diagnosis, which leads to greater access of services."

"Some of the increases are due to better detection, particularly among children who may not have come to attention in the past," said the CDC's Catherine Rice, who led the study, in the press conference announcing the results.

While it is clear that there has been a significant increase in diagnoses among Latino/a children, the study does not confront the fact that many of these young-



Marco R. Damiani, MA

sters are falling through the cracks because of language and other barriers.

Dr. Fabricio Balcazar, Professor in the Department of Disability and Human Development at the University of Illinois at Chicago and Director of the Center for Capacity Building on Minorities with Disabilities, addressed this issue when he presented to families and professionals at a free Latino Health Care Conference, sponsored by the YAI Network and the Center for Latin American, Caribbean and Latino

Studies at the City University of New York.

"Parents of children with autism and other developmental disabilities who are Latinos are lagging behind most other groups," Dr. Balcazar said. "In terms of the need for addressing their issues, concerns and anxieties about the futures, these efforts are enormously valuable to them."

"I Was My Son's Doctor"

Sandra Lugo, a guidance counselor at a high school in Brooklyn and former teacher, has a 3-year-old child with autism. When she realized that her son needed help, she took action right away.

"I was my son's doctor. He was frequently falling and that wasn't normal. He seemed not to hear me when I called his name and by the age of two, he was only talking in one or two word sentences and not interested in being around other children," Sandra recalled. "These were all eye openers, and I knew deep in my gut that my son needed help and I needed to act fast. I wasn't prepared for the diagnosis. When he was evaluated, I was devastated and cried out of sadness, but I also cried out of relief because he was going to get the help he needed."

Sandra's son now attends a YAI Network preschool and has made great progress. The Lugos are fortunate, because they are bilingual and familiar with the education system in New York.

However, many Latino families only

have family members who speak Spanish, so it's much more difficult to communicate their concerns about their child and learn how to access the proper services.

Confronting Barriers

Mara Henriquez, Supervisor of Community Targeted Outreach at the YAI Network, says that Latino/a parents face unique barriers to finding services, including cultural and language differences.

"When Spanish-speaking families don't know that services exist or where to go for help, a sense of isolation creeps in," Mara said. "They may even think that they are the only family who has a child with a disability."

It doesn't help that the most available and comprehensive information is solely in English and includes terms that families may be unfamiliar with, even if they are bilingual.

"If doctors and other professionals don't speak Spanish, it can take families a long time to build trust," Mara said. "Everyone wants to feel as if their doctors are listening to them and truly care, and that can be difficult if there is a language barrier."

After the Diagnosis

Terese Sanabria, Bilingual Social Worker, and Erica Pitman, Social Worker,

see Spanish Families on page 18

Cartwright Interview from page 1

that comes with having a child with autism. That means helping tackle conflicts in the marital relationship, which is common in families dealing with autism, and also help reduce the stress on the siblings.

Q: There is such an enormous range of information on the Internet, some good, some harmful. In this day and age, many people first look to the Internet as their primary resource of information. If you were a parent whose child was just diagnosed with autism, how would you go about seeking clinical services for your child?

A: If I were a parent of a child between 18 months and age 2 who was told by a pediatrician that my child appeared to be on the autism spectrum, I would immediately seek out as many services for which my child is eligible. Early diagnosis allows families to seek out the best science-based clinical treatments for their children and start those interventions as soon as possible.

Resources such as YAI [LINK](#) are very helpful starting points that provide information about early intervention centers in your area. They can give parents information about who to call, what services to look for and how to schedule an appointment for an evaluation that will result in the formulation of an early intervention plan. They can also help locate support groups in the community. It is important to reach out and make those connections with other families who have been through a similar experience and who can provide social support.



Charles Cartwright, MD

There are specialized academic centers around the country that conduct research into the causes, early detection and treatment of autism, and then publish and distribute their latest research findings. Examples are the Yale Child Study Center and the MIND Institute in California.

It is also helpful to get information from support and advocacy organizations that are focused on autism and hold events and activities in local communities; they also advocate for policies that will improve the lives of families affected by autism.

Autism presents a lifelong challenge. Here is a common scenario that many parents face: Their child is receiving autism services at a public school and begins

to have severe behavioral issues, such as obsessive compulsive behaviors and anxiety. This gradually becomes more and more of a problem to the point where it interferes with the child's ability to learn and is having a disruptive effect on classroom involvement. What do you do and where do you go then? Again, it is important to reach out to services that keep databases with a range of resources and services for the evaluation of emotional/behavioral issues in children and adolescents with autism spectrum disorders.

Support groups can be vital sources of information where parents can talk with each other and ask questions such as, "Have you been with a particular organization for help, and was it helpful to you and your child?"

Q: What is important for families to be aware of when choosing a clinical treatment center for their children?

A quality treatment center has an established reputation and relationships with key academic centers doing research in the assessment and treatment of children with autism, and has expertise in evidence-based practices. That means the center uses treatments or interventions that have been proven effective through scientific research and clinical trials. It is also important that the center has professionals with expertise in different specialties such as pediatrics, neurology, psychiatry, speech and language therapy, occupational therapy, behavioral specialists, family therapists — all the different disciplines that are involved in the care of children with ASDs.

Professionals should show the parents that they are really listening to their concerns, and include them in decision making about the care of their child. They should show respect for the family's cultural background. And they should be available over time, as the family faces the challenges of living with a child with autism. Parents have a right to know that when they need their clinicians/doctors, they know that they can get hold of them. That means having their calls answered in a timely way. I think that one of the most powerful things we can do as service providers is to be responsive and accessible both in time of crisis and when the family has questions and concerns that are not as urgent.

Q: So many parents rely on anecdotal information. They hear one thing worked for a friend's child so, based on that single instance of success, they are going to go ahead and use that treatment for their child. We know that early intervention is so crucial and months spent on an intervention that hasn't been backed by science can result in wasted precious time and financial resources. What are your thoughts on treatment and support services accountability to ensure that treatment goals and objectives are being followed and progress will be documented?

A: I can answer this by describing the "Secretin" story. Back in the 1990s, there was great interest in Secretin and claims that this hormone involved in digestion led to tremendous gains for children with autism spectrum disorders. Secretin became a

see Cartwright Interview on page 27



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Understanding ABA Intervention

By Mary Jane Weiss, PhD,
Cece McCarton, MD, and
Ivy Feldman, PhD
The McCarton Foundation

One of the most difficult aspects of navigating autism treatment decisions for families is making sense of the vast array of claims of effectiveness. Many treatments claim to be effective, though few have data to support those claims. Parents are confronted with such claims and with the complexity of the disorder. Many are confused about which interventions might have relevance for their child. It can be difficult for parents to choose a treatment path, and many worry that they may later regret not trying a particular treatment.

Most of the treatments that claim to be relevant or effective have little scientific evidence to support those claims. An exception to this is Applied Behavior Analysis (ABA). ABA intervention has been widely documented as highly effective for individuals with autism (e.g., Fenske, Krantz, & McClannahan, 2001; Lovaas, 1987; MacDuff, Krantz, MacDuff, & McClannahan, 1988; McEachin, Smith, & Lovaas, 1993; Sallows & Graupner, 2005). The data base supporting the effectiveness of ABA interventions distinguishes it from other approaches. The success of ABA intervention is likely the result of several



Cece McCarton, MD

core characteristics of ABA, including: the provision of intensive intervention, clear and specific targets of intervention, precise techniques of instruction, the collection of objective data to evaluate learner progress, data-based decision making, and dynamic alterations in programming in response to the learner's needs.

Behavior analysis has been described as having seven dimensions that define it

(Baer, Wolf, & Risley, 1968). A description of each of these characteristics appears below:

Applied - Behaviors targeted must be socially significant. An intervention must address a behavior that has *immediate* importance to the individual.

Behavioral - The behavior studied must be one in *need of improvement* (social significance). Additionally, it must be possible to *measure* the behavior in need of improvement. This is why behavior analysts put so much emphasis on the observability of behavior.

Analytical - There must be an attempt to identify a *functional relation* between the manipulated events and the behavior.

Technological - All of the procedures used must be completely *identified* and *precisely* described. We must have operational definitions of our behavioral targets and/or goals, and all of our procedures must be clearly defined.

Conceptually Systematic - Procedures for behavior change are described in terms of the *relevant (basic, behavioral) principles* from which they were derived.

Effective - Applied behavior analysis must produce *clinically or socially* significant results to be judged effective.

Generality - Behavior change lasts over *time*, appears in environments *other than* the one in which the behavioral techniques were applied, or spreads to other behaviors not directly treated by the behavior change techniques. In other words, treatment extends into untrained environments and to untrained behaviors.

All of these characteristics are essential to behavior analytic treatment. They are especially relevant to the problems faced by individuals with autism, whose needs are so profound and pervasive. It is imperative that changes are socially significant and extend to the natural environment. Increasingly, behavior analysts have attended to issues of social significance in selecting and defining targets for behavior change. Evaluation of impact is determined not just by skill acquisition, but by maintenance over time and generalization to other behaviors, settings, and contexts.

Perhaps most importantly in this list of characteristics, behavior analysts value effectiveness as a primary characteristic of intervention. In fact, the ethical code of behavior analysts mandates this. Section 2.09 (Treatment Efficacy) of the Behavior Analyst Certification Board's Guidelines for Responsible Conduct (bacb.com) states that:

(a) The behavior analyst always has the responsibility to recommend scientifically

see *ABA Intervention on page 23*



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Parent-Implemented Interventions for Children with Autism Spectrum Disorders

By Dana Levy, PsyD and
Elizabeth V. Roberts, PsyD
Child Study Center
NYU Langone Medical Center

While the background noise of daily life includes a stream of fascinating new findings concerning the neurobiology of autism, parents of children with ASD face the urgent, present-day challenge of enhancing their children's social, cognitive, linguistic, and adaptive development in every possible way. There is no time to lose. Two clear needs in this regard are early intervention, which has been repeatedly demonstrated to be a central feature of better outcomes in ASD, and methods for reducing non-compliant and other maladaptive behaviors that interfere with learning.

We profile two evidenced-based, parent-implemented behavioral intervention programs that address these needs. Early Social Interaction (ESI) is an early intervention program developed specifically for toddlers at risk for ASD. ESI aims to maximize the development of social communication by offering intervention during the earliest years of life. Parent Child Interaction Training (PCIT) was originally developed for young, non-autistic children to treat non-compliance, and other maladaptive behaviors that interfere with learning. PCIT is a potentially prom-



Dana Levy, PsyD

ising intervention in young children with milder forms of ASD.

While behavioral interventions for autistic children have always included parent training, the past fifteen years has witnessed a growing trend to increase the involvement of family members and other non-clinicians and to embed teaching in naturalistic environments. PCIT and ESI go far beyond merely involving parents as partners or collaborators by teaching them



Elizabeth V. Roberts, PsyD

the skills to independently implement treatment in the naturalistic environment of the home and community.

Early Social Interaction Project

The Early Social Interaction (ESI) Project, developed by Wetherby and Woods, was designed to apply the 2001 recommendations of the National Research Council (NRC) of the National Academy

of Sciences to toddlers with ASD. The project's aim is to develop a parent-implemented intervention that embeds naturalistic teaching strategies in everyday routines and is compatible with the mandate of the 2004 Individual with Disabilities Education Improvement Act (IDEIA), Part C. ESI treatment focuses on the core deficits of ASD, in joint attention, shared affect, communication, and play.

In ESI, parents are taught a repertoire of skills in the domains of communication, language, play, and social skills through coaching. Coaching occurs in both home and clinic settings. Parents are taught to integrate strategies into everyday routines. Based on the longstanding finding that intensity of treatment matters in early intervention, parents are taught to use the skills twenty-five hours per week in everyday predictable routines. ESI uses a developmental sequence for goal setting and emphasizes teaching and learning in daily routines and activities. ESI uses evidence-based practices driven by data collection and outcome measures, yet goals are formed based on individual and family needs. Interventions are embedded in naturalistic situations, and treatment goals are strategically planned within typical contexts. Some areas that ESI addresses are: Social Communication, Joint Attention, Symbol Use, Emotion Regulation, Active Engagement, Arousal States,

see Parent-Implemented on page 30



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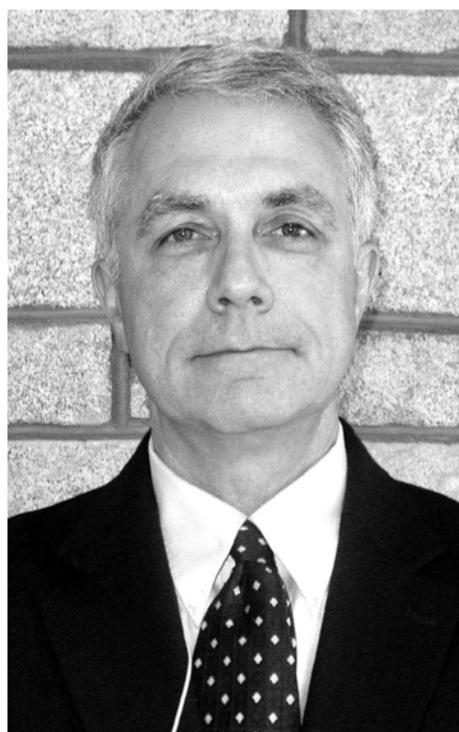
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The Use of Pre-Post Test Designs to Evaluate Effectiveness of Autism Treatments

By Thomas Zane, PhD, BCBA, Director Center for Applied Behavior Analysis at The Sage Colleges



Thomas Zane, PhD, BCBA

This current issue of *Autism Spectrum News* focuses on understanding and accessing clinical treatment services. A prerequisite to accessing clinical treatment is to understand what treatments might be effective and have a chance of delivering positive results. And a prerequisite to determining what treatments have actually been proven to be “evidence-based” is understanding what allows a research study to give valid and believable results.

Consider a study recently published by Rossignol and Rossignol (2006), in which they assessed the effect of a hyperbaric oxygen chamber on a range of symptoms of six children diagnosed with autism. Prior to starting the hyperbaric oxygen therapy (HBOT), the researchers assessed the participants on three measures, the Autism Treatment Evaluation Checklist, the Childhood Autism Rating Scale, and the Social Responsiveness Scale. The children then participated in HBOT for 40, 1-hour sessions, and the researchers then re-assessed the participants using the same measures as in the pretest. For most of the children, the post-test scores were lower on each assessment (for these instruments, a lower score suggests fewer symptoms of autism and improved functioning). The

authors suggested that the HBOT was responsible for the improvement.

Consider a study by Gutstein, Burgess, and Monfort (2007), in which they assessed the effectiveness of Relationship Development Intervention, an autism treatment. The authors selected 16 children with autism and reviewed their files, noting

their test scores on various measures prior to receiving RDI - subsets of the Autism Diagnostic Observation Schedule and Autism Diagnostic Interview-Revised. Additionally, parents provided information about each child’s educational placement (on a continuum of intrusiveness) and level of “flexibility” (i.e., child’s comfort level reacting to change in his/her life and routine). After obtaining these measures, the participants received RDI for an average of 18 months. Following treatment, Gutstein, et al. conducted post-test assessments using the same measures as the pretest. For most children, the authors concluded that the post-test scores improved over pre-test scores, and suggested that RDI was responsible for the improvement.

Researchers and clinicians often attempt to demonstrate the effectiveness of an autism treatment by using this common “pre-post” test design (also called “before-after,” “AB,” and “one-group, pretest-posttest design; e.g., Drew, Hardman, & Hosp, 2008; Fraenkel & Wallen, 2009). The general strategy in a pre-post test study is to recruit one group of subjects, obtain some measurement of the critical dependent variable(s) hypothesized to be changed by the treatment, implement the treatment protocol, and then the re-administer the same measurement as pretest. There is an assumption that if the post-test scores have changed positively from the pretest scores, then the change is due to the treatment. Many researchers

and treatment developers use this basic design (e.g., Krantz, 2009; Linderman & Steward, 1999; Rossignol, Rossignol, James, Melnyk, & Mumper, 2007).

The important question is, does this design provide convincing proof that the treatment caused the improvement in the variable(s) being measured? The answer is unambiguous - this basic design never permits confirmation of cause and effect between the treatment and positive changes in the dependent measures (e.g., autism symptomology; Drew, Hardman, & Hosp, 2008; Gay, Mills, & Airasian, 2009).

The weakness of this design (to demonstrate causal relationships) relates to its inability to minimize “internal validity” threats. The internal validity of a research study refers to the level of confidence in believing that changes in the variables being measured are due to the treatment protocol being used. If the research study is designed to eliminate any explanation other than the treatment changing what is being measured, then that study has strong internal validity. On the other hand, if the research study is designed in a way that allows explanations other than the treatment variable to possibly be influencing what is being measured, then that study will have weak internal validity, and the conclusion must be that the treatment may not be the only reason for the change in the dependent measurements. And if there

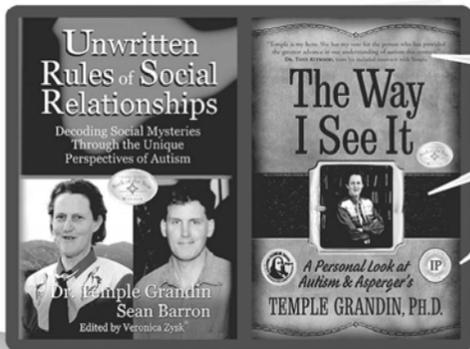
see *Effectiveness on page 29*

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My Grandson May Have Autism - How to Discuss This With Family Members

By Peggy Halliday, MEd, BCBA and David Celiberti, PhD, BCBA-D

I am concerned that my grandson may have signs of autism, but I am uncomfortable bringing this up with my son and daughter-in-law. Do you have any suggestions about how best to approach them?"

It is natural to be unsure of how to share your concerns with your grandson's parents. As is the case with many concerned family members, you may worry that such a discussion may not be well received. If autism is a possibility, you would not want to delay screening and referral for possible evaluation and services, because this may waste valuable time during which intervention can be most beneficial for your grandson. Even knowing that best outcomes are associated with early diagnosis and intensive intervention, it still may be difficult to talk to your son and daughter-in-law if they have not expressed concerns to you.

As a grandparent, you have already raised at least one child, so you probably have a good sense of what is typical in child development, and what is not. You may feel that your grandson is not making expected gains or may appear delayed in some areas such as communication or play relative to other children his age. This may create in you a sense of urgency which must be balanced with the need to support your son and daughter-in-law.



Peggy Halliday, MEd, BCBA

There are a number of important things to consider. The way in which you approach your son and daughter-in-law will depend in large part on the quality of your pre-existing relationship and on the nature of how you communicate with one another. You may possess a relationship where difficult issues are frequently and easily discussed. On the other hand, this may not typify the type of relation-



David Celiberti, PhD, BCBA-D

ship that you have. Regardless of your relationship, it is important that you bring this up from a place of love and concern, rather than judgment and blame. Many parents who have been carefully and respectfully approached by a relative later admit that they already had concerns of their own, and it was a relief to discuss them with someone else close to the child.

We would like to offer some concrete suggestions that may increase the likelihood that your discussion will be constructive:

- Plan your discussion ahead of time. Find a time and place when you will not be interrupted.
- Take some time to think about what you want to share and how you want to frame your concerns. You might begin by commenting on the child's strengths and praising the parents' love and dedication to their child. It is important not to appear judgmental.
- Try to keep the conversation free flowing. You may want to ask a few questions that will allow the parents to express their own concerns, if they have them.
- The role you take in the child's life depends, of course, on geographic proximity, but offer concrete, practical help whenever possible. For example, you might offer to babysit siblings while parents pursue evaluation of the child, or offer a respite weekend of childcare so that your son and daughter-in-law might have time to discuss the situation without interruption. Whatever assistance you offer, the important thing is that your

see Grandson on page 20



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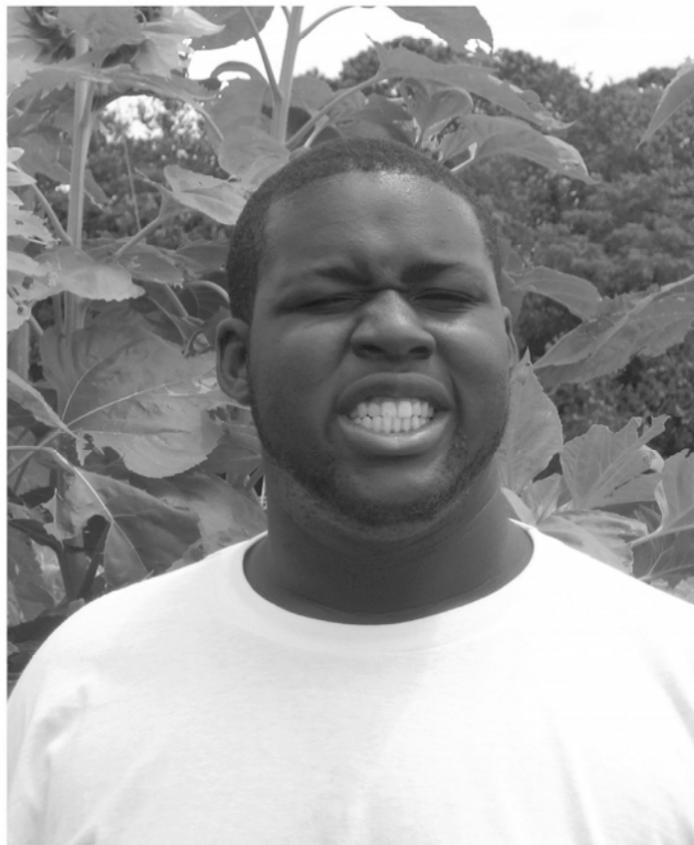
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Autism Science Foundation 2010 Doctoral Training Award Recipients Announced

Staff Writer
Autism Spectrum News

The Autism Science Foundation recently announced that it had awarded doctoral training fellowships to six pre-doctoral students committed to pursuing careers in basic and clinical scientific research relevant to autism spectrum disorders. In all, \$180,000 in grants will be distributed to student/mentor teams conducting research in autism treatment, biomarkers, animal models, and epidemiology.

"We are thrilled to be funding grants after less than ten months of fundraising and operations" said Autism Science Foundation co-founder Karen London. "Outstanding research is the greatest gift we can offer our families. We are so grateful to all our donors and volunteers who have come together to support autism research."

"Too much time has been spent looking backwards at the now debunked theory that vaccines caused autism," said Alison Singer, president of the Autism Science Foundation. "We need to re-group; we need to look forward and invest in discovering biomarkers that can lead to earlier diagnosis, in animal models that can illuminate biological pathways, and in treatments that target the most debilitating aspects of autism. This round of grants is aimed in that direction."



Grant applications were reviewed by members of the Autism Science Foundation's Scientific Advisory Board (SAB) as well as by outside scientific experts in specific subject areas. Grants were also reviewed by ASF's Stakeholder Review Committee, comprised of parents, individuals with autism, a special education teacher and other stakeholders.

The following projects were selected for funding (student/mentor):

- Karen Burner/Dr. Sara Jane Webb; University of Washington, Seattle: *Observational and Electrophysiological Assessments of Temperament in Infants at Risk for Autism Spectrum Disorders*

- Sarita Austin/Dr. Rhea Paul; Yale Child Study Center: *Enhancing Understanding and Use of Conversational Rules in School-Aged Speakers with Autism Spectrum Disorders*
- Rhonda Charles/Dr. Joseph Buxbaum; Mt. Sinai School of Medicine: *A Pre-clinical Model for Determining the Role of AVPR1A in Autism Spectrum Disorders*
- Sarah Hannigen/Dr. Mark Strauss; University of Pittsburgh: *Defining High and Low Risk Expression of Emotion in Infants at Risk for Autism*
- Matthew Maenner/Dr. Maureen Durkin; University of Wisconsin, Madison: *Phenotypic Heterogeneity and Early Identification of ASD in the United States*
- Michael Sidorov/Dr. Mark Bear; MIT: *Investigation of Postnatal Drug Intervention's Potential in Rescuing the Symptoms of Fragile X Syndrome in Adult Mice*

Alison Singer is President of the Autism Science Foundation. Visit www.AutismScienceFoundation.org to learn more about the Autism Science Foundation. Ms. Singer can be reached at asinger@autismsciencefoundation.org.

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Spanish Families from page 8

at the YAI Network's Gramercy School, recommend that families take the following steps to access services:

- Seek out education on what a possible diagnosis of autism might mean. One website to check is <http://espanol.ninds.nih.gov/trastornos/autismo.htm>
- Speak to your pediatrician – ask questions!
- If you do **not** have a pediatrician, go to a larger medical center or teaching hospital where they are more likely to have bilingual specialists available.
- Advocate for your child to see a specialist — a developmental pediatrician or a child neurologist is a good place to start.
- Pursue an Early Intervention evaluation by calling an Early Intervention provider agency in order to assess if your child needs services (or a CPSE evaluation if your child is turning 3 or older).
- If you do not obtain services based upon the evaluation you receive, revisit the issue in six months for a possible re-evaluation.
- Most importantly, trust your instincts and follow them. If you believe there is something not right with your child, pursue additional opinions.



Gathering for a free Latino HealthCare Conference are, from left, Mariela Dabbah, author and speaker, New York City Council Member Fernando Cabrera, and Stephen E. Freeman, YAI Network Chief Operating Officer

is something not right with your child, pursue additional opinions.

Forming a Community

As a demonstration of the YAI Network's commitment to serving the needs of

diverse communities, the Latino Health Care Conference brought together more than 300 Spanish-speaking families for a day of support and empowerment, helping to alleviate isolation and lack of information, as well as to break down some of the cultural barriers.

"This conference brings together families from throughout the Latino community to provide them with information and supports that will help their loved ones with disabilities enjoy the highest quality of life," said Stephen E. Freeman, Chief Operating Officer of the YAI Network.

"Seeing is believing," said Sandra Lugo, who spoke at the conference. "You can't ignore what is there. You have to take a stand and act on getting the necessary services!"

"We as parents have to stop placing limits on ourselves and our children and fight for services," said Luz Barrales, a conference attendee who has a son on the autism spectrum. "We can't wait for people to fight for us. We have to help our children be independent and find the best services for them."

Marco Damiani is Senior Director of Clinical and Family Services at YAI/National Institute for People with Disabilities. For more information on services available to Spanish-speaking families who have a child with autism, please contact YAI [LINK](http://www.yai.org) at 1-866-2-YAI-LINK.

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Introducing the Compass Project at JCCA

By **Elise Hahn Felix, LMSW, Director**
JCCA Compass Project

There is a relatively large array of services available to high-functioning young children with special needs, through early intervention, special education, and enrichment programs. However, as these young people age, service availability dwindles, and there virtually are no supports available to help youth and their families navigate the challenges of transition from high school to college and/or the world of work.

Jewish Child Care Association (JCCA) has been providing services to special needs youth and their families on Long Island and in Queens for more than 14 years. The JCCA Compass Project serves high-functioning youth in high school and college who have disorders on the Autism Spectrum (ASD) and other special needs, such as learning disabilities (LD) and Attention Deficit Disorder (ADD). Compass helps young people and their families to prepare for college or alternative post-secondary programs and careers, through information, referral, assessment, individual and group support, and a range of innovative socialization programs. Serving more than 500 youth and their families last year, the Compass Project minimizes stigmatization and maximizes convenience by offering services in partnership



Elise Hahn Felix, LMSW

with community-based “gateway institutions” which these families may already work with, including the many Jewish Community Centers (JCCs) and Ys on Long Island and in Queens, as well as local colleges, synagogues, schools, and parenting centers.

Recently, JCCA’s Compass Project expanded into Westchester and also serves Manhattan and Brooklyn. The program offers six main transition services to high school and college-age

youth, which include: 1) assessment; 2) vocational preparation; 3) socialization; 4) counseling and support; 5) referral; and 6) professional training.

Assessment - Compass social workers conduct comprehensive assessments for youth in high schools to evaluate their readiness for college or an alternative post-secondary school, and with college students to gain a picture of their options for employment. The assessments include a three-session series consisting of: a) individual career assessment and testing; b) a consultation session with youth and parents; c) peer group discussions of career directions.

Vocational Preparation - Compass staff conducts college and career guidance and counseling and work internship programs. It holds work preparation workshops and develops innovative programming to help youth ready themselves for and adjust to college and/or the workplace.

Socialization - Compass provides organized social activities to help youth build social skills and to give respite for parents, including supervised volunteer opportunities. Ongoing socialization groups are offered to high school and college youth. Each group meets on a weekly basis and once a month, and both groups convene for dinner together. The topics of these monthly dinner meetings are dat-

ing, sexuality, and establishing boundaries, since this population often has a difficult time gauging boundaries and social cues when it comes to interacting with the opposite sex.

Counseling and support - Compass staff provides individual, family, and group support, both for youth and parents, to help them adjust and plan to live with their learning challenges.

Referral - Based on assessments of children and families, Compass social workers provide linkages with existing services in the community, e.g., therapy, socialization, learning specialists, and training. Westchester Jewish Community Services has the capacity to provide these linkage services.

Professional training - Compass provides training for professionals working with this population in JCCs, synagogues, and school districts, with an emphasis on working with older children. Compass staff and guest speakers deliver lectures about topics affecting this population and are available to consult with other programs developing services for these youth.

The JCCA Compass Project is designed to help individuals with learning

see *Compass Project* on page 25

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Pictured here: Peer mentor and program participant

New York's Interagency Task Force on Autism Issues Recommendations

Calls for Improved Delivery of Services, More Access to Screening and Diagnosis, and Greater Training

By **Dixie S. Yonkers**
Senior Administrative Analyst
NYS OMRDD

In January, at the conclusion of 13 months of deliberation, the New York State Interagency Task Force on Autism sent its report to Governor David Paterson, the leaders of the New York State Legislature, and the Chancellor of the New York State Board of Regents. The report describes the needs and challenges faced by individuals with autism spectrum disorders (ASDs) and their families. It also makes numerous recommendations for how New York State agencies should address those needs within systems that support people with many different disabilities and needs. Within those recommendations, however, a focused message emerged: New York must improve its autism competency. It needs to focus on providing information and training for a host of different parties – physicians, educators, families, and even the community at large – so that knowledge of how to best serve, support, educate and understand individuals with ASDs spreads throughout our state, effectively elevating our communal ability to respond effectively.

New York's Task Force on Autism grew out of the Office of Mental Retarda-



Dixie S. Yonkers

tion and Developmental Disabilities (OMRDD) and its Autism Platform which put forth a wide range of activities that the agency would undertake to ensure its system was well prepared to support increasing numbers of individuals with ASDs. OMRDD is but one of several agencies that provide services and supports to individuals with autism, and as such, could only effect a small portion of the needed

statewide response to autism. The Task Force, co-chaired by the Commissioners of OMRDD and the State Education Department, would provide an opportunity for the leaders of New York's various service systems to examine how their respective parts of State government – in areas such as health, education, and disabilities services – together could provide lifelong support to New York citizens. The examination that ensued engaged the leaders and staff of eleven state agencies, each of which plays a key role in supporting New York's individuals with ASDs and their families to lead meaningful and productive lives.

The Task Force Process

The Task Force began its work in November 2008. It set out to examine how New York State government can prepare for providing a comprehensive system of lifelong support to the increased numbers of New Yorkers living with ASDs. It gathered input from a range of stakeholders on the needs and desires of those with ASDs and examined all the ways New York State agencies were already responding. In crafting its recommendations, the Task Force members agreed they would specifically seek to improve interagency coordination of services, to maximize the effectiveness of State ser-

vices and activities, to elevate New York State's ASD competency, and to identify opportunities for bringing private and public parties together in support of individuals with ASDs. And, they would do so in roughly twelve months.

With this time-limited charge, the Task Force members recognized the need to be efficient in their outreach. Still, they also knew they had to hear from New York citizens to confirm what they thought were the needs of individuals with ASDs and their families and to identify any newly emerging issues. The Task Force sought input from families, individuals and professionals through regional forums facilitated by the six regional Centers for Autism and Related Disabilities (CARDs) and through an online survey open to the public and posted on member agency Web sites. As a result, the Task Force obtained valuable insight from a wide range of parties in both a detailed discussion and questionnaire format (at the regional forums) and also through a very brief and specific survey. The input the Task Force received confirmed the trends and issues the State agency leaders and staff expected, but also provided new information about what the public feels are the most important priorities related to supporting individuals with ASDs and

see Task Force on page 26

Grandson from page 15

grandson's parents perceive it to be helpful, so try and gauge their reactions carefully.

- Avoid labels and technical terms, which may trigger fear or upset with the parents. Focus instead on discussing milestones, which are observable indicators of a child's development and accomplishments.
- In some cases, it may be beneficial to think about the discussion as a series of tiny conversations. This would be more appropriate if you have frequent contact with your son or daughter-in-law. It may then be helpful to share some observations that may provide a backdrop for later discussion (e.g., "Little Peter seems overwhelmed by noise levels" or "I have noticed that he does not seem to know how to use words to get his needs met."). It may also be helpful to discuss observations surrounding worrisome or absent peer or sibling interaction.
- Emphasize the need to simply get any concerns checked out in order to "rule out" anything serious or to get some guidance in how to promote skill development. You might follow this up by mentioning that the earlier a potential problem is recognized and addressed, the easier it is to help the child.

Most parents begin to become concerned that something may be wrong

when their child is between the ages of 12 and 18 months. If the parents are beginning to realize a potential problem exists, you want to gently urge them not to delay a preliminary assessment and evaluation. You should never take for granted that developmental concerns will automatically be addressed during routine visits to the pediatrician. Refer parents to resources such as books and good websites they can explore on their own (we emphasize the word "good" as there is a tremendous amount of misinformation about autism both in the media and on the Internet, particularly many false promises about autism treatment). The most helpful websites at this stage are often the ones that discuss developmental milestones. Parents often know when to expect their infant and toddler to sit up or take their first steps, but they do not know when they should begin to babble with inflection, point to things they notice or want, imitate gestures, or show interest in another child.

The following websites include milestones checklists, booklets, and charts, and a wealth of other helpful information:

Centers for Disease Control and Prevention
www.cdc.gov/ncbddd/actearly

The *Act Early* website contains an interactive and easy-to-use milestones checklist you can create and periodically update for children ages three months through five years, tips on sharing concerns with the child's doctor, and free materials you can order, including fact sheets, resource kits, and growth charts.

Autism Speaks

www.autismspeaks.org

The Autism Speaks website includes an Autism Spectrum Disorder Video Glossary of video clips designed to help parents and professionals learn more about the early red flags of autism, information about how autism is diagnosed, a resource library, and a free 100 Day Kit designed to help families of newly diagnosed children make the most of the first 100 days following a diagnosis of autism.

First Signs

www.firstsigns.org

The First Signs website contains a variety of helpful resources related to recognizing the first signs of autism spectrum disorder, and the screening and referral process. There is a directory of local resources for at least eight states and we think it is likely that the number of states represented will increase over time.

American Academy of Pediatrics (AAP)

www.medicalhomeinfo.org/health/autism.html

The AAP website contains information for families, links to many other web sites, information about pediatrician surveillance and screening, and early intervention. This site contains great tools for pediatricians as well and parents.

Association for Science in Autism Treatment (ASAT)

www.asatonline.org

On the ASAT website, you will find extensive information about the scientific support (or lack thereof) behind the full array of treatments proposed for autism, research reviews, articles and guidelines on how to make informed choices and weigh evidence in selecting treatment options, a section of frequently asked questions such as the one you asked, information about upcoming conferences of interest, and links to helpful sites and other science-based organizations. You can also sign up for ASAT's free quarterly newsletter, [Science in Autism Treatment](#).

In summary, we think it is commendable that you desire to share your concerns in a sensitive way with your son and daughter-in-law. We hope that this advice has been helpful to you, and we wish the best for your grandson's future. In the event that your concerns are founded and your grandson receives a diagnosis of autism, we recommend that your family refer to the 100 Day Kit from Autism Speaks and learn all they can about applied behavior analysis, the treatment for autism that has the most compelling scientific support. The website of the Association for Science in Autism Treatment would be an incredible resource for families as well.

Peggy Halliday, MEd, BCBA is Director of Outreach Services at the Virginia Institute of Autism. David Celiberti, PhD, BCBA-D is President at the Association for Science in Autism Treatment.

The Transition from Preschool to School-Age Special Education: CPSE to CSE

Ilene Solomon, PhD
Institute for Cognitive Diversity
Bank Street College of Education

Transitions from one school setting to a different school setting may be cause for anxiety for parents. This article is intended to provide information on the transition from special education services in the preschool setting to special education services in kindergarten.

From three to five years of age, special education services are deemed appropriate by the Committee on Preschool Special Education (CPSE). During the transition to kindergarten and through high school, these decisions will be made by the Committee on Special Education (CSE). Funding for services under CPSE are provided by the county in which the child resides and the New York State Education Department. Funding for CSE services are provided by your local school district. Your local district is reimbursed for some but not all of the expense through state and federal funding.

What is the CSE?

The CSE is a multidisciplinary team that consists of a school psychologist, special educator, general educator and a representative of the school district who is qualified to understand the instructional



Ilene Solomon, PhD

implications of the evaluations and is knowledgeable about the district resources. The school psychologist or one of the educators may serve as the district representative. You as the parent are also a member of the CSE. There may be a parent member who has a child with a disability and resides in the school district. As the parent you may request that the parent member not participate. Any

person who has knowledge of the student may be invited to the CSE by either the parent or the district. These people usually include professionals who have worked with the student in an ancillary capacity such as speech and language therapists, occupational therapists, etc. A district physician can be a member of the CSE but her presence usually requires a request be made at least 72 hours prior to the meeting.

What Type of Services
 Will My Child Receive?

Children on the autism spectrum who are receiving special education services in a preschool setting are receiving interventions of varying types and intensities. These interventions can range from itinerant services given in a regular education preschool to a self-contained special education setting with ancillary services. The services provided in preschool are based on the child's functioning and development in various domains (language, fine motor, gross motor, cognitive, behavioral/emotional) and how the functioning impacts **appropriate activities** such as communication skills. There is no interest in formal educational skills during the preschool years. A range of services may also be provided in kindergarten. Services will be based on your child's current functioning and how this functioning might interfere with **educational attainment**. Not all children with an autism spectrum disorder will receive the same services.

There are two guiding principles for providing special education services. One is a "free appropriate public education" (FAPE) and the second is "the least restrictive environment" (LRE). That is, students with a disability have a right to be educated with typically developing peers to the greatest extent possible and they should be provided with this at no cost to parents. Students should have access to the general education curriculum and extra-curricular activities. Some students will need a more "restrictive" setting either in a special education classroom or in a special education school. That is, some students need a more protected and controlled environment in order to best learn at various points in time. Since there are differences among students with disabilities, there is no single definition of what a LRE will be for all students.

How Will the Type of
 Services Be Determined?

To determine what an appropriate setting is for a student, a team will review the student's needs. Several approaches may be utilized. These may include:

- Reviewing preschool records which include reports and evaluations.
- Observing your child at his current

see Transition on page 28

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Robin's Voice

A Resilient Mom's Commentary on Autism



Accessing Clinical Treatment - Parents Must be Educated Consumers

By Robin Morris
Freelance Writer

It is human nature to bristle when we are told to calm down, while our inner cry is screaming, "Why my child!" We will stop at no roadblock to make a difference, to find a cure or an intervention that will temper the behaviors that autism presents. However, this feverish pitch can render parents vulnerable and willing to buy anything from snake oil to shaman ritual.

Autism awareness prompts a kaleidoscope of interventions. What disturbs me is the relationship between those receiving remuneration and those vulnerable parents who simply want to believe. Navigating the journey through accessing clinical treatment for autism is a daunting task. Unguarded parents are not prepared for the onslaught of opportunists. There is money in autism, and it is not unreasonable to advise the buyer beware policy. Nevertheless, parents have to start somewhere, and it is



Robin H. Morris

advisable to ask as many questions as you deem necessary.

I have worried about the criticism of conventional medicine. It is the tease for truth from fact that begs reprimand. The notion of a "one stop shop" to tempt parents living with autism is seductive. I bear no umbrage toward individuals who integrate hands on therapy with a data-taking trial process for behavioral intervention. I worry about the potions and anecdotal testament of success.

Conflict of interest is the operative term. We know the obvious answer as to who profits from vaccine sales and drug sales; however the population benefits as well. The next question is, who gains from book sales, bio medical sales, vitamin sales, and hyperbaric oxygen therapy sales etc.? It is a tricky conundrum because all roads do not lead to one simple answer. A few short years ago the touted "cure" was a series of Secretin injections that cost parents thousands of dollars. Ultimately, it proved no more effective than placebo.

We need to be educated consumers. Be pro-active!

- Make a list. Create a hierarchy of what about autism impedes the life of your child and your family. Establish your priority needs.
- Look for resource websites (example, Autism Speaks resource guide: www.autismspeaks.org/community/fsdb/search.php).
- Investigate services within your state and what are your child's rights.
- Ask questions about success with evidence (data), inquire about references.
- Remember, no question is too insignificant. You are the driver here!

Robin Hausman Morris is a freelance writer and can be reached at Robin-HausmanMorris@gmail.com. Robin is a parent examiner for *Examiner.com* - www.examiner.com/x-3565-Hartford-Parenting-Examiner.

ABA Intervention from page 11

supported, most effective treatment procedures. Effective treatment procedures have been validated as having both long-term and short-term benefits to clients and society.

(b) Clients have a right to effective treatment (i.e., based on the research literature and adapted to the individual client).

(c) Behavior analysts are responsible for review and appraisal of likely effects of all alternative treatments, including those provided by other disciplines and no intervention.

These guidelines are pivotal in defining how behavior analysts treat individuals with autism. Behavior analysts recommend interventions that have demonstrated effectiveness. Behavior analysts are familiar with levels of evidence, and recommend evidence-based interventions. They remain familiar with the research literature and with the evolution of clinical practices in the field, so that they continually alter their recommendations in response to the evolution of scientific knowledge.

In addition to recommending interventions that are evidence-based, behavior analysts may assist parents and teachers in evaluating the impact of alternative or ancillary interventions. They use their knowledge of the science of behavior and of research design to help determine functional relationships for individual clients. There is a value on understanding func-

tional relations across all interventions used for individuals. (In other words, behavior analysts want to determine cause and effect relationships. They want to be able to identify the specific variables responsible for behavior change. They seek to show relationships between variables - social greetings increased when reinforcement was used, stereotypy decreased in the presence of preferred music, aggression decreased when tasks were modified or choices were provided, etc.).

Behavior analysts want to help parents and educators make treatment decisions that are data-based and that are based on a demonstrable level of effectiveness. Behavior analysts possess the skills to design methods to study an intervention on an individual level. This approach helps to objectify the question of whether a particular intervention should be tried with a particular learner. There are some interventions that are clearly harmful or ineffective for individuals with autism, and these would not be recommended by behavior analysts (e.g., facilitated communication). However, many interventions have yet to be shown to be effective or ineffective. They may lack data regarding their effectiveness, data may be mixed, available studies may be weak or flawed, or there may be a paucity of data that are meaningful or objective.

These are the interventions that a behavior analyst might design a strategy to evaluate on an individual basis. It is not likely that a behavior analyst would recommend such interventions, but it may be the case that they could assist the family or

members of the educational team to assess the impact systematically and rigorously.

However, the value on effectiveness overrides a desire to explore ancillary interventions that are not likely to be effective or that have not shown promise with the learner. Most importantly, a behavior analytic view requires that the data determine the treatment. If interventions do not show merit, they should be discontinued.

Summary

To understand ABA intervention, one must understand the dimensions of behavior that are so highly valued by practitioners. It is essential that we target behaviors that are important, that we evaluate our success by transfer of skills to real-world contexts, that we assess for generalization, and that we identify controlling variables. Our recommendations for treatment come from the research literature. We can use our science to investigate the impact of experimental interventions, as long as they do not diminish access to effective intervention. In behavior analytic intervention, data guide decisions about treatments to recommend and to continue. Practice evolves based on the objective verification of success.

References

Baer, D. M., Wolf, M. M., & Risley, T. R. (1968). Some current dimensions of applied behavior analysis. *Journal of Applied Behavior Analysis*, 1, 91-97.

Fenske, E. C., Krantz, P. J., & McClannahan, L. E. (2001). Incidental teaching: A not-so-discrete-trial teaching procedure. In C. Maurice, G. Green, & R. M. Foxx (Eds.), *Making a difference: Behavioral intervention for autism*. Austin, Texas: Pro-Ed.

Lovaas, O. I. (1987). Behavioral treatment and normal intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, 55, 3-9.

MacDuff, G. S., Krantz, P. J., MacDuff, M. A., & McClannahan, L. E. (1988). Providing incidental teaching for autistic children: A rapid training procedure for therapists. *Education and Treatment of Children*, 11, 207-211.

McEachin, J., Smith, T., & Lovaas, I. (1993). Long-term outcome for children with autism who received early intensive behavioral treatment. *American Journal of Mental Retardation*, 97, 359-372.

Sallows, G. O. & Graupner, T. D. (2005). Intensive behavioral treatment for children with autism: Four-year outcome and predictors. *American Journal on Mental Retardation*, 100, 417-438.

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Psychologist from page 1

with the goal of modifying them in positive ways. This kind of approach may be most beneficial as parent or teacher training for those who need assistance helping a child with AS manage.

No matter what the orientation of a particular psychologist, the consumer should inquire about their expertise in dealing with individuals on the autism spectrum and the specifics about how their intended treatment is appropriate and useful. Sometimes adolescents and adults complain that they have spent years with a therapist who did nothing to change their skills or help them solve problems, so not only is it important to choose wisely initially, but it is also critical to reevaluate periodically the effectiveness of ongoing treatment. In recent years, researchers have developed more effective therapeutic tools that psychologists may employ that truly address the unique issues of individuals with AS. But this knowledge is by no means common and professionals who have it must be sought out if one wishes to participate in meaningful treatment.

Psychologists may provide individual psychotherapy, group psychotherapy, individual social skill/cognition treatment, group or dyadic social skills treatment, consultation to schools and programs, parent training, psychoeducation, couples therapy and other unique treatments. An evaluation of an individual's particular issues should lead to a recommendation of what types of approaches would be most beneficial. As individuals with AS vary so widely it is important that the professional understands that treatments must be as diverse as the individuals who need them. Any of the following may be an individual's prominent issue, and changes in age or circumstances may moderate some problems but reveal others.

- Individuals with AS may have particular difficulty with the speed of processing visual, social, or auditory information. When everyone around



Lynda Geller, PhD

you understands input more efficiently than you, you may quickly become confused or lost. Years of such experience can create a wide gap between the person with AS and the neurotypical world. There are particular strategies to address this issue. If this is a significant problem, it would be wise to ask a provider about what direction treatment for this issue might take.

- Many, but not all, individuals with AS have difficulty with facial recognition and/or understanding nonverbal communication. There are evidence-based interventions that address these specific issues and treatments that can improve function in this area.
- Many individuals on the autism spec-

trum have a variety of sensory issues. Some diminish with age and others may not. There is a relationship between impaired social skill and degree of sensory over-responsiveness (Hilton et al., 2010.) A psychologist may help an individual, a family, or a teacher understand the effects of sensory sensitivity and how to cope in various environments. An occupational therapist (with expertise in sensory issues) may provide evaluation and treatment of sensory dysfunctions and sensitivities.

- Executive function refers to a wide range of abilities including planning, organization, goal selection, patterns of remembering, flexibility, self-regulation, inhibition, and shifting set. They are called executive functions because they represent the organization and control mechanisms of the brain. Individuals with ADHD, AS, nonverbal learning disability and related conditions may struggle with these issues. Individuals with AS often have particular problems with the self-regulation aspects of behavior associated with executive function deficits (Semrud-Clikeman et al., 2010). Psychologists and neuropsychologists may be able to intervene in productive ways to teach children and adults with these challenges how to cope with these differences or may instruct families or schools who may not understand this type of disability in the context of an otherwise very intelligent person.
- So-called comorbid conditions are those that co-occur with something else. Anxiety disorders and depression are more common for individuals with AS than they are in the neurotypical population (Matilla et al., 2010) and require specific knowledge of Asperger Syndrome to be treated effectively. Gaus (2007) published a
- Anger management treatment is widely available, but does it take into account the causes for anger a person with AS might have? Generic treatment is unlikely to be useful as individuals with AS may have unique issues that affect anger including poor executive skills, rigid thinking, histories of bullying, poor recognition of specific emotions, or unfair hiring and firing procedures in employment. Carefully assessing the precursors of anger problems requires a thorough understanding of the effects AS may have and the specific circumstances and history of the client.
- Meltdowns (inappropriate behavioral dyscontrol often inconsistent with a person's age or intellectual maturity) are most often considered to be childhood issues, but adolescents and adults with AS may continue to struggle with behaviors that appear inappropriate, and even frightening to others. Meltdowns may be caused by high levels of anxiety, rigid expectancies, confrontational interactions styles of authority figures and various other difficulties specific to AS. Recognizing the particular cause and having an array of treatment strategies is critical to helping the child

see *Psychologist on page 29*



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Internet Resources for Science-Based Treatment of Autism Spectrum Disorders

By Lauren Agoratus, MA
Parent
Family Voices NJ

There are a variety of treatment options for children with autism. Families may be overwhelmed with the number of different therapies available and how to figure out what's best for their child. It's important to remember that the cause of autism is not known (possibly multiple genetic and environmental factors), and as of now there is no cure. But there is treatment, and hope.

Research shows that early intervention, which means treatment at a younger age, is the most effective and has the best outcomes for children with an autism spectrum disorder. A good starting point for families to sift through the tremendous amount of treatments available is to find out what science says works. "Educating Children with Autism" was a national study of all the clinically re-



Lauren Agoratus, MA

searched interventions proven effective and can be read online for free at [http://books.nap.edu/openbook.php?](http://books.nap.edu/openbook.php?record_id=10017&page=R1)

record_id=10017&page=R1.

The American Academy of Pediatrics (AAP) also has guidelines on treatment. They focus mostly on behavior management and "habilitative therapies" such as speech, occupational, and physical therapy as well as educational interventions. The AAP stresses the importance of family involvement and parent/professional teamwork. At this point, there are no medications specifically recommended for autism but pharmacological options are also mentioned in the guidelines. They can be found at: <http://aappolicy.aappublications.org/cgi/content/full/pediatrics;107/5/e85>.

The AAP also recognized that there may be secondary conditions possibly associated with autism such as sleep disorders, gastrointestinal problems, and seizures. They also discuss consideration of "complementary" medicine. This article can be found at: <http://aappolicy.aappublications.org/cgi/content/full/pediatrics;120/5/1162#SEC3>.

It is important for families to recognize that *there is currently no single*

treatment for autism. They should also remember that if their child is referred to a specialist, the provider should be a *pediatric* specialist who works with children. The Centers for Disease Control guidelines for autism treatment can be found at: www.cdc.gov/ncbddd/autism/treatment.html. These guidelines discuss the effectiveness of behavioral intervention, therapies (speech, OT, PT), sensory integration, communication techniques, dietary approaches, and medication.

These internet resources offer vital information for families of children with autism to learn about what evidence-based clinical treatment best practices are available.

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Compass Project from page 19

differences identify, plan for, and achieve a realistic career and educational direction. The program does not accomplish this through a regimented evaluation of a client's ability to collate and copy papers, fold clothing, or bag groceries. We accomplish this by evaluating each unique individual, and not by simply seeing how he or she fits into society's preconceived notion of what a person on the Spectrum is capable of doing to earn a living.

The Compass Project aims to educate clients through exploration of self and work. First, Compass staff speaks with an individual and administers a variety of assessments to help gain an understanding of three important factors: interests, values, and personality preferences. The conversation focuses on these factors because Compass clients are more likely to be successful in a work setting if they have passion and drive. Unfortunately, a large number of people in the world—whether neurologically typical or with special needs—don't work in jobs that

are intrinsically motivating. Ultimately, such individuals find themselves unhappy and dissatisfied with their work. As a culture, we spend a majority of our lives working, even more time than we spend with our family, friends, or in leisure pursuits. Since it is necessary to earn a living, everyone might as well do something they enjoy. The Compass Project realizes that this is especially crucial for people with special needs.

Compass Project's mental health professionals help individuals gain an understanding of their unique interests, values, and personality preferences in order to help develop a realistic picture of what it takes to achieve one's goals. This is accomplished primarily through finding experiential internships where clients gain a deeper understanding of the types of work that are most interesting to them. The variety of internship and job settings has been astounding. Examples include: a marionette puppet theater, an animal shelter, a local library, a physical therapy clinic, an assisted living home, summer camp programs, and a cable television studio.

Often these teens and young adults have unrealistic expectations. The program must then offer advice on how to explore alternative, but related visions of their goals and aspirations. If clients on the spectrum decide to pursue a college education, the Compass Bridges program provides support services on nine college campuses throughout Long Island, Westchester, Manhattan, and Queens County, with expansion in the works to many other institutes of higher education.

The JCCA Compass Project understands that clients often require additional assistance in developing their social and interpersonal skills. The program offers social and work skills programs for high school teens and college-age youth in the Bridges program. Additionally, Compass works directly with the internship staff to help sensitize employers to special accommodations clients might require. Working with parents helps them recognize their children's strengths and develop realistic expectations of what their children can accomplish. Through education

in the community, Compass fosters an environment where individuals on the Autism Spectrum can translate their skills to the workplace and their neighborhood.

Compass clients have battled all sorts of preconceived notions and low expectations imposed by a society that has not historically understood their needs. Participants in Compass often go on to graduate high school and college, and become happily employed. With individualized attention from trained professionals, a solid education plan, and patience from the community, every person on the Autism Spectrum can build an independent, fulfilling, and successful life.

Jewish Child Care Association is responding to the scarce and often unmet needs of high-functioning ASD and other special needs high school and college-aged youth in this region by providing hands-on, skill-based services

Elise Hahn Felix, LCSW, is Director of the Compass Project at the Jewish Child Care Association.

Free Support Group For Families of Adults with Asperger's Syndrome and High Functioning Autism

The focus of the support group is to assist families in understanding the complex issues related to their adult child impaired with Asperger's Syndrome or High Functioning Autism. At many of our meetings, we have speakers address various topics of importance related to these syndromes.

For further information contact the facilitators: Bonnie Kaplan - Parenttalk@gmail.com | Judith Omidvaran - Judyomid@aol.com

Socialization and Life Skills Group For Asperger's Syndrome and High Functioning Autistic Adults

Focused on: Employment & Vocational Issues, College Coaching & Supports, Socialization Self-Advocacy, Dating, and Relationships

For further information contact the facilitators:

Patricia Rowan, LMSW - (914) 736-7898 - Patrowan@bestweb.net | Susan Cortilet, MS, LMHC - (845) 406-8730 - Susan.cortilet@gmail.com

Meeting Dates: 5/23, 6/13

Westchester Arc
The Gleeson-Israel Gateway Center
265 Saw Mill River Road (Route 9A)
Hawthorne, NY 10532

Task Force from page 20

ASD research. Among the respondents, it was clear that New York State's top priority should be providing services to individuals. After that, providing training to service providers, educators and families was the second most important activity to undertake.

Public input to the Task Force also revealed the greatest need for services to be in special education, followed by behavior management training, access to clinical specialists with ASD expertise, transition services to assist students as they leave school, and respite opportunities. The lack of insurance coverage and the cost of services were identified as significant obstacles to service delivery, as were the availability of services and trained educators, clinicians and direct support professionals. Respondents voiced the need for all parties – teachers, families, physicians, direct support staff and emergency responders – to have greater information, information on behavior management, evidence-based treatments, accessing services, and local resources. Finally, the public told the Task Force that ASD research must focus first on early identification of young children with ASD and secondarily on the development of new treatment and educational methods.

Findings and Recommendations

With this information, the Task Force began searching for possibilities within the intricate workings of New York State's service systems. Five workgroups looked closely at how New York State could better respond to needs related to the early identification of children with ASDs, the adequacy and capacity of State services, the coordination of services for individuals over their lifetime, information dissemination, and the coordination of ASD research. Over several months, the workgroups identified 13 separate findings of need and numerous recommendations for overcoming those needs.

Recommendations of the New York State Interagency Task Force on Autism
A Call to Action for New York State

Early Identification

- Increase the use of screening for ASD in young children.

- Provide information and training on the assessment and diagnosis of ASD to physicians, mental health professionals and families throughout the state.

Information Dissemination

- Develop and maintain a New York State Web site on autism that provides information on ASD and New York State's autism initiatives and services.
- Use effective, non-Internet mechanisms to inform New Yorkers about ASD, the need for early detection, and New York State supports and services.
- Increase translation services, promote awareness of translation services and where possible, provide information in Spanish.
- Implement training programs to increase the cultural awareness and competence of service coordinators and case managers.
- Increase support and technical assistance for agencies service non-English speaking communities.

Adequacy and Capacity of Services

- Promote the use of evidence-based services through guidelines and training.
- Identify and disseminate information on evidence-based practices that support improved educational outcomes for students with ASD.
- Promote the availability of educational opportunities related to ASD for teachers, administrators and related service personnel.
- Continue investing in residential services that support individuals living in their own home, their family homes or in provider-managed housing.
- Develop a state-of-the-art model for delivering residential services for young adults and adults with ASD.
- Develop sufficient in-state Children's Residential Program opportunities for children whose needs require specialized residential settings.

- Establish mechanisms to support collaboration between State agencies and school districts in transition planning for students.

- Identify effective crisis avoidance and response practices and promote these practices throughout New York's service systems.

- Provide information to parents regarding reliable, evidence-based practices to address behavior issues in the home, classroom and community.

- Monitor ongoing national studies regarding barriers to employment for young adults with ASD and effective practices for supporting individuals with ASD in employment and initiate improved New York State services for adults with ASD seeking employment.

- Disseminate information on best practices and training related to supported employment services and fostering successful school-to-work transition for students with disabilities, including ASD.

Coordination of Services

- Develop and implement training programs throughout New York State to help service coordinators work in multiple systems.

- Explore innovative forms of delivering primary care which can provide medical care and social and educational services coordination.

- Identify ways to ensure that families and individuals are provided access to service coordination.

- Examine the need for guidance regarding payment by private insurers for medical and mental health services associated with ASD.

- Publish clear, concise information regarding eligibility criteria for services provided by the different New York State agencies.

- Explore options for clarifying and streamlining the eligibility and intake processes for New York State's numerous service systems.

- Identify the number of individuals in New York State who fail to meet service eligibility criteria and their unmet service needs.

Coordination of Research

Develop a State Autism Consortium to advance greater understanding of ASDs and effective treatment and services. Make the study of ASD treatment methods and the translation of research results into improved practices priorities for a New York State Autism Consortium.

Continuing Momentum and Gaining Ground

The Task Force was challenged to identify a State response to the needs of its citizens with ASDs that can occur within the current economic decline and resulting budget crisis. Its findings and recommendations speak to what the State must do, what the needs demand, but could fall victim to shortages in staff and resources. The Task Force members intentionally went further, however, to identify short-term steps that will direct meaningful and manageable actions State agencies can take today, within the present fiscal crisis, to move New York's services systems toward the recommended actions and toward greater effectiveness and efficiency. These very specific short term steps are described in the Task Force report and represent the next chapter in ongoing agency collaboration that must remain at the heart of New York State's response to autism.

The Task Force report was submitted to Governor David Paterson, the leaders of the New York State Senate and Assembly, the New York State Board of Regents, and the Inter-Office Coordinating Council which promotes and directs solutions to cross system needs. Through the Task Force process, New York's service agencies effectively identified the course ahead, both in the long and short term. They are now poised together at the starting line, with a shared line of sight on the immediate steps before them.

For a copy of the Task Force report, visit: www.nyacts.com and click on "New York State's Response to Autism."

**New York State Launches Autism Web Site – NYacts!**

In examining the many needs of New Yorkers related to autism, the New York State Interagency Task Force on Autism found a tremendous need for information about autism spectrum disorders (ASDs) and about the many services and supports available to individuals and families from New York State agencies. In response, the Task Force created NYacts — New York's Initiative for Addults and Children on the Autism Spectrum. NYacts

(www.nyacts.com) now provides citizens with a one-stop, online resource about autism and New York State services.

"NYacts will bring reliable, current information to the public about autism and assist New York's families to easily find State services for their loved ones with ASDs," said New York State Office of Mental Retardation and Developmental Disabilities Commissioner Diana Jones Ritter.

Because individuals with ASDs may need services from different State systems – education, health, mental health and developmental disabilities services – NYacts offers a dedicated site from which people can get the information they need without any prior knowledge of New York's service agencies.

"NYacts has resulted from and will continue to demonstrate how our government is working together in an effective and integrated way," said Ritter.

In addition to information on autism and New York State services and supports, NYacts provides news stories related to ASDs, the answers to frequently asked questions, profiles of New York citizens of all ages living with ASDs, and information on important laws, events and trainings, New York's network of Centers for Autism and Related Disabilities (CARDs), and New York State's many autism initiatives. A cross-agency committee will maintain the Web site. As scientists and others improve our understanding of ASDs and identify effective practices in diagnosis, assessment, treatment and education for individuals with ASDs, the committee will continue to promote and expand NYacts as a means to bring the latest information to a wide range of parties.

The following New York State agencies participated in the Interagency

Task Force on Autism and the development of NYacts:

- Office of Mental Retardation and Developmental Disabilities (Co-chair)
- State Education Department (Co-chair)
- Department of Health
- Office of Mental Health
- Office of Children and Family Services
- Developmental Disabilities Planning Council
- Commission on Quality of Care and Advocacy for People with Disabilities
- Council on Children and Families
- Office of Temporary and Disability Assistance
- Office of Alcohol and Substance Abuse Services
- State Insurance Department

Cartwright Interview from page 9

huge media story and many parents spent thousands of dollars and traveled long distances to find centers that would give their children intravenous infusions of this substance with no follow-up and no adequate evidence of positive outcomes. Great public pressure was placed on the National Institutes of Health to invest millions of dollars in Secretin research. Since then many studies have shown that Secretin has no ability to improve the symptoms associated with autism. The hype was never based on evidence.

So what did we learn from that? Be careful of anecdotal reports especially when they make claims of significant improvements based on the experiences of just a few individuals. When a clinician prescribes a particular treatment, it should be based on knowledge of the latest scientific literature, as well as a very good assessment of the problems faced by that particular patient. Let's use the example of obsessive compulsive symptoms in a child with autism. I would clearly identify the behaviors/symptoms that will be targeted; obtain a baseline measure of their severity, frequency, and how much they interfere with functioning by talking to the family and using a scale such as the Yale-Brown Obsessive Compulsive Scale; and then choose between the treatments that have been proven effective in the scientific literature. My follow-up will include a reassessment using the same scale so there is some objectivity in measuring progress over time.

In addition, it is important to consult with teachers, therapists and other professionals working with the child about how they experience the child in different settings, and combine this information with the reports given by the parents about the behaviors. I ask, "How much change has there been?" I am aware that there may be a positive change, no change or a negative change in symptoms. When prescribing medication, it's always important to have a very detailed assessment of safety. We might see great improvement in a par-

ticular behavioral domain, but we need to be equally vigilant of the side effect issue and the ongoing safety of the medication. We need to constantly weigh the benefits versus the risks of being on a psychotropic medication, that's the efficacy (how effective is this medication in reducing the severity of the symptom that you have identified), in relation to the safety (ongoing vigilance in determining short-term, medium-term, and long-term side effects).

This requires monitoring over time. A medication may work well initially and then shift. For example, parents may describe a significant improvement in anxiety in the first couple of weeks but two months later there may be a subtle but important deterioration. It's important to remain vigilant and keep adjusting treatment.

Q: What evidence-based treatments do you feel hold great promise for your patients with autism? Is there anything new on the horizon?

A: The Early Start Denver Model that was published in a manual form late last year demonstrated clearly that an early intervention model that is short-term (10-12 weeks) training parents to interact and intervene with their children can significantly improve the developmental outcome of their children. Models of intervention that use both relational and structured behavioral techniques (such as Applied Behavioral Analysis) in an integrated way can lead to significant improvements. Studies show that the earlier we make the diagnosis and offer interventions, the better the outcome. Children can improve their social and emotional skills, their language, their level of curiosity in their environment, and have fewer repetitive behaviors.

From a pharmacological and biological point of view, the promise is what genetics is bringing to this field. New genetic syndromes are being identified. Some people who were given the diagnosis of autism may be found to have a different diagnosis based on genetic testing. With time, we will be able to tailor treatments that are specific to the genetic

mechanisms that give rise to the disability. This has happened with Fragile X Syndrome where the gene has been identified and treatments are being tailored to this syndrome. And this is what we can look forward to in the field of autism.

Another exciting development is in the translation of findings from animal studies to clinical treatment. For example, a recent study published in the *Proceedings of the National Academy of Science* showed that a small group of adults with high-functioning autism and Asperger's syndrome who were given oxytocin inhalations showed distinct improvements in their sociability and distinct changes in the way that they looked at social signals. This included the way that they viewed faces — where they would spend more time looking at eyes in contrast to looking at other parts of the face that were not as socially relevant. This study is promising because it points to a treatment that may improve the core symptoms and behaviors of people on the autism spectrum, namely social/emotional skills. We have a lot to learn about oxytocin inhalations because we are not sure what the dose should be, how often it should be administered, who might benefit, and most importantly, what the safety issues are. So we need to learn a lot more as we pursue this potential line of treatment.

Q: It certainly is a very exciting time with all the groundbreaking research and new science being conducted in the autism field.

A: Absolutely. When I speak to medical students and residents who are considering careers, I stress how interesting and groundbreaking the field of autism spectrum disorders is and how optimistic I feel about the rapid progression of new science which is being incorporated into current clinical practice every day. The research has as its goal to improve the quality of life for people with autism spectrum disorders and their family members.

Q: What hopeful message would you like to leave with parents?

A: It is never too late to learn and grow and develop. We are discovering that the brain has an amazing ability to adapt and change. In the past it was assumed that there are windows of opportunity and if you intervene during that period, then improvement can occur but if you intervene outside of that window, then treatment won't help. That's just not the case. People of all ages can improve given the proper type of biological and behavioral treatments. New treatments and interventions are currently being tested and many of these show promise. There are life-long opportunities for your child, adolescent or adult with an ASD to participate in effective interventions.

Charles N. Cartwright, M.D., is Director of the YAI Autism Center at the YAI Network. He is an expert in the diagnosis and treatment of autism spectrum disorders in children, adolescents and adults. He is a board certified child and adolescent psychiatrist and a faculty member in the Department of Psychiatry, Child and Adolescent Division, at the University of Medicine and Dentistry of New Jersey.

Previously, Dr. Cartwright served as the Director of the Autism Center at UMDNJ where he directed autism clinical, research and educational outreach activities. He ran a large clinical practice, lectured widely on autism-related topics, advocated for legislative and policy initiatives as a member of the New Jersey Governor's Council on Autism, which enhanced autism clinical centers throughout the State of New Jersey, and conducted research in autism genetics, neuroimaging and psychopharmacology.

Dr. Cartwright completed a general psychiatry residency in Cape Town, South Africa, as well as fellowships in child and adolescent psychiatry at New York University/Bellevue Hospital and autism research at the Seaver Autism Center for Research and Treatment at the Mount Sinai School of Medicine.

For more information about the YAI Autism Center visit yai.org/autism or call 1-888-YAI-AUTISM (1-888-924-288476).

Vaccine Court from page 7

to be compensated. And if you look at other rulings, this court tends to err on the side of overcompensating to avoid a big spillover into civil courts. Another goal of the vaccine court is to avoid massive civil litigation that could put us back where we were in the early 1980s where companies were exiting the vaccine manufacturing business over fear of litigation.

Several anti-vaccine organizations have complained that the "deck is

stacked against children in vaccine court because the court is government run, investigating a government-recommended vaccine schedule," but the facts do not bear out this claim. In fact, over 2,400 vaccine court plaintiffs (80% of whom were children) have received compensation from the vaccine court. The difference is that these families were able to tie a reported vaccine injury to the vaccine. The plaintiffs in the autism cases were not.

It's natural to want to understand why

your child was diagnosed with autism and hard to accept the idea that a child may struggle and have huge challenges all their life. It's also natural to want to blame someone or something. But families need to look at the data. Parents can't be so focused on anger that they lose sight of what the science is saying because that's not in the best interest of the kids. At the Autism Science Foundation we always encourage parents to look at the science and make decisions based on the science. And this is what the special

masters did. They looked at the data.

Hopefully after today's ruling, we can put this issue behind us and move forward and direct our scarce autism research dollars to studies that will provide new information about what causes autism and how best to treat it.

Alison Singer is President of the Autism Science Foundation (www.autismsciencefoundation.org). She has a daughter and an older brother with autism.

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GOT ASPERGER'S?

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Child, Adolescent, Adult, Family
PDD, Autism, Asperger's Syndrome,
ADHD, Behavior Problems, Parenting,
School Consultation, Supervision

Transition from page 21

program and/or discussion with your child's current teachers.

- Obtaining information from you as the parent.
- Kindergarten screening (it is required that all children be screened for kindergarten).

The CSE will determine whether any other evaluations are necessary and if deemed necessary will conduct them. Decisions will be made from evaluations, professional reports and parent input. Any new evaluations should take place by April or March prior to September entry into kindergarten. A meeting with the CPSE will take place toward the end of your child's stay in the preschool program to recommend special education services (if any) for kindergarten. The CSE will then conduct a meeting with the preschool team. Sometimes these meetings occur consecutively. If at all possible, it is better for parents to ask for the CPSE meeting to take place before the CSE meeting and not have them one after the other. It can be daunting for parents to absorb all the information, and it is better if parents have time to think about and digest the recommendations from the preschool before meeting with the CSE. If there must be consecutive meetings, then it is advisable that parents familiarize themselves with the transition recommendations of the preschool team.

What Types of Services Exist?

There are a range of services that districts may provide. These may include **related services** such as psychological, speech and language, physical and occupational therapy, social work services, etc. These services will be given a certain number of times per week. Sometimes they are given as "pull-out" services where the child goes to another location and sometimes they are given as "push-in" services where the appropriate service is provided in the classroom. Sometimes there is a combination of the two. **Supplementary services** include services that support the student in the regular education setting such as: one to one paraprofessionals, assistive technology and consultant teachers. **Testing accommodations** may include testing in another venue, increased test time, use of a calculator and modification of test items. **Special Education** means that your child is entitled to "specially designed instruction" that meets the particular needs of your child. This may happen in a regular education classroom with pull-out resource room, an inclusion or co-teaching classroom where there is a special educator and a regular educator or any combination of the above services. It will depend on what your child's needs are and how the district proposes to meet those needs. Some children will not receive any services after preschool because it is deemed that they are no longer necessary.

Will My Child Be Classified?

Yes. This is one of the major differences between CPSE services and CSE services. Under CPSE your child had a generic classification, "preschool child

with a disability." Under CSE your child must have an educational classification in order to receive services. Educational classifications are different than medical diagnoses. For example, your child might have a medical diagnosis of ADHD; however there is no educational classification that directly corresponds to ADHD. This does not mean that your child will not get services. There are 13 classifications which are used. These include: *Autism, Deafness, Deaf-Blindness, Emotional Disturbance, Hearing Impairment, Learning Disability, Mental Retardation, Multiple Disabilities, Orthopedic Impairment, Other Health Impairment, Speech or Language Impairment, Traumatic Brain Injury and Visual Impairment*. Children who have an autism classification are entitled by NY state law to particular services which **may** include parent training for behavior problems as well as daily speech and language therapy.

In addition, NY State has developed guidelines for educational programs for children with autism. They can be found at www.vesid.nysed.gov/specialed/autism/apqi.htm. The guidelines were developed by a group of professionals who were experts in autism spectrum disorders and describe criteria necessary for appropriate educational programming for students with autism.

The Individual Education Program (IEP)

An IEP may also be called an Individual Education Plan. A school-age IEP will be developed at the CSE meeting. It should include:

- A description of your child's "present levels of educational performance." This includes how your child's disability affects her involvement and progress in the general curriculum.
- **Measurable** annual goals for your child to reach and who is responsible for helping the child reach these goals.
- A statement of the special education and related services needed for the child to meet the goals and to progress in both the general education curriculum and extra-curricular and nonacademic activities.
- Supports for the student's teacher to help reach the goals (i.e., consultant teacher, training).
- The student's placement and when it will begin.
- If your child will not be participating with typically developing peers then the IEP needs to provide an explanation of why this is appropriate and the extent of non-participation.

Re-evaluation

Annual goals and placements are reviewed at least yearly. They can be reviewed more frequently if a particular program needs revision. Both parents and the school district have the right to convene a new CSE meeting to modify a student's program. Every three years there is a more in-depth review when your child will be re-evaluated (triennial evaluation).

As a parent, you have the right to disagree with the school district's IEP. You may disagree with the findings of their evaluations and the services they think should be provided based on the results of their evaluation. You are entitled to request an **Independent Educational Evaluation (IEE)**. An IEE is defined as "an evaluation conducted by a qualified examiner who is not employed by the public agency responsible for the education of the child in question." (Steedman, W). An evaluation is not limited to educational or cognitive skills. It may include the evaluation of any skill related to the child's educational needs. The results of the IEE must be considered by the school district. This does not mean that the district must implement the recommendations of the IEE but they must consider it. Many times parents pay privately for an IEE. The district is responsible for payment when:

1. The school district does not have the personnel to conduct a particular type of evaluation (i.e., a psychiatric evaluation) that the CSE has recognized may be necessary.
2. When the school district determines that an IEE is necessary.

Sometimes a district is forced to reimburse parents for an IEE after it has refused to pay for one. This may happen when:

1. The district may be required to pay when the IEE that the parent obtained provides information that affects the child's education, services, or placement.
2. If the parents disagree with a school district evaluation and request an IEE at public expense and the school district refuses to pay for it, unless the district requests a due process hearing and the hearing officer rules that an IEE is not necessary.

Parents are permitted to choose any qualified evaluator for an IEE. Sometimes a school district has a list of people they use to perform IEEs. Parents are not required to choose only from evaluators on the list. Basically, the point of obtaining an IEE is to get another **expert opinion** that will better help the school district understand the needs of your child. It is important for parents to seek out evaluators who have experience and expertise in these types of evaluations.

Parent's Responsibility

It is very important that parents have a good understanding of their child's strengths and weaknesses and how these may impact the student's functioning in an educational setting. You are your child's best advocate.

- Make sure that you have familiarized yourself with evaluation results, observations, and progress reports.
- Make notes to bring to the IEP meeting.
- Ask questions.
- Know the continuum of services your district provides.

- You do not have to agree with the school's recommendations. There are due process procedures and laws when you do not agree. There are particular laws and rules that apply to the transition from CPSE to CSE.

If you don't agree with the district's evaluations you may request a private impartial evaluation known as an IEE (Independent Educational Evaluation). There are procedures for making this request.

Special Considerations for High Functioning Children on the Autism Spectrum

School-based evaluations often use measures that are not sensitive to the complex challenges that these children have. For example, these children often have excellent vocabulary (semantic knowledge). However, they are weak in pragmatic skills (social aspects of language and communication). Children with HFA (High Functioning Autism) will often perform well on standard language measures because standard measures are so loaded on semantic knowledge. It is important that parents request that pragmatic skills be evaluated or observed. Frequently school therapists are unfamiliar with just how to assess these issues and they often go unmet unless parents are well informed and assertive.

Children with HFA have social skill problems as a core deficit. It is important that these areas be included in any IEP and that annual goals are developed to help students with these deficits. Parents should insist on evidence-based programs for social skill deficits. These types of programs provide opportunities for practice and foster family communication to ensure generalization of skills beyond the social skill development setting.

Most school-based evaluations do not assess executive functioning and again school personnel are often unfamiliar with how to evaluate them. These skills which underlie most tasks include motivation, persistence, flexibility of thought, getting started and organization. Most children with Autism Spectrum Disorders have some difficulties in these areas which makes learning more difficult for them. It is important to make sure that these challenges are evaluated and addressed in an IEP.

Advocacy Tips
(From Special Education Process in NY State - www.eastislipsepta.org)

- Be **involved** in every step of your child's life.
- Know your rights in the education process.
- Keep lines of **communication** open with the people who deal with your child (provide positive as well as negative feedback).
- Always work toward **solutions** when there is a problem. Insist that your child's educators create positive plans for change to correct any problem that exists. Be collaborative.
- **Be persistent.**

see Transition on page 30

Psychologist from page 24

- or adult with AS remain in inclusive settings and enjoy an acceptable quality of life. Finding a psychologist who understands this issue may make the difference between regular and special education, employment or none, or developing relationships or not.
- Social cognition is a prerequisite for the development of social skills, yet many people try to teach specific social skills in a vacuum. The development of social ability relies on learning to think socially and having an opportunity to practice and generalize. Many different kinds of professionals may offer social skills training. Geller (Autism Spectrum News, 2008) describes ways of judging the usefulness of particular social skills interventions. Professionals in private practice, clinics, or schools should be able to justify their approaches based on research and the individual's particular skill needs. Psychologists, speech and language pathologists, social workers, mental health counselors and others may provide useful social skills interventions, but should be queried as to their program and experience delivering it, and their specific plans for generalizability in the real world.

Finding a Psychologist

There are many organizations that may be able to help individuals or families get started finding a suitable psychotherapist. Parent groups or adult support groups may

well know professionals who have provided high quality care and they may be able to make specific recommendations. University programs that train professionals in autism spectrum conditions may also be a source of this kind of information.

Attending conferences about autism spectrum where clinicians present can also provide a window on a therapist's level of knowledge, attitudes, and manner. In addition, a conference venue can be a good place to network.

Networking among friends, acquaintances, or professionals you know may also be a good beginning. However, even positive recommendations do not negate the need to ask important questions about experience and understanding of the wide variety of issues that individuals with Asperger Syndrome may present.

The internet has lists of individuals who claim experience with Asperger Syndrome. In addition, there are multiple sites about Asperger Syndrome that can be a starting point for understanding specific issues and finding people with expertise. (www.aspergersyndrome.org, www.faaas.org, www.autism-society.org, www.autismspeaks.org, www.tonyattwood.com.au, www.grasp.org, www.ahany.org, www.aane.org). As with anything on the internet, resources found this way should be carefully vetted.

What Questions Should I Ask?

Nick Dubin (2009) has specifically described approaches for assessing psychotherapists. He notes that it is particularly difficult to find qualified therapists who treat adults. Of particular importance, in his experience, is to avoid professionals whose lack of understanding of AS causes harm.

As an adult with AS, Dubin stresses that asking good questions is important to finding someone who can really be of help. As has been enumerated above, there are so many variations of people and problems with AS that one should be seeking a person who "takes a highly individualistic approach with each client and doesn't use just one particular modality with everyone who has Asperger's" (Dubin, 2009).

Questions that can help you determine who can best help should include:

- What is your specific training about AS?
- How long have you been working with individuals with AS?
- Do you specialize in children or adults?
- What is your treatment orientation?
- How do you assess what kind of intervention you choose for your clients?
- Are you willing to learn about AS and seek mentorship from a knowledgeable professional in order to provide competent treatment?
- Do you have a working relationship with other clinicians in case other treatment modalities are needed?

In addition to specific questions, it is important to try to gain a feeling for the person's level of warmth and understanding.

- Explain why you are seeking treatment and listen to how the person responds to your particular issues.
- Assess if the person expresses genuine caring for individuals on the spectrum. A certain level of investment is neces-

sary to work out what can best help individuals with such diversity of being.

- Be prepared to let an introductory session be just that. If a psychologist cannot communicate an initial concept for treatment, he or she may be too inexperienced. It is not uncommon to meet two or three psychologists before making a decision of who is the best person to provide treatment.

In addition, even if you have been in treatment for some time, whomever you are working with should be willing to review progress every so often so that the joint decision to continue, refer elsewhere, or discontinue treatment can be fully considered.

There are a wide variety of professionals who provide psychotherapy including psychologists, psychiatrists, social workers, mental health counselors, or marriage and family therapists. Genuine understanding of Asperger Syndrome may be more important than any particular degree, and finding the right match of knowledge, approach, and authenticity is the key to effective treatment.

Lynda Geller, PhD, is Director of the Institute for Cognitive Diversity at the Bank Street College of Education. She is the founder of the Asperger Center for Education and Training (www.aspergercenter.com), a collaborative effort designed to 1) provide evidence-based, practical, current information about Asperger Syndrome and related conditions and 2) develop and provide innovative services to the community of children and adults with Asperger Syndrome and their families. She is also in private practice in New York City.

Effectiveness from page 14

is an assumption that variables other than the treatment could have produced the changes in what is measured, one must conclude that the treatment probably did not cause the changes.

The pretest-posttest design is fatally flawed with respect to internal validity. For example, if participants improve from pretest to posttest, the improvement could be due to simply the participants maturing (physically or psychologically) over the course of the experiment. Consider a research project done over the course of a year with preschoolers with autism. An improvement in assessment from pretest to posttest (after one year) could be due simply to the natural maturation of the participants, rather than influence of the treatment. Another possible threat to believing that a treatment caused any positive changes relates to participants who were chosen on the basis of extremely low scores (or extremely low performance) on the variable(s) being measured in the pretest. Generally, extremely low scores will often improve, and extremely high scores will often decline, given repeated assessments, just because they are so extreme. Thus, any study that involves participants because they scored very low or very high on the dependent measures, and that uses a pretest-posttest design, is open to this particular threat and thus one cannot believe that the treatment caused any improvement.

The one group pretest-posttest design is flawed by several additional internal validity threats not discussed here. The reality is that any attempt to demonstrate

the effectiveness of a treatment by using a pretest on one group of participants, then applying a treatment, followed by a reassessing the variables being tracked, will always be open to skepticism of linking improvement to treatment. This type of design will never allow strong confidence in the belief of a cause and effect connection between treatment and improvement.

All research is not equal in quality. Just because a research study has been conducted and shows positive changes in some aspects of autism does not necessarily mean that the treatment was responsible for those changes. Since autism is said by some to be a "fad magnet" (e.g., Jacobson, Foxx, & Mulick, 2005), parents and other consumers must critique any research study that purports to show a positive effect of a treatment, and try to determine if the positive changes could be due to other explanations, or could only be due to the treatment. By activating their "baloney detectors" (Sagan, 1999), parents, care givers, and service providers can avoid adopting treatments that have no proof of effectiveness, and thus be more likely to embrace treatments for which there is a body of well-designed research supporting a cause and effect relationship. Research in autism treatments that purportedly shows evidence of effectiveness, but that utilizes only pretest-posttest studies, needs to be viewed with caution and must not be thought of as producing valid conclusions that allow consumers and caregivers to believe that the treatment in fact works. Accessing clinical treatment services could be enhanced by better understanding of the flaws in this basic and commonly used research design.

Dr. Thomas Zane is an Associate Professor in the School of Education and the Founder and Director of the Center for Applied Behavior Analysis at The Sage Colleges. Dr. Zane earned his Bachelor's and Master's degree in psychology at Western Michigan University and his doctorate in Applied Behavior Analysis at West Virginia University. He is a licensed psychologist in New York and Massachusetts. Dr. Zane has published in various journals and books, presented at regional, national, and international conferences, and been an invited lecturer in Ireland and the Republic of China. He is the Director of the Center for Applied Behavior Analysis at The Sage Colleges, and offers a Master's of Science Degree in Applied Behavior Analysis and Autism, a distance-learning graduate program.

References

- Drew, C. J., Hardman, M. L., & Hosp, J. L. (2008). *Designing and conducting research in education*. Thousand Oaks, California: Sage Publications, Inc.
- Fraenkel, J. R., & Wallen, N. E. (2009). *How to design and evaluate research in education. Seventh edition*. New York: McGraw-Hill.
- Gay, L. R., Mills, G. E., & Airasian, P. (2009). *Educational research: Competencies for analysis and applications, Ninth Edition*. Upper Saddle River, NJ: Pearson.
- Gutstein, S. E., Burgess, A. F., & Montfort, K. (2007). Evaluation of the Relationship Development Intervention program. *Autism*, 11, 397-412.
- Jacobson, J. W., Foxx, R. M., & Mulick, J.A. (2005). *Controversial therapies for developmental disabilities: Fad, fashion, and science in professional practice*. Mahwah, NJ: Lawrence Erlbaum Associates, Inc.
- Krantz, S. (2009). Craniosacral therapy: Helping improve brain function. Retrieved March 8, 2010 at <http://www.upledger.com/content.asp?id=76&mid=2>.
- Linderman, T. M., & Steward, K. B. (1999). Sensory integrative-based occupational therapy and functional outcomes in young children with pervasive developmental disorders: A single subject study. *American Journal of Occupational Therapy*, 53, 207-213.
- Rossignol, D. A., & Rossignol, L. W. (2006). Hyperbaric oxygen therapy may improve symptoms in autistic children. *Medical Hypotheses*, 67, 216-228.
- Rossignol, D. A., Rossignol, L. W., James, S. J., Melnyk, S., & Mumper, E. (2007). The effects of hyperbaric oxygen therapy on oxidative stress, inflammation, and symptoms in children with autism: An open-label pilot study. *MBC Pediatrics*. Retrieved on March 8, 2010 at <http://www.biomedcentral.com/1471-2431/7/36>.
- Sagan, C. (1996). *The demon-haunted world: Science as a candle in the dark*. New York, NY: Random House.

Parent-Implemented from page 13

Pretend Play, Social Engagement, Flexibility, and Reciprocity.

While research into the efficacy of ESI and other parent-implemented programs is in its infancy, there is growing evidence of the generic value of teaching parent *responsiveness* in any intervention program. Siller and Sigman (2002) compared samples of children with ASD with parents showing low- and high-level synchronization skills (defined as following the child's focus of attention and engagement) during an initial sample of play behavior. They found that children of parents with high-level synchronization skills had better joint attention skills a year later and better language outcomes a full ten and sixteen years later.

A preliminary study of ESI using a sample of young toddlers at risk for ASD indicated significant improvement on eleven of thirteen social communication measures. For example, gains were evident in the areas of joint attention (i.e., gaze shifts, shared positive affect, gaze/point follow, and communicating for joint attention) for toddlers who entered treatment at two years of age (Wetherby and Woods, 2006). These preliminary results suggest that for families who are successful at learning and can provide this intervention at adequate intensity, ESI is a cost-effective and naturalistic means of delivering appropriate early intervention to very young children with ASD. While the long-term impact is yet unknown, the efficacy of ESI is currently being evaluated in a large, multi-site randomized control trials (RCT) study funded by Autism Speaks.

Parent-Child Interaction Training

Parent-Child Interaction Therapy (PCIT) is an empirically-based, time-limited parent training program that was originally developed to treat disruptive and oppositional behavior in non-autistic young children. Children with ASD were historically

excluded from PCIT because it was assumed that they would not respond to a program that relied on social contingencies. Recently, however, children with milder forms of ASD who are motivated by social attention have been referred in increasing numbers for PCIT due to the growing recognition that it may be effective in reducing problematic behaviors.

PCIT is conducted in weekly, clinic-based, one-hour sessions attended by parent and child together. PCIT differs from many other parent training programs in that it involves live coaching, treats parents and children together, and is data-driven. During sessions, parents are invited to play and interact with their children. They are provided with a "bug-in-the-ear" microphone device with which a trained clinician coaches them from a one-way observation room.

PCIT has two phases of treatment. The first phase is Child Directed Interaction or "CDI." CDI includes teaching parents specific communication skills to use in play-time routines that have been found to improve the parent-child interaction through the systematic use of skills involving labeled praise, imitation, and others during play. When a parent masters CDI skills, they then begin learning the second phase of PCIT, Parent Directed Interaction or "PDI." PDI includes teaching parents how to give effective, developmentally-appropriate instructions or directives. In PDI, parents learn how to use visual cues, simple, clear language, and a set of specific steps in response to compliance and non-compliance. The goals of PDI are individualized based on target behaviors identified for each child. Parents' use of CDI and PDI skills is coded during each session, and results guide further coaching. Data including the coding of parent skills, the child's behavior, and the frequency of skill practicing outside of sessions is collected each week and reviewed with parents at the end of each session. The data is analyzed and used to monitor treatment progress. Once PDI skills are met, the

family graduates from PCIT and is deemed independent with this method.

PCIT blends many therapeutic techniques that are recognizable features of well-established therapies for children with ASD. For example, the emphasis on compliance training in the PDI phase of PCIT is similar to ABA-based methods. PCIT's stress on parent-child interaction and the quality of the parent-child bond is similar to central aspects of two, well-known methods of teaching children with autistic disorder, Greenspan and Wieder's Floortime approach and the TEACCH model. Like pivotal response training (PRT), another time-honored, empirically-based approach, PCIT stresses the importance of using familiar play materials in a comfortable environment. Thus PCIT is a natural and familiar-feeling choice of treatment for young children with milder forms of ASD.

PCIT has strong empirical support with non-autistic groups. Controlled studies have found PCIT to be effective in reducing disruptive behavior. Other studies have found that gains are maintained over time. There is to date only one controlled study of PCIT for autistic children. This pilot study found improvements in parents' perceptions of their child and increases in shared positive affect and parent positive affect (Solomon et al., 2008). Clinician-researchers at West Virginia University report success in the use of PCIT in building language and conversation, reducing stereotyped, repetitive behaviors, and increasing compliance, flexibility, and attention span in children with milder forms of ASD (Masse et al., 2008). They have found that PCIT was ineffective in more severely affected children whose language was developmentally below the age of two years or who were not motivated by social attention. With less affected children, however, PCIT showed signs of promise as a possible "gateway" treatment that can prepare children with milder forms of ASD to cooperate with other learning therapies.

Conclusion

Parents of autistic children are confronted with an array of treatment programs. Interventions for young children with ASD that are implemented entirely by parents are a new trend but one that occurs in the context of a growing interest in increased parent involvement. When parents are successful at learning and can offer the required degree of intensity of therapy, these approaches may offer a more cost-effective and naturalistic method of teaching skills and reducing problem behaviors than those that rely on service delivery by professionals. For these families, ESI and PCIT are two potentially valuable ways to help their children.

Dana Levy, PsyD, is Clinical Psychologist and Elizabeth Roberts, PsyD, is Neuropsychologist at the Child Study Center, at NYU Langone Medical Center.

References

Masse, JJ, McNeil, CB, Wagner, SM, Corney, DB (2008). Parent-Child Interaction Therapy and High Functioning Autism: A Conceptual Overview *J Early and Intensive Behavioral Intervention*, 4(4), 714-735.

Siller, M & Sigman, M (2002). The behaviors of parents of children with autism predict the subsequent development of their children's communication. *J Autism and Dev Dis*, 32, 77-89.

Solomon, M, Ono, M, Timmer, S, Goodlin-Jones, B (2008). The effectiveness of parent-child interaction therapy for families of children on the autism spectrum. *J Aut Dev Dis*, 38, 1767-1776.

Wetherby, AM, Woods, JJ (2006). Early Social Interaction project for children with autism spectrum disorders beginning in the second year of life: A preliminary study. *Topics in Early Childhood Special Educ*, 26:2, 67-82.

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and implement interventions accurately.

"We have been overwhelmed with the response to this effort," said Susan M. Wilczynski, PhD, BCBA, Executive Director of the National Autism Center. "We created this manual specifically for educators as a means of promoting evidence-based practice for ASD in schools because we know that research-supported interventions are most likely to produce positive outcomes."

The development and publication of the manuals were made possible through support from the American Legion Child Welfare Foundation, Inc., and the Niel M.

Wreidt 2003 Revocable Trust.

"The American Legion Child Welfare Foundation is proud to help fund the National Autism Center's project and provide a resource tool that will enable schools to more effectively serve the over 329,000 students nationwide with ASD," said Dennis Boland, President, American Legion Child Welfare Foundation, Inc.

To provide a wider audience of professionals and families with important information about the scientific evidence that supports a broad range of treatments for ASD, the National Autism Center is disseminating the manual, the 53-page *Findings and Conclusions* report, and the full 160-page National Standards Report via its

website at www.nationalautismcenter.org.

About the National Autism Center

The National Autism Center is dedicated to serving children and adolescents with Autism Spectrum Disorders (ASD) by providing reliable information, promoting best practices, and offering comprehensive resources for families, practitioners, and communities.

An advocate for evidence-based treatment approaches, the National Autism Center identifies effective programming and shares practical information with families about how to respond to the challenges they face. The Center also

conducts applied research and develops training and service models for practitioners. Finally, the Center works to shape public policy concerning ASD and its treatment through the development and dissemination of national standards of practice.

In 2009, the National Autism Center completed an unprecedented multi-year project—the National Standards Project—to establish a set of standards for effective, research-validated educational and behavioral interventions for children on the spectrum.

For more information about the National Autism Center, please call 877.313.3833 or visit www.nationalautismcenter.org.

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- **Never lose your cool.**
- Bring along a respected member of the community or clinicians to meetings if you feel your views are not being well respected. While you want to keep a partnership and good relationships with your school district, sometimes it may help to include an advocate or even an education lawyer in meetings. In addition, there are times when it might be in your child's best interest to request an impartial hearing.

- **Keep things in writing:** Keep a notebook for yourself of all communications with school personnel and outside clinicians; use opportunities to back up conversations with written confirmation - that way promises will be kept and you will have proof of your active involvement.

- Send all important information by certified mail, return receipt requested. Keep copies of all documents for yourself.

Dr. Ilene Solomon is a clinical and pediatric neuropsychologist practicing in Roslyn and Manhattan, NY. She is an associate of The Institute for Cognitive Diversity at Bank Street College of Education in New York City. She can be reached at (516) 747-8583.

References

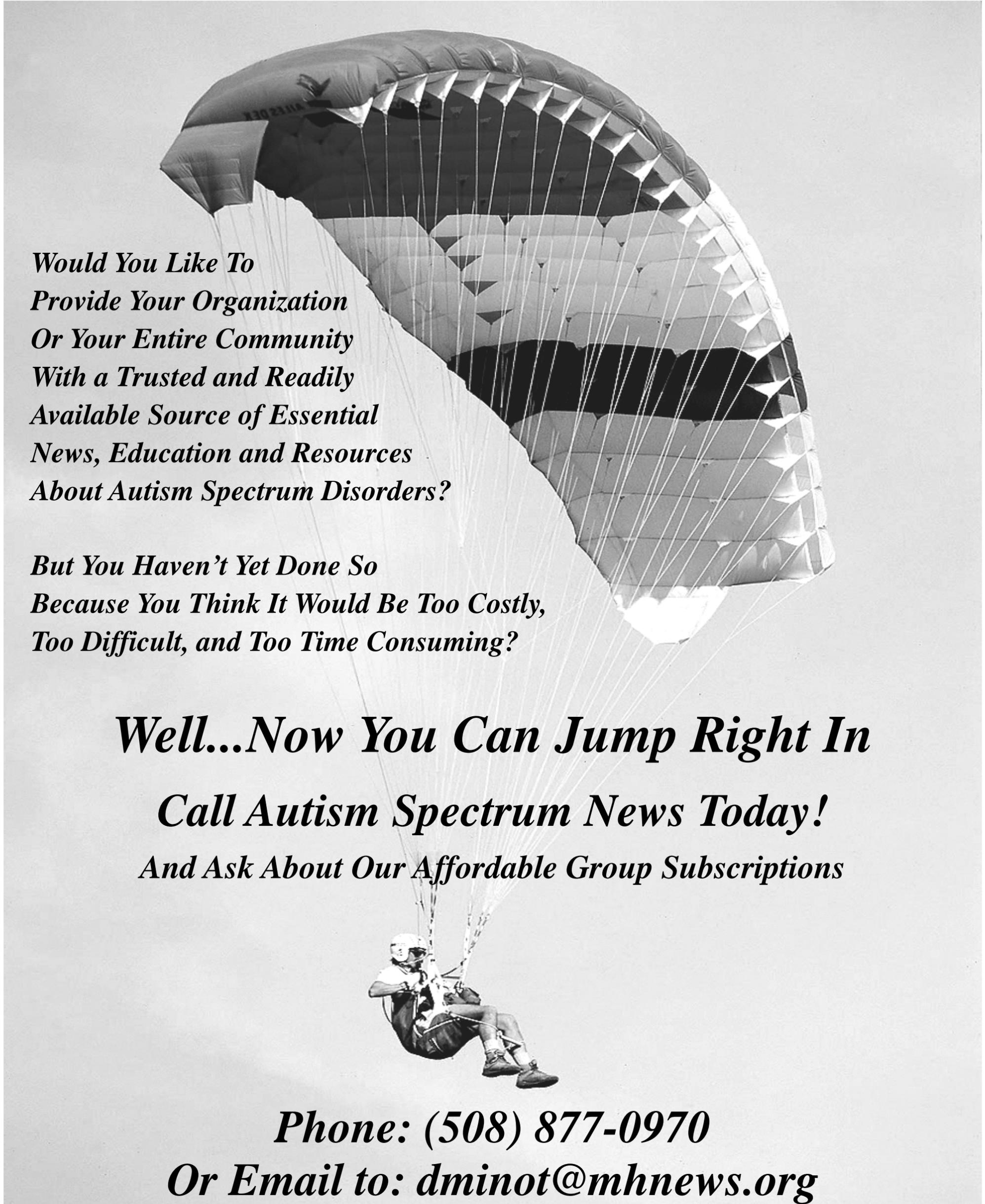
"A Guide to Special Education," b, captured from the internet 2/25/2010

"Autism Program Quality Indicators,"

www.vesid.nysed.gov/specialed/autism/apqi.htm, captured from the internet 3/8/2010

"Special Education Process in NY State," eastislipsepta.org/Special_Education_in_NYS.htm, captured from the internet 2/25/2010

Steedman, W. "Independent Educational Evaluations: What? Why? How? Who Pays?" wrightslaw.com/info/test.lee.steedman.htm, captured from the internet 3/6/2010



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