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WINTER 2011

FROM THE LOCAL, STATE, AND NATIONAL NEWS SCENE

VOL. 3 NO. 3

Understanding and Treating Conditions Associated with Autism

An Interview with Alexander Kolevzon, MD, Clinical Director of the Seaver Autism Center for Research and Treatment at Mount Sinai School of Medicine

Staff Writer
Autism Spectrum News

We are indeed fortunate to have an opportunity to speak with Dr. Alexander Kolevzon, Clinical Director of the Seaver Autism Center for Research and Treatment at Mount Sinai School of Medicine, located in New York City.

Dr. Kolevzon eloquently provides us with an overview of our current understanding of what causes autism, and outlines the medical and psychiatric conditions currently understood to be associated with ASD. In addition, Dr. Kolevzon discusses the vital research and clinical trials being conducted at the Seaver Autism Center, in collaboration with other international research centers. He explains how this will help us to understand more about the genetic basis of autism spectrum disorders and how this knowledge will then be used to develop novel treatments. His comments conclude with a message to families that they should remain hopeful that our



Alexander Kolevzon, MD

understanding of the relationship between genetics and autism is rapidly improving, and

is leading to increased early detection of an autism spectrum disorder in individuals as early as 12-18 months.

Q: Can you give us a general overview of our current understanding of the cause(s) of Autism?

A: Our understanding of autism has evolved dramatically since Kanner's original description of the disorder in 1943. Twin studies carried out since the 1970s and more recent genetic analyses have come to demonstrate autism as primarily a genetic disorder. For example, research has shown that if one identical twin has autism, then the likelihood that the other identical twin will have an autism spectrum disorder (ASD) is approximately 90%. On the other hand, when a non-identical twin has autism, the chance that the other twin will have autism is no more than 5-10% - even though they share the same uterine, household, and family environment. This is a very convincing argument for a strong genetic contribution of autism.

Soon after the early twin studies, theories of common susceptibility variants arose where estimates of between 10 and 100 genes were thought to contribute to autism, all interacting with some degree of weak effect. These susceptibility genes are thought to be common variations in our genetic code resulting from single nucleotide polymorphisms (ie, SNPs) that in and of themselves may not produce clinically significant changes but when several come together and interact, can produce autism. While there may still be a role for common variants in the etiology of autism, these variants remain elusive and studies identifying them have not been consistent. Much larger sample sizes will be required to reliably detect common variations with weak effect.

Today, most scientists in the field of autism recognize that rare variations in the genetic code account for a significant proportion of cases. Such rare variants can arise from copy number variations

see Interview on page 30

Psychiatric Disorders Associated With Autism Spectrum Disorders

By Charles N. Cartwright, MD,
and Victoria Bein, MA, MS
YAI Network

Co-existing psychiatric disorders in individuals on the autism spectrum are common. Based on clinical and community studies, there is strong evidence that up to 70 percent of people with autism meet diagnostic criteria for at least one emotional or behavioral disorder.

The presence of these co-existing disorders have a dramatic impact on the lives of individuals with autism, as well as their families and caregivers. Clinicians and families need to be vigilant and watch for emotional and behavioral changes. If these disorders exist, a referral for a comprehensive psychiatric evaluation is necessary. These evaluations should be performed by professionals with specific expertise in the assessment and diagnosis of autism spectrum disorders with co-occurring psychiatric disorders.



Charles Cartwright, MD

It is important to understand these comorbidities. How do they present? At what ages? What treatments are effective?



Victoria Bein, MA, MS

Professionals need to provide treatment and intervention directed at the specific symptoms and behaviors. Effective

treatments are available which include intensive behavioral, cognitive-behavioral and other psychotherapeutic approaches. Pharmacological strategies can be very effective in achieving significant control of symptoms and behaviors.

"Emotional dysregulation" is a commonly used term when discussing emotional and behavioral issues in those diagnosed with an autism spectrum disorders (ASD). The symptoms and behaviors may include irritability, temper tantrums, hyperactivity and self-injurious behaviors.

We need to separate these symptoms and behaviors and understand whether they reflect underlying mood, anxiety, impulse control and psychotic disorders.

It is critical to differentiate emotional dysregulation from other emotional/behavioral presentations of autism that are often described as new onset disorders. This differentiation may be difficult to determine because many new onset

see Disorders on page 32

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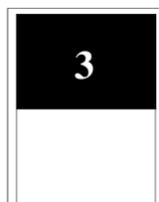
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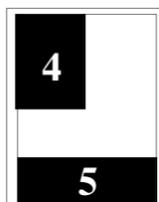
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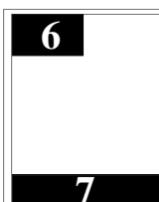
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From the Executive Director

Autism Leaders Outline the Medical and Psychiatric Conditions Associated with Autism

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

In this Winter 2011 issue of *Autism Spectrum News*, you will find educational articles written by trusted leaders in autism science, clinical treatment professionals and service providers dedicated to improving the lives of individuals on the spectrum. This issue is dedicated to addressing the medical and psychiatric conditions currently understood to be associated with Autism including: Fragile X Syndrome, ADHD, Obsessive Compulsive Behaviors, Epilepsy and Seizure Disorders, Social Anxiety, Depression, Tic Disorders, Mood Disorder, Sleep Disorders, Oppositional Defiant Disorder, Aggression, Panic Disorder, etc.

Featured in this issue is an exclusive interview with Alexander Kolevzon, MD, Clinical Director of the Seaver Autism Center for Research and Treatment at Mount Sinai School of Medicine. Dr. Kolevzon, recognized for his vital research involving biological causes and effective treatment of autism and related pervasive developmental disorders, provides an in-depth look at our current understanding of what causes autism, and gives an outline of the medical and psychiatric conditions currently understood to be associated with autism.

Our additional cover story comes from Charles N. Cartwright, MD, Director of the YAI Autism Center and Chief of the Pre-



Ira H. Minot, LMSW

mier HealthCare Autism Research and Treatment Institute, and Victoria Bein, MA, MS, Coordinator at the Premier HealthCare Autism Research and Treatment Institute at the YAI Network. Cartwright and Bain explain that, "Co-existing psychiatric disorders in individuals on the autism spectrum are common. Based on clinical and community studies, there is strong evidence that up to 70% of people with autism meet diagnostic criteria for at least one emotional or behavioral disorder.

The presence of these co-existing disorders have a dramatic impact on the lives of individuals with autism, as well as their families and caregivers. Clinicians and families need to be vigilant and watch for emotional and behavioral changes. If these disorders exist, a referral for a comprehensive psychiatric evaluation is necessary. These evaluations should be performed by professionals with specific expertise in the assessment and diagnosis of autism spectrum disorders with co-occurring psychiatric disorders."

In addition to our featured cover articles, there are many more that address other vital areas of interest including the latest advances in autism science, legal issues, transitioning into adulthood, helpful information for parents of a newly diagnosed child etc., 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 spring issue's theme will be "Autism and the Law Throughout the Lifespan." The deadline for articles and advertising for this important issue is March 15th, 2011.

Our calendar continues with our summer issue which will focus on "The Need for Science-Based Treatment and Services for Individuals with ASD." Next fall we will take an in-depth look at "Understanding and Addressing the Unique Needs of Individuals with Asper-

ger's Syndrome and High Functioning Autism," and next winter our theme will be "Science Matters - The Latest Advances in Autism Research."

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 at 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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Deadline: September 15, 2011

Winter 2012 Issue:

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Deadline: March 15, 2011

Letter to the Editor

Dear Editor,

I was dismayed by Dr. Thomas Zane's review of the efficacy of Hippotherapy as a treatment tool (A Horse of a Different Color: A Review of the Effectiveness of Hippotherapy, Fall 2010, p. 34).

Dr. Zane consistently conflates Hippotherapy and therapeutic horseback riding. Hippotherapy is a treatment strategy employed by a licensed physical

therapist, occupational therapist or speech-language pathologist to achieve documented treatment goals. Therapeutic horseback riding, conducted by a riding instructor, aims to teach a person with a disability to ride a horse.

As a result of confusing a clinical service and a recreational one he concludes that Hippotherapy ought not be recommended because of the lack of clinical evidence to support its efficacy. This de-

spite the fact that he cited one study which met his methodological requirements that showed statistically significant results when Hippotherapy was used as a treatment tool.

The American Hippotherapy Association agrees that the evidence base for Hippotherapy should be expanded, which is why we are funding a study at the University of New Mexico on the use of Hippotherapy for children with ASD.

And although I have never seen a double blind study on the use of parachutes, I still recommend them to my friends who are jumping out of airplanes...in some instances, anecdotal evidence can be very compelling.

Meredith S. Bazaar, MA-CCC, SLP, HPCS
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AUTISM SPECTRUM NEWS DESK

Toddlers with Autism Show Improved Social Skills Following Targeted Intervention

The National Institute of Mental Health (NIMH)

Targeting the core social deficits of autism spectrum disorders (ASD) (www.nimh.nih.gov/health/topics/autism-spectrum-disorders-pervasive-developmental-disorders/index.shtml) in early intervention programs yielded sustained improvements in social and communication skills even in very young children who have ASD, according to a study funded by the National Institute of Mental Health (NIMH), part of the National Institutes of Health. The study was published online Dec. 8, 2010, in the *Journal of Child Psychology and Psychiatry*.

Although some research suggests that ASD may be reliably diagnosed earlier (www.nimh.nih.gov/science-news/2007/half-of-children-with-autism-may-be-diagnosable-soon-after-their-first-birthday.shtml) than the current average age of 3 years, few interventions have been tested in children younger than 3.

During the course of typical development, children learn to interact with others in socially meaningful ways. Measures of social communication include:



- Initiation of joint attention-spontaneously directing others' attention to something of interest, such as by pointing or holding something up to show for social purposes rather than to ask for help
- Affect sharing-sharing emotions with others through facial expressions paired with eye contact
- Socially engaged imitation-imitating others' actions while showing social connectedness through eye contact.

Deficits in such measures are hallmark symptoms of ASD and can severely limit a child's ability to engage in and learn from interactions with others or from the world around them.

"This new report is encouraging, as the effects on social behavior appear to provide a scaffold for the development of skills beyond the research setting," said NIMH Director Thomas R. Insel, M.D. "We need better early interventions for the core deficits of autism."

Funded through the Studies to Advance Autism Research and Treatment (STAART) Network (www.nimh.nih.gov/health/topics/autism-spectrum-disorders-pervasive-developmental-disorders/nih-initiatives/staart/index.shtml), Rebecca Landa, Ph.D., of Kennedy Krieger Institute, Baltimore, and colleagues randomly assigned 50 toddlers, ages 21-33 months old, who were diagnosed with ASD to one of two six-month interventions: Interpersonal Synchrony (IS) or Non-Interpersonal Synchrony (non-IS). Both interventions incorporated classroom-based activities led by a trained intervention provider, and a home-based component involving parents who received specialized education and in-home training.

The interventions were designed to encourage children to make frequent and intentional efforts to engage others in communication or play. The single difference between interventions was that the

see Toddlers on page 26

New Study Affirms Handwriting Problems Affect Children with Autism into Their Teenage Years

By Amy Bastian, PhD, Director
Motion Analysis Laboratory
Kennedy Krieger Institute

The handwriting problems that affect children with autism spectrum disorders (ASD) are likely to continue into their teenage years, according to a study from the Kennedy Krieger Institute in Baltimore, MD. The research is published in the November 16, 2010 issue of *Neurology*, the medical journal of the American Academy of Neurology (www.neurology.org).

In 2009, Kennedy Krieger researchers conducted the first study to examine handwriting quality in children with ASD, finding that motor skills (e.g., timed movements) predicted handwriting deficits. This latest study revealed that, like children with ASD, adolescents with ASD (ages 12 to 16) have poor handwriting quality and motor skill impairments when compared to typically developing peers. However, unlike younger children, perceptual reasoning was the main predictor of handwriting performance in adolescents. Perceptual reasoning is a person's ability to reason through problems with nonverbal material.



Amy Bastian, PhD

"The importance of this research was not 'if' children and adolescents with autism struggle with handwriting, which many individuals can already attest to, but rather to document the

extent of the challenge and determine if we could reveal anything about 'why' it is the case," said study author Amy Bastian, PhD, Director of the Motion Analysis Laboratory at the Kennedy Krieger Institute.

Researchers at the Kennedy Krieger Institute have been using the study of motor execution and perceptual reasoning as an important window into the neurobiological basis of autism. Examining these skills provides researchers a way to study the basic brain systems important for learning and guiding actions, which has implications for all learned behavior, including complex communication and social skills.

"While adolescents with autism are more likely to have handwriting problems, there are several techniques available to improve handwriting quality, such as adjusting pencil grip, stabilizing the writing hand with the opposite hand or forming letters more slowly," said Dr. Bastian. "Our research suggests that adolescents with autism may be able to learn and utilize compensatory strategies that involve reasoning skills to compensate for their motor impairments."

About the Study

The study included 24 girls and boys between the age of 12 and 16. Half of the group had ASD and all of the adolescents scored within the normal range of perceptual reasoning on an IQ test. The teens were given the Minnesota Handwriting Assessment Test, which uses a scrambled sentence to eliminate any speed advantage for more fluent readers. The sentence used on the test was "the brown jumped lazy fox quick dogs over." Participants were asked to copy the words in the sentence, making the letters the same size and shape as the sample using their best handwriting. The handwriting was scored based on five categories: legibility, form, alignment, size and spacing. The adolescents' motor skills, including balance and timed movements, were also examined and given a rating. The research found that the adolescents with autism earned 167 points out of 204 total possible points on the handwriting assessment, compared to the 183 points scored by those in the group without autism.

The Kennedy Krieger research team

see Handwriting on page 32

AUTISM SPECTRUM NEWS DESK

Ira and David Minot

The Father and Son Team Behind Mental Health News and Autism Spectrum News

Staff Writer
Autism Spectrum News

Ira and David Minot, Publishers of *Mental Health News* and *Autism Spectrum News*, were recently featured in the "Who's Who" section of AHA's Fall 2010 magazine, *On the Spectrum*. "We were honored to be highlighted by AHA because of our shared personal connection with mental illness, and a strong desire to help others in the community. We both believe in the vital need to provide a trusted source of science-based education and resources to the community," said Ira and David Minot. "The real praise, however, should be given to our readers, and the individuals and community organizations who support and contribute content to our publications. We are also blessed to have two wonderful Boards to work with: the MHNE Board of Directors and the *Autism Spectrum News* Editorial Board (see page 2)." Below is Ira and David's story that was published in *On the Spectrum*.

Surviving an extreme hardship in a person's life can often provide them with a unique perspective on the difficulties they have had to endure. It can also ultimately



David and Ira Minot at the Seventh Annual "Journey of Hope" Community Mental Health Awards Luncheon in 2009, where Ira was honored with the "Man of the Year" Award

make them stronger and lead them down a path to helping others.

That is the story behind Ira and David Minot, the father and son team who publish *Mental Health News* and *Autism Spectrum News*.

Ira Minot, who founded *Mental Health News* in 1999, is a survivor of mental illness that began in his mid 30s. His 10-year life and death battle with depression left him homeless, destitute and having to begin his life all over again. His son

David grew up in the shadow of his father's illness and witnessed firsthand how an illness and the stigma attached to it can bring even the strongest person to their knees.

Following his ten-year ordeal, Ira finally received the treatment that broke the chains of his depression. Out of the ashes of his illness, and with the support of many dedicated leaders of the mental health community, he created a small local newsletter dedicated to providing hope through education for people with mental illness and their families. Today, *Mental Health News* is the nation's leading provider of evidence-based community mental health education.

Inspired by his father's vision and with his own understanding of the importance of providing community education, David joined his father in 2007 to help launch and is now the publisher of *Autism Spectrum News*.

With help from some of the nation's leading minds in the field of autism and leaders of many of the Northeast's leading autism organizations, including the Asperger Syndrome and High Functioning Autism Association (AHA), *Autism Spectrum News* premiered in the fall of 2008

see Minot on page 37

CDC Programs Provide Vital Research and Awareness for Autism Spectrum Disorders

The Centers for Disease Control and Prevention (CDC)

The Centers for Disease Control and Prevention's (CDC) most recent data suggest that 1 in 110 children in the U.S. have an autism spectrum disorder (ASD). Like many families, educators, health professionals, and organizations, the CDC considers ASDs an urgent public health concern and undertakes efforts to find out how many children have ASDs, understand the risk factors and causes, and raise awareness of the signs and symptoms.

The Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) and the Autism and Developmental Disabilities Monitoring (ADDM) Network are two of the autism activities supported by the CDC. Since 1991, MADDSP has been an ongoing system for monitoring the occurrence of selected developmental disabilities – intellectual disability, cerebral palsy, hearing loss, vision impairment, and autism spectrum disorders – in the metropolitan Atlanta area. MADDSP has been collecting data on autism spectrum disorders since 1996.



The surveillance data generated by MADDSP are also used to identify potential risk and protective factors of select developmental disabilities and these data form a case series for special studies.

CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network is currently comprised of 12 sites across the United States that are using the MADDSP methods to obtain estimates of the number of children affected by ASDs,

describe the population affected, and evaluate changes in ASDs over time. The ADDM Network is the only ASD surveillance network using common methods to track ASDs across multiple regions of the United States. Understanding the characteristics of children with ASDs provides critical information to help plan for services for individuals with ASDs and to improve our understanding of the risk factors and causes of this condition.

CDC also currently conducts the Study to Explore Early Development (SEED) – one of the largest studies in the U.S. to help identify factors that may put children at risk for ASDs. SEED is studying potential risk factors that may be related to genes, health conditions and other factors that affected the mother's pregnancy and the child's first few years of life. The study has enrolled about 2,700 children and their parents from six states.

In addition to research and surveillance activities, CDC also is helping to change perceptions about the importance of identifying autism and other developmental disabilities early. CDC's "Learn the Signs. Act Early." program (www.cdc.gov/actearly) educates parents about the importance of tracking their child's developmental milestones and acting early - by talking with their child's doctor or child care administrator - if there are concerns or warning signs. The earlier a delay is recognized, the more that can be done to help a child reach his or her full potential.

To learn more about CDC's activities related to autism, please visit www.cdc.gov/autism.

Swimming, Arts and Crafts, and Socialization: A Summer Camp for Children on the Spectrum

By Marco R. Damiani, MA
Director of Clinical and Family Services
YAI Network

For many parents of children on the autism spectrum, hopes of sending their child to summer camp can seem like an impossible dream, as most traditional camps do not have the staff trained to work with children with special needs.

Where do arts and crafts, swimming and campfire stories find a balance with social and communication skill development? If you ask the families of 10-year old best friends Michael L. and Michael Y., the answer is simple.

During the past four summers, Michael and Michael, classmates in Staten Island, have attended the YAI/National Institute for People with Disabilities Mainstreaming at Camp (MAC) program, a collaboration with the Frost Valley YMCA in New York's Catskill Mountains. Since 1988, MAC has offered inclusive camping opportunities to children with disabilities. Campers between the ages of 6-18 live in their own cabins with the support of specially trained counselors, and enjoy the full range of activities alongside their typically-developing peers.

Last summer, however, both boys participated in an Autism Pilot Program at the camp. The program was developed by a team of professionals – Dr. Charles Cartwright, Director of the YAI Autism Center, Joe Medler, Assistant Coordinator of YAI Camping and Travel, and Becky Lewin, Occupational Therapist and YAI Clinical Consultant. For the very first time at MAC, six boys on the autism spectrum, ages 8-12, shared a cabin and enjoyed activities which incorporated clinical interventions and evidence-based best practices for working with children with autism.

A former camper and counselor, herself, Lewin's combined familiarity with the camp setting and experience working professionally as an Occupational Therapist proved extremely valuable. She easily related to counselors and families.



Michael L, left, and Michael Y enjoyed YAI's Mainstreaming at Camp (MAC) Autism Pilot Program last summer and are looking forward to returning this summer

Lewin worked with MAC counselors to emphasize communication, socialization and greater independence within the cabin. She introduced several sensory tools which resulted in positive outcomes.

A simple visual schedule resonated with the campers, helping them understand what activities were planned for the day.

To teach campers calming techniques, she implemented sensory integration objects, such as a squeeze ball and kaleidoscope. These tools aided in focus, productivity, communication and self-soothing.

"The sensory tools helped us better meet the kids' needs in a way that naturally integrates within the structure of camp," Lewin said.

"When I visited the camp, you could immediately sense that the staff had tremendous respect for Becky," Dr. Cartwright said. "She spoke their language."

"It's all about finding unique ways for the kids to express themselves and grow," said counselor Clara Flaherty.

Another key component of the Autism Pilot Program was a research-based LEGO® activity in which MAC campers and typically-developing campers worked together in small groups.

LEGO® Therapy was developed more than 15 years ago and has been evaluated in research studies conducted by Daniel LeGoff, PhD, and a replication study completed at Cambridge University in England under the supervision of autism expert Simon Baron-Cohen, PhD. The creative approach to therapy has been found to provide structure, fun and reinforce socialization skills for children with autism.

"The LEGOS® offered orderliness, structure and routine," said Kevin Travers, Assistant Director of YAI Clinical & Family Services. "More importantly, they offer children an opportunity to probe their creative sides and to express themselves within a comfortable medium."

"The LEGO® activity works on so many levels," Lewin added. "All children at this age are learning about sharing, creative thinking, communicating and team-building. It's mainstreaming based on a common interest."

Counselor Ryan Balkler noticed the impact of the LEGO® activities immediately. "Each day, you can really see a change in thought process," he said. "Campers stopped asking for help and began to problem solve independently. It was remarkable."

"We took evidence-based scientific practice and successfully implemented it into the real world," Dr. Cartwright noted of the LEGO® Therapy. "It just took off and was a phenomenal success. The typically-developing children were encouraged to interact with campers on the spectrum. They all were engaged in an activity they really enjoyed and they were communicating with one another to reach their goal. I never expected it to be this successful."

Lewin also collected her observations about each camper on the spectrum and prepared written reports for parents outlining skills that emerged by the end of the session as well as techniques for parents to utilize once their campers returned home. After camp was over, Lewin remained connected by making herself available to parents who wanted to discuss her observations.

"The goal, as a parent with a special-needs child, is to give him as many opportunities for independence as possible and camp provides a chance to develop daily living skills," said Kirsten, Michael Y.'s mother. "Michael got to socialize with typically developing kids from other cabins. Since returning from camp, he has been far more open to interacting with other children. The focus on occupational therapy was tremendously supportive in helping both boys develop routines. The program was incredibly effective."

"Going to camp with his best friend creates an immediate level of comfort," said Mary of her son Michael L. "There's no stress about being alone, so all of his energy and focus can go into activities and socializing. It's great practice for functioning in society because the kids are coexisting, and that's the way real life is."

To that end, Travers added: "MAC is a win-win-win. Campers increase self-esteem and learn coping and social skills, families

see *Summer Camp* on page 37

Announcing YAI Network's 32nd Annual International Conference May 2-5, 2011 at New York Hilton to Focus on Autism

By The YAI Network

Autism spectrum disorders will be a major focus throughout the YAI Network's 32nd Annual International Conference "Bridges to Success in Developmental and Learning Disabilities" on May 2-5, 2011, at the Hilton New York Hotel, 1335 Avenue of the Americas in mid-town Manhattan.

Known for its comprehensive and hands-on trainings, the YAI conference features some of the most prominent experts from throughout the world. The con-

ference is designed for professionals at all levels, family members and individuals with developmental and learning disabilities. Extended sessions provide attendees with even more in-depth training.

This year's conference, with presenters and attendees from 35 different countries, is expected to be YAI's largest conference ever. It serves as a major forum for the exchange of ideas and the introduction of new models and strategies that have a positive impact in the field of autism and other developmental and learning disabilities.

In 2011, in conjunction with the International Conference, the YAI Network will host the International Society on

Early Intervention's conference on early intervention and early childhood. Many of the sessions in this conference will address autism spectrum disorders.

For more information, including early-bird registration packages, discounts for organizations sending six or more staff member and a special hotel conference rate, visit yai.org/conference. The conference brochure is available on the website and online registration is available. You may also contact, Tina Sobel, conference co-director, at tina.sobel@yai.org, or 212-273-6457.

For more than 50 years, the YAI Network has provided a place of hope and

opportunity for people with developmental and learning disabilities. Comprised of seven not-for-profit, independent health and human service agencies, the YAI Network serves people of all ages throughout the New York metropolitan area, including Long Island, New Jersey and Westchester, Rockland, Orange, Dutchess, Ulster and Sullivan counties, New Jersey, Puerto Rico and the U.S. Virgin Islands. The YAI Network is recognized nationally for its conferences, training seminars and publications. For more information about the YAI/NIPD Network or to obtain services, call 1-866-2-YAI-LINK or visit www.yai.org.



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Autism and Epilepsy

What We Know, What We Don't Know, and How We Are Creating Awareness

By Dr. Ruth Nass, MD and
Linda Walder Fiddle, Esq

People with Autism Spectrum Disorders (ASD) have a shorter life expectancy than the general population mostly because of various co-morbid medical conditions that affect their health. We do not know why but young people, those with severe intellectual disabilities, and females are at greater risk. It has been documented by population studies in California and Denmark that nearly one-third of deaths of autistic individuals are associated with or caused by epilepsy. The authors of the studies stress the importance of including internists and neurologists in the ASD care system to assure that physical and neurological illnesses are recognized and properly treated.

Epilepsy occurs at a higher rate in the ASD population as compared to the general population. The brain abnormalities that underlie autism also probably act as a focus for epileptic discharges vs. cause the epilepsy. About 30% of children and adults with autism develop epilepsy. Those who are more intellectually disabled or who have a specific cause of their autism (like Down's syndrome or Fragile X syndrome) are more likely to have epilepsy. About 30% of children



Ruth Nass, MD

with epilepsy seen at major medical centers have autism. Children who have both autism and epilepsy tend to have more developmental issues than those with either autism or epilepsy alone. The most common times for seizures to start in patients with autism are infancy and adolescence. Seizures persist into adult life in most.



Linda Walder Fiddle, Esq

Sudden unexpected death unfortunately occurs at every age in both the well and the ill, but it is rare. People with epilepsy are at greater risk. Sudden unexpected death in epilepsy (SUDEP) accounts for almost one fifth of all deaths in patients with epilepsy. Risk factors include: young age, early onset of seizures, difficult to control epilepsy, grand mal

seizures, and male sex. SUDEP probably occurs during a seizure and most often occurs at night.

Many investigators are trying to determine the cause(s) of SUDEP in order to figure out ways to prevent it. Molecular autopsies, which look for genes that are associated with heart rhythm issues, are likely to advance our understanding of SUDEP. Almost 10% of infants with sudden infant death syndrome (SIDS) turn out to have genetic cardiac arrhythmias. The Autism Tissue Program (ATP), run by Jane Pickett, recruits brain donors for standard and molecular autopsies. Studies of brain tissue is particularly important for learning about epilepsy related deaths and her project is definitely critical to understanding and then preventing SUDEP, as well as determining causes of autism.

Since epilepsy is common in autism, a number of studies have looked at the value of doing EEGs in children with autism even when they do not have obvious seizures. Abnormal EEGs are seen in anywhere from 10% to 70% of children with autism. But, abnormal EEGs can occur in people who don't have epilepsy. Indeed, only 5% to 30% of people with autism who have abnormal EEGs actually have epilepsy. Currently, neurologists think there is insufficient medical evidence to

see Epilepsy on page 37

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Distinguishing Stereotypy From Obsessive-Compulsive Behavior

Differential Diagnosis in Persons with Autism Spectrum Disorders

By Mary Jane Weiss, PhD,
Thomas Zane, PhD, BCBA,
Nicole Pearson, MA, and
Cece McCarton, MD
The McCarton Foundation

Individuals with autism exhibit a wide variety of repetitive and ritualistic behaviors. Such patterns of behavior are a defining characteristic of autism spectrum disorders, and are generally expected as part of the behavioral profile of individuals with autism. While often conceptualized as stereotypy, these behaviors are similar to those which characterize obsessive compulsive disorder, leading to the question of how to differentiate between the two in those with an autism spectrum disorder.

Stereotypy is defined as nonfunctional, repetitive behaviors that may be verbal or nonverbal and can present very differently in form and complexity across individuals, contexts, and time (e.g. Rapp & Vollmer, 2005; Cunningham & Schreibman, 2008). Examples of vocal stereotypy include repeating portions of previous conversations or imitating voices and sounds heard in videos or on television. Motor-oriented stereotypy examples include hand waving, eye gazing, rocking, and twirling objects. More complex forms of stereotypy may manifest in individuals with autism as engaging in very spe-



Cece McCarton, MD

cific, yet nonfunctional rituals or routines or exhibiting a rigid demand for sameness.

A significant body of research examining the function of stereotypic behaviors in individuals with autism suggests it may serve a sensory (i.e., self-stimulatory) function that is maintained by automatic reinforcement (e.g. Lovaas, Newsom, & Hick-

man, 1987; Rapp & Vollmer, 2005). Consistent with this function, individuals with autism may engage in such behaviors for prolonged periods of time, when alone, or when bored or in distress. Although these behaviors may sometimes serve automatic functions, they may also be maintained or mediated by social consequences or tangible reinforcement (Durand & Carr, 1987; Cunningham & Schreibman, 2008). In educational settings, stereotypy can interfere with a child's ability to learn, and may slow down the rate of instruction or lead a teacher to change tasks. Similarly, stereotypy may increase teacher attention or redirection. Outside of school, such behaviors can be socially stigmatizing, making community outings difficult for parents and restricting opportunities for peer interactions.

The examination of the functions of stereotypic behaviors in these instances is consistent with a behavior analytic frame of reference. Behavior analysts may seek to determine if a stereotypic behavior is serving multiple functions (e.g. sensory, social, tangible). For an automatically reinforcing function, they may seek to limit the contexts in which such behaviors are emitted. Additionally, they may endeavor to find alternate, more appropriate sources of the sensory input that could serve as replacement sources. These interventions are commonly part of a comprehensive ABA approach to reducing stereotypy.

At times, however, such behaviors are described as something more than stereotypy. They may be labeled as obsessive and/or compulsive and as indicative of a dual diagnosis of OCD. It seems (anecdotally) that the use of such terminology to describe the repetitive behaviors of individuals with autism is increasing. To what extent is the extension of OCD appropriate to the population of individuals with autism?

Obsessions are defined in psychiatric literature as persistent ideas, thoughts, and impulses that are intrusive and inappropriate, and which cause marked distress or anxiety in the individual. Compulsions are defined as repetitive behaviors (or mental acts) that are engaged in to prevent or reduce anxiety and distress (American Psychiatric Association [DSM-IV-TR], 2000). The definitional nature of these symptoms requires that the individual be able to describe their subjective experience and emotional state. In children, self-report as to the intrusiveness of the compulsions or obsessions is not a requirement for an OCD diagnosis due to the recognition that they "may lack sufficient cognitive awareness to make this judgment" (DSM-IV-TR, 2000, p. 457). Instead, physicians rely on parental report and clinical observations to confirm

see Distinguishing on page 40



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Cognitive Behavioral Therapy for Co-Occurring Mental Health Issues in ASDs

By Samara Pulver Tetenbaum, PhD
and Shana Nichols, PhD
ASPIRE Center

We are frequently reminded that often we do not in fact treat "autism," but rather the co-occurring mental health and behavioral issues associated with ASDs. Youth and adults with ASDs have social and emotional difficulties which, if not addressed as part of a comprehensive intervention program, often lead to significant mental health issues. Not only do social skills deficits make it difficult for youth with ASDs to understand the thoughts and emotions of others, they also contribute to difficulties understanding and interpreting one's own thoughts and feelings. These deficits in turn can lead to difficulties with modulating emotions and behavior. Further, coping skills, or our ability to manage challenging life situations, are learned socially, most often in ways that are not explicitly taught. Therefore, many high functioning youth and adults with ASDs struggle with experiencing negative thoughts and feelings without possessing the skills necessary to problem solve and cope with such situations. The unfortunate combination of experiencing difficulties with emotion regulation along with having ineffective coping skills can lead to behavioral episodes, social rejection, im-



Samara Pulver Tetenbaum, PhD

paired self esteem, anxiety, and depression, and can increase the risk of inpatient hospitalization. These outcomes place stress on the importance of effective psychotherapy for individuals with ASDs.

Almost 10% of children presenting in community settings have an ASD (Brockman-Fraze, 2010). Psychotherapy for these youth is intended to treat co-occurring symptoms such as emotion dysregulation, anxiety, and depression. These



Shana Nichols, PhD

tend to be individuals with average to above average cognitive abilities who are therefore expected to play an integral role in the therapy process and use behavioral as well as cognitively mediated strategies. However, they often cannot understand and take part in therapy. Emotion identification and understanding are *pre-requisite skills* for therapy, as is metacognition, or thinking about thinking. With neurotypical youth, it is assumed that they possess

the underlying skills necessary to begin cognitive behavioral therapy (e.g., can identify their own and others' emotions, can label thoughts). With youth, and often adults with ASDs, the discrepancy between ability and required skill, necessitates either the teaching of these skills to increase "therapy readiness" or the adaptation of treatment strategies. In our clinical practice, it is a combination of these two approaches which we have found to be most effective in treating mental health issues facing individuals with ASDs.

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Cognitive behavioral therapy (CBT) is an evidence based form of psychotherapy that is structured and goal oriented. It was initially developed for the treatment of depression but has been successfully adapted for the treatment of a wide range of issues, including anxiety, social skills deficits, and anger management. Although originally developed for adults, CBT has been shown to be highly effective in the treatment of children and teens. CBT focuses on the thoughts, feelings, and behaviors that contribute to an individual's distress. By focusing on the connection between thoughts, feelings, and behaviors CBT teaches children and teens to develop more effective coping skills. CBT also targets social skills deficits by directly

see *Therapy on page 36*

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Demystifying Aggression: Developing Effective Interventions

By Lynda Geller, PhD
Spectrum Services and Asperger
Center of Education and Training

Aggression is likely the most problematic of all issues that may accompany autism spectrum conditions in terms of separating individuals from the mainstream and significantly affecting many aspects of quality of life. For children and adults alike, problems with aggression can sabotage life direction in significant ways. Social distancing is an obvious consequence as others avoid involvement with an individual who is unpredictably aggressive, and with distancing comes decreased ability to develop relationships, as well as the danger of losing existing ones. For students, aggression can mean loss of inclusion in mainstream education, severely limiting options for academic stimulation and educational achievement. For adults, aggression can result in job loss, which for individuals on the spectrum is often tenuous anyhow. For children, adolescents, and adults physical aggression can lead straight to psychiatric admission and treatment, and in some circumstances arrest and legal proceedings.

When we consider aggression, we need to think about all types and how they manifest. Herein lies the rub for those on the spectrum. Aggression is really a natural part of life that is more or less ac-



Lynda Geller, PhD

cepted when it is expressed within socially acceptable circumstances, but clearly understanding these specifics can elude those on the spectrum. There are many kinds of aggression (Nelson et al., 2008) and each has its rules for expression. They include:

- Direct physical aggression that causes overt physical harm.

- Indirect physical aggression that covertly or inadvertently causes physical harm or damages property.
- Verbal aggression including verbal intimidation or disparagement such as insulting, slandering, or verbally attacking.
- Passive aggression designed to cause harm but shield the perpetrator, such as undermining.
- Non-verbal aggression that purposefully avoids or excludes, such as gestural expressions of disdain.
- Direct relational aggression including confrontational or direct behaviors that cause harm by damaging relationships or group inclusion.
- Indirect relational aggression including covert behaviors that damage reputation or group inclusion, such as gossiping.

In reviewing all these types of aggression, one is struck by the fact that those on the spectrum are frequently the victims or targets of such behaviors, yet they are the ones who often are in trouble for "aggression." Clearly a key element of aggression is the social appropriateness of its expression.

The use of aggression is part of social-emotional development. Physical aggression generally emerges early in life and comes under self-control as a child learns alternate ways of managing behavior. As communication capabilities increase it is generally replaced by verbal aggression. As an individual matures, relational aggression emerges and sophistication in its uses increases with age. Early adolescence marks an increase of many types of aggression as social roles emerge and the world of play is left behind. Yet for those on the spectrum, the development of social communication and understanding may be delayed or different, retarding the emergence of the skilled use of aggression. It is the developmentally inappropriate use of aggression that causes the problems individuals on the spectrum so often encounter. While we accept that a two year old can have a tantrum, a ten year old may find himself suspended from school for such behavior. Similarly, those who resort to uncontrolled verbal aggression at an age where self-control is expected may find themselves fired from their job. Meanwhile, such individuals are often themselves victims of covert aggression in the form of bullying, gossiping, and group exclusion and have no real ability to handle these behaviors. Sometimes the mere knowledge that an individual on the spectrum has no defense will encourage covert

see Aggression on page 39

Addressing Sensory Processing Differences in Children with ASD

By Moira Pena, OT
Holland Bloorview Kids Rehab Hospital
Instructor, University of Toronto

There is a growing body of literature describing unusual sensory processing patterns in individuals with Autism Spectrum Disorder. A proliferation of writing from individuals with ASD such as Temple Grandin, Donna Williams and others have noted sensory processing impairments as one of the key elements that interferes with their ability to carry out daily tasks and engage in successful social interactions. The incidence of sensory processing impairments in individuals diagnosed with ASD reported in the literature range from 42% to 95% (Baranek, 2002.; Kientz & Dunn, 1997; Le Couteur et al., 1989; Volkmar, Cohen & Paul, 1986; Watling et al., 2001, Tomchek and Dunn, 2007).

The "Sensory Integration" originated from Dr. Jean Ayres's research in the mid 1960's. In her book, *Sensory Integration and the Child*, Dr. Ayres noted that some children's atypical behaviour, problems with learning and physical clumsiness stemmed from sensory-based deficits and began to develop what is now known as Ayres' Sensory Integration Theory. However, there has been some confusion and controversy around the term 'sensory integration'. Occupational Therapists most often refer to such dysfunction using the umbrella term of Sensory Processing Disorder (SPD).



Moira Pena, OT

There is accumulating research to support the presence of such deficits in ASD. Differences in auditory processing are one of the more commonly reported sensory processing impairments in children with ASD (Greenspan & Weider, 1997). Tomchek and Dunn (2007) reported that in a sample of 281 children ages 3-6 years, diagnosed with ASD, 95% demonstrated some degree of sensory processing dys-

function, and this was most notable in the areas of under-responsivity, auditory filtering and tactile sensitivities. In a follow-up study (Ben-Sasson et al., 2007), extreme sensory modulation behaviors in toddlers with autism spectrum disorders (ASD) were investigated. Parental report of sensory behaviors in 101 toddlers with ASD was compared to 100 toddlers who were typically developing matched on chronological age and 99 toddlers matched on mental age. Children with ASD were different from typically developing children in their high frequency of under-responsiveness and avoiding behaviours. The findings were interpreted as pointing to an early onset of an "extreme sensory profile in ASD." Crane et al (2009) recently reported that up to 94% of adults continue to present with severe sensory difficulties in at least one domain of the Sensory Profile suggesting that sensory differences persist across the life span. In a meta-analysis (a form of systematic review) of 14 studies, Ben-Sasson et al (2009) reported a significant difference in the presence/frequency of sensory symptoms between ASD and typical groups, with the greatest difference in under-responsiveness, followed by over-responsiveness and sensation seeking.

Dysfunction of both sympathetic and parasympathetic systems have been observed in children who experience sensory processing difficulties and results from small studies measuring electrodermal

responses (a measure of sympathetic nervous system activity) have also suggested that children with ASD are physiologically under-responsive to sensory input (Miller et al. 2001) However, one should keep in mind that behavioural ratings by parents demonstrated significant sensory over-responsivity in the tactile, taste, smell, visual and auditory domains. Possible genetic etiologies to sensory processing deficits have also started to be explored (Goldsmith et al 2006).

Identification of sensory processing difficulties is particularly important in the context of recent data suggesting a relationship between sensory difficulties and core symptoms, adaptive function and maladaptive behaviors. In a recent study (Hilton et al 2010), the relationship between sensory responsiveness and social severity in children with high functioning autism was examined. Significant relationships were found between the social responsiveness scale (SRS) scores and the six sensory profile sensory system (SPSS) scores, suggesting that the relationship between sensory responsiveness and other autism related traits is more important than previously recognized, and addressing sensory modulation issues in children with autism may be more critical than previously thought. Two very recent studies (Boyd et al 2010 and Gal et al 2010) examined the relationships of repetitive

see Sensory on page 42

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Steer Clear of Fad Treatments for Autism Spectrum Disorders

By Jenny Tuzikow, PsyD, BCBA-D,
and Steve Holburn, PhD, BCBA-D
New York State Institute for Basic
Research in Developmental Disabilities

Parents of children with autism spectrum disorders (ASDs) have the formidable responsibility of ensuring that their children receive the most effective treatments available within a sufficient time period. However, many parents are ill prepared to make timely and well-informed decisions about what to do in this situation. When selecting treatments for their child, parents are faced with two challenges simultaneously. First, they need to respond relatively quickly; they cannot wait months or years to decide on their course of action. It is clear that early intervention for children with ASDs is associated with higher gains when implemented at an early age (Fenske, Zalenski, Krantz, & McClannahan, 1985). This predicament hardly provides parents with an adequate amount of time to evaluate their options, especially if their child was diagnosed at an older age. Second, parents need to choose an effective treatment, which should be implemented as soon as possible. The investment of time, money, and emotional interest on an ineffective treatment for their child could be devastating. To assist parents with these difficult decisions, we discuss a few ways to identify



Steve Holburn, PhD, BCBA-D, and Jenny Tuzikow, PsyD, BCBA-D

fad treatments (popular treatments lacking empirical support), and two fad treatments that lack empirical support are reviewed.

How to Identify a Fad Treatment

In selecting an effective treatment, we recommend that parents familiarize themselves with three critical issues: (a) the

therapist's qualifications; (b) the validity of the treatment; and (c) the treatment plan. Perhaps most importantly, parents should evaluate their child's therapist or doctor to determine if the individual is actually qualified. Simply having a degree does not mean the person is qualified to provide services. Parents should consider if the therapist has a degree, possesses a

state or national certification or license, and has sufficient experience in the specific area in which their child needs assistance. For example, it is ill-advised to receive behavior therapy from a psychologist whose training is in psychoanalysis. Qualification to provide a treatment requires formal training and supervision in the given treatment area. We recommend conducting an internet search for the prospective professional who might be providing services to the child. If accusations or negative reports are evident, parents might wish to consider a different therapist.

In addition to identifying the credentials of the therapist, parents should find out about the veracity of the treatment. To identify a fad treatment, it is helpful to know about the essential components of an effective treatment. An effective treatment is one that has been documented in a respectable scientific journal, has adhered to procedures and standards required of scientific study, and has been peer reviewed and determined to be of quality by other qualified specialists. In short, an effective treatment is based on evidence of its effectiveness. Often, if parents can even locate research on fad treatments, the available support tends to consist of personal stories, interviews by the founder of the treatment,

see Fad Treatments on page 38



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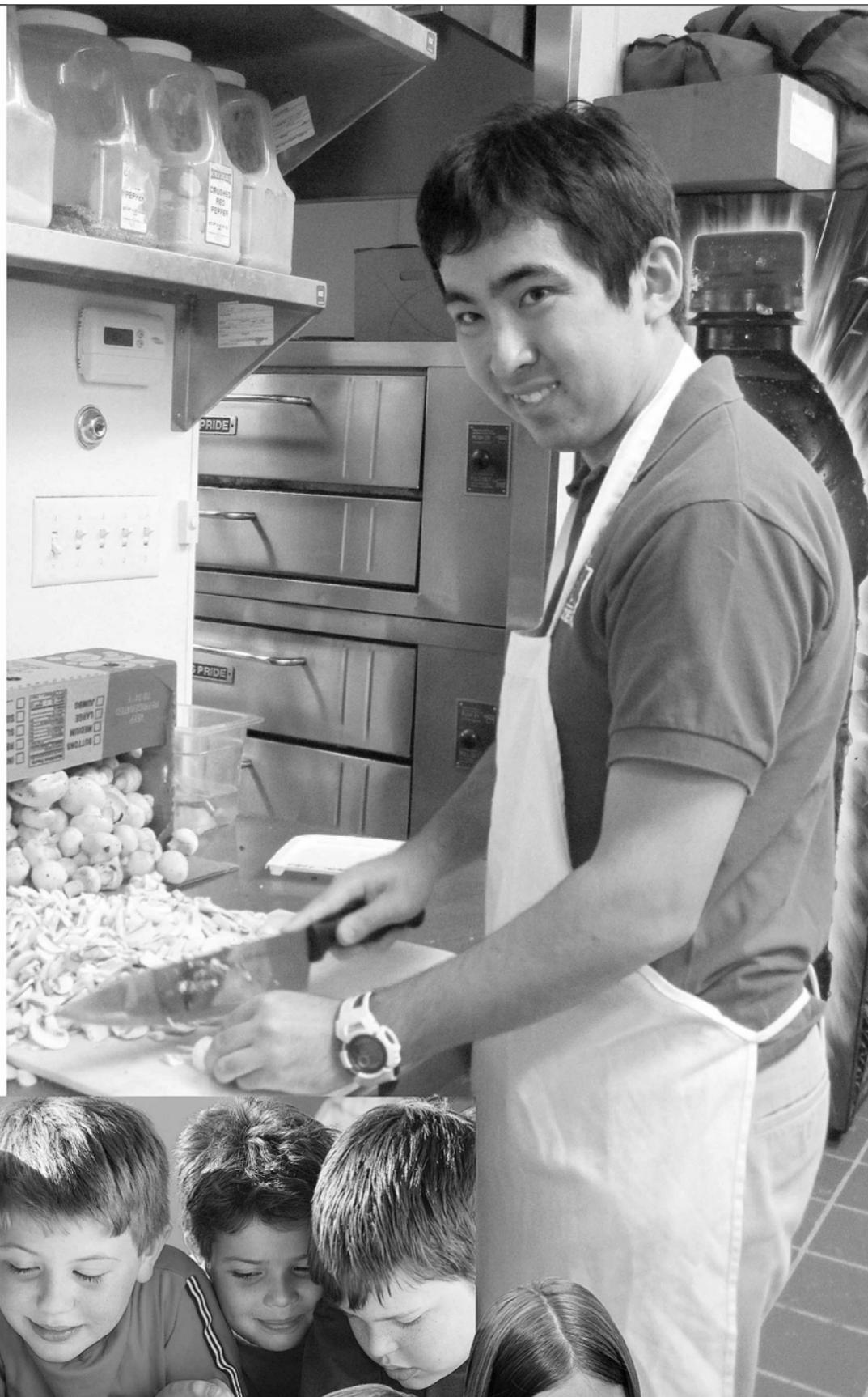
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Understanding and Treating the Comorbid Symptoms of Autism Spectrum Disorders and Attention Deficit/Hyperactivity Disorder

By Cathleen M. George, MSW
Clinical Director
Newmark Schools

As with many childhood neuropsychiatric and emotional disorders, symptoms often overlap causing assessment, diagnostic and treatment planning difficulties. With children on the autistic spectrum, it is crucial to have a thorough evaluation process and multiple treatment options to avoid the enduring, life-long complications these comorbid conditions bring with them. Research studies point to the clinically significant rate of comorbidity of Autism Spectrum Disorders (ASD) and Attention-Deficit/Hyperactivity Disorder (ADHD) symptoms, and also to a less positive prognosis in terms of: academic functioning; substance use/abuse; decreased self-esteem; increased difficulty in social interactions and long-term relationships; criminal and other antisocial behaviors; and difficulty maintaining independence as a result of trouble managing the demands of activities of daily living. This article will provide a greater understanding of how ASD and ADHD overlap, what diagnostic steps are necessary and how to best provide clinical treatment and academic support.



Cathleen M. George, MSW

Autism Spectrum Disorders and ADHD fall into distinctly different diagnostic categories. The DSM-IV-TR states that ADHD cannot be diagnosed "if the symptoms of inattention and hyperactivity occur exclusively during the course of Pervasive Developmental Disorder." However, studies support what is apparent

when working with these children; there is a strong overlap and incidence of comorbidity with ASD and symptoms of ADHD. For example, when reading the histories of our students at the Newmark Schools, it is clear that quite often it was the symptoms of ADHD that brought these children to the attention of either the school system or mental health providers. Hyperactivity, impulse control difficulties, trouble maintaining attention (especially to topics that are perceived to be uninteresting), and problems with monitoring and self-regulating behavior are all hallmark symptoms of ADHD and difficult to manage in young children. It is these disruptive behaviors that frequently cause initial concern to parents and school staff.

As the treatment and prognosis for ADHD and ASD are quite different, it is crucial to have a skilled clinician/diagnostician sort out the overlapping symptoms. Early intervention is key for optimal treatment of ASD, so time lost on an ADHD misdiagnosis can be harmful and unsuccessful, leading to negative feedback to the child from his environment, especially in regard to his unique learning and social challenges. Long term exposure to this type of negative experience, whether it is in school, at home or in the social arena, can lead to self-esteem issues, acting out, learned helplessness,

depression or anxiety. In my ten years of experience as a clinical Social Worker, a thorough Neuropsychological evaluation completed over time by a seasoned Neuropsychologist with input from the family (including a comprehensive family history), school staff, previous educational and psychological evaluations, and private therapists is often the most helpful way to distinguish the multiple neurological challenges often found in children with ASD and ADHD. The outcomes of medication treatment of ADHD in children who also carry a diagnosis of ASD are inconclusive at this time. However, a concern is that a larger focus and treatment on the ADHD component could create higher or unfair expectations of the child's ability to function socially. Again, this could set up a pattern of exposure to negative feedback from the child's environment. In addition, the learning and language challenges that both disorders present are different and require individualized academic interventions that are ideally created by an accurate understanding of the diagnostic picture.

A student with overlapping ASD and ADHD symptoms will require educational support in the following areas: managing the wide gaps between verbal abilities and nonverbal abilities; reading comprehension; memory retrieval; higher level Math

see *Comorbid on page 35*

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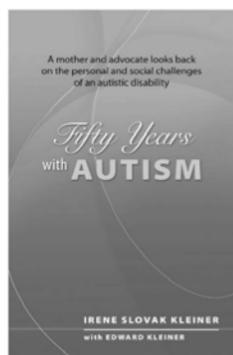
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Using Applied Behavior Analysis to Improve Social Functioning of Youth with Autism Spectrum Disorders

By Dan Lesinski, Leader
Youth Developmental Disabilities Services
Hillside Children's Center



Dan Lesinski

Hillside Family of Agencies, a provider of care for youth and families in Central and Western New York, has been utilizing aspects of the Applied Behavior Analysis (ABA) method for many years. Recently, the organization has more widely practiced this therapeutic approach to help children with autism spectrum disorders lead more independent and socially active lives.

Using ABA, Hillside has been able to both support challenging behaviors that have long been exhibited and improve the quality of life for youth with autism spectrum disorders (ASD). The stories of two youth, Adrienne and Sarah, demonstrate how ABA intervention has led to increased independence and improved social functioning for youth with ASD in a variety of environments.

Adrienne's Story

Adrienne enrolled in Hillside services when she was eight years old, presenting with ASD and obsessive compulsive disorder (OCD). At that time, Adrienne had very limited communication skills and

was only able to express herself using just a few words. Adrienne also would not allow anyone to touch or hold her. This was especially distressing to Adrienne's father who longed to give his daughter a hug and physically express to her signs of his affection.

Adrienne also had oral and physical sensory challenges. Adrienne's mother provided Hillside with a limited list of

only eight different foods that Adrienne would eat separately and never together. Adrienne also had extreme preferences related to her clothing. She only liked to wear pink and white clothes and would daily wear only one specific pair of sneakers by stepping on the back of the heels, but not tie the laces. Another concern of Adrienne's parents was her frequency of illness, which was exacerbated by the fact that she would never wear a winter jacket, hat, or gloves during cold weather.

Implementing ABA in Adrienne's treatment, Hillside was able to address these limiting behaviors that had existed for most of Adrienne's eight years to improve her quality of her life and independence.

First, Adrienne's therapists began to use repetition to teach her to wear a jacket, hat, and gloves during the winter months. Instead of trying to teach Adrienne an entire complex behavior in one session, her therapists broke out the behavior into a series of simple tasks. As Adrienne mastered each task, another sequential step was introduced. Adrienne was asked to begin wearing the jacket unzipped for just a few seconds and with each trial was encouraged to keep her jacket on for a longer duration. Adrienne was provided with rewards that were meaningful to her every time she wore her coat. Through this repetitive process, Adrienne eventually wore her jacket for

one minute. Now Adrienne puts her jacket on all by herself and often follows that behavior with a self-initiated search for her hat and gloves. According to her therapists, Adrienne has expressed a sense of accomplishment and increased independence in learning this new set of skills.

In the second phase of therapy, Adrienne's therapists purchased for her a new pair of sneakers of the same type she currently owned and preferred. Breaking down this complex behavior into smaller simple steps, therapists were also able to get Adrienne to wear her sneakers with her feet completely in the shoes and teach her to tie her own laces.

In subsequent phases of therapy, Adrienne has been taught how to say her own name, verbally identify colors, and increase her conversational vocabulary. She also has been introduced to additional foods beyond the designated eight first provided to Hillside by her mother.

And perhaps of greatest impact to Adrienne in her relations with her family, she will now allow her father to hold her and demonstrate signs of his physical affection towards her. Adrienne will also initiate her own physical exchanges with her father and she has begun to communicate with him. Through ABA, Adrienne has been able to have the kind of deeper

see *Functioning on page 43*

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Social Skills and Asperger's Syndrome: "Big Picture" Thinking

By Marcia B. Eckerd, PhD
Psychologist
Associates for Children and Families

By definition, children with Asperger's Syndrome (AS) have problems with social skills. Books and programs teach a wide variety of social skills, everything from greetings to compromising on play dates, giving a compliment to accepting criticism. There are many reasons why these programs face uphill challenges.

In their book, *"Helping the Child Who Doesn't Fit In (1992)"*, Stephen Nowicki and Marshall P. Duke cite a critical study showing that 55% of emotional meaning is found in facial expression, posture and gesture, and another 38% of meaning is communicated through tone of voice. They state, "Only 7% of emotional meaning is actually expressed in words." Most AS children have neuropsychological profiles of a nonverbal learning disability; they miss nonverbal cues. As a result, they don't "get" what's going on: who's friendly and who's not, what's appropriate and what's not. They misperceive the behavior and intentions of others because they miss the vital cues that convey meaning. AS children often over-react to their perceptions of the behavior of others, often getting into trouble and alienating instead of engaging their peers.



Marcia B. Eckerd, PhD

Additionally, AS children are black and white thinkers, so they make judgments about what's right and wrong. Theory of mind, or understanding that others have a unique (and different) point of view, is a weakness for these children, so it is difficult for them to recognize that others might perceive situations differently from themselves. They tend to think that their perception is the only way of

understanding or behaving. It's challenging to get an AS child to budge from an opinion. These limitations can make it hard for AS children to know how and when to use the social skills they learn and sometimes, to feel that using these skills makes sense.

The complaint about social skills programs is that the skills learned "don't generalize" to everyday situations. Just as an AS child might not recognize an academic problem if it's framed differently, he might not recognize a social situation if it's presented differently. Unfortunately, social situations are complex, rapid and multi-dimensional, and even similar situations present somewhat differently each time. The child must integrate information and shift sets according to different situations. He must stay in control, and monitor the accuracy of his perceptions as well as the way his behavior affects others. Social skills, therefore, involve the behavioral executive functions of inhibition, emotional self-control and shifting, as well as metacognitive functions such as initiation, planning and self-monitoring in order to function smoothly and transfer from training to real life.

Working with children (and young adults) with AS on social skills therefore means that in addition to teaching skills, one must teach social cognition and address a broad range of executive functions; one has to address perception of social situations, cognitive flexibility and awareness of the perspective of oth-

ers. For the clinician or parent, this is a much more complicated task than teaching a child how to introduce himself.

Over 15 years of teaching social skills to children, Maureen Foley, LCSW, CCC-SLP and I developed a conceptual framework for teaching social skills that includes all of these elements. We defined six "building blocks" that underlie social skills. These building blocks are in play simultaneously. Unfortunately, social situations do not present themselves in discrete categories; however, understanding this framework can point to how to initiate an intervention and focus on one salient area, later moving on to a second "block" and a third. It's always important to take on one area at a time to avoid overwhelming a child, and to accept gradual progress.

The building blocks incorporate executive functions, social cognition and social skills into a fairly simple framework that can easily be communicated to parents and children. The six blocks are:

- Awareness (of self and others)
- Emotional Self Control
- Big Picture Thinking
- Adaptability
- Predicting Outcomes
- Social Resiliency

see Asperger's on page 32



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Parents: Give the IEP Team Quality Evaluations with Recommendations

By Tracey Spencer Walsh, Esq.
Senior Counsel
Mayerson and Associates

In my last article (*The Best Kept Secret*, Autism Spectrum News - Summer 2010) I discussed what might be the best kept secret of parent counseling and training (PCT) for parents of children with autism. Under the Federal Regulations of the IDEIA, PCT is to be provided to parents as a related service on your child's IEP. It is often through PCT that parents begin to learn about treatments that may be appropriate for their child. It is a given that, "when you've met one child with autism, you've only met one child with autism." Each child, of course, presents differently and deciding on an appropriate treatment for the child depends on the child's unique needs.

How do you know how to treat the many components of your child's autism condition? By consulting with professionals who can properly advise you. Your child will likely have deficits across several domains: occupational therapy, physical therapy, communication, behaviors, social skills, vision problems, among others. Once you get recommendations from your professionals you should give those recommendations to your school district's special education committee. For example, in New York, you would submit the



Tracey Spencer Walsh, Esq.

recommendations to the committee on special education "CSE" and in Connecticut, you would submit them to the pupil planning team "PPT" and ask them to convene an IEP meeting so that the "team" can consider the recommendations, reports and evaluations when planning your child's program and placement for the school year.

Parents will want to make sure that their child's needs are appropriately met and, as always, the first step is getting quality evaluations and recommendations. You may have a friend or neighbor who also has a child with autism that receives "floortime" therapy (Dr. Stanley Greenspan) and, based on what they tell you, you think that your child should receive the same intervention. You may or may not be right. You should take steps to find a professional to assess your child to see whether this intervention would be appropriate and effective. A quality assessment may confirm that floortime would be an effective intervention but it may also reveal that 1:1 ABA therapy would be a more appropriate intervention for your child. Until your child is evaluated, however, you will not know the answer and it is important to keep in mind that the school district won't have the answer either. If your school district recommends a "methodology" without assessing or evaluating your child to make that determination, ask that they do so. Be insistent on that point.

When you are at your child's IEP meeting, you want to make sure that everyone on the IEP "team" has a copy of the evaluations and reports that you submitted; you want to make sure those reports are "meaningfully" considered. Your reports may recommend intensive levels of ABA intervention for your child and you want that on your child's IEP. I have of-

ten heard from parents that they are told that ABA cannot go on an IEP or "there is no way" that a specified level of ABA can go on an IEP. Neither is true - ABA and its intensity can absolutely be added as a specified service on your child's IEP if recommended by your professional. It is true that some school districts are reluctant to add these services because they are expensive, but under the federal IDEIA statute, an anticipated expense is not a bar to meeting a disabled child's unique needs.

It is important that you attend your child's IEP meetings "armed" with reliable recommendations. While no one knows your child better than you do as a parent, "just because you say it's so doesn't make it so." This means do not go to the IEP meeting asking for services for your child because "your neighbor's child gets them." Your opinion and demand will be immediately discounted. Think about it. You do not want your child to get fewer services because "other children are not getting those services or that level of services," right? It would be completely inappropriate (but unfortunately not uncommon) for an IEP team to tell you just that - we cannot offer your child five hours a week of speech therapy, because no other child in the district is receiving such an intensive level of speech services. Your reaction must be, "What? Are you kidding me? You are denying my

see IEP on page 37

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The Center for Career Freedom's ASD Employment Program

By Donald M. Fitch, MS
Executive Director
Center for Career Freedom

Chris and Kenny were smiling – they were “wowing the crowd” with their recently acquired computer skills generating business letters, tables, flyers, entering data without errors and in less than thirty minutes. Their Housing and Case Managers were speechless. Their instructors Peter and Steve were beaming. Their mothers had tears in their eyes. “Where did you learn this?” one Case Manager asked. “Here at the Center,” Kenny replied. “I taught myself,” said Chris. “Do you have computers at your Group Home?” “No.” “Would you practice your keyboarding and data entry skills if you did?” “Yes.”

That’s where the idea came from for the Center to donate a refurbished personal computer with Microsoft 2007, a monitor, printer and software to Rehabilitation Support Services (RSS) in Tarrytown, New York - the home where Chris, Kenny and eight other adults with special needs live. Nicole Brown, Assistant Program Manager at RSS, was excited for her clients with “the hope of their acquiring computer skills that could someday provide paid employment.”

The Center for Career Freedom is a 501(c)(3) New York State Department of Education licensed Business School, a Microsoft Office Training Center, a Social Security Administration Employment Network, and a Department of Social Services (DSS) One-Stop Provider. For the past twelve years we have served over eighteen-hundred students with psychiatric and Autism Spectrum Disorders/Asperger’s Syndrome who have a passion to raise their computer skills to competitive employment levels. Our goal is self-sufficiency for our student-interns with disabilities.

About a year ago, with the encouragement of three parents; Judy Omidvaran, Loris Nevers, and Monsi Arns, and Ira



Donald M. Fitch, MS

Minot, LMSW, Chairman of our Board and Executive Director of Mental Health News Education, Inc., we began to explore ways to adapt our Microsoft Word Curricula to the demands of the workplace. Instead of teaching to Microsoft’s Certification Test, we focused on teaching only those tasks that employers would actually pay for, such as data entry. This freed up the Instructors to skip the theory and little used program features that don’t directly relate to the work task.

Joanne Casablanca was chosen to head up the curriculum development phase because of her extensive business and corporate executive secretarial experience at Reader’s Digest, IBM and Pepsi-Cola.

Each week, for twenty weeks, Joanne, Peter and Steve would set-up their students to create letters; typed and hand-written tables, charts, business cards, Google searches, etc. It is import to help them continue to practice on their own, with minimum supervision – just like in the real world of business.

After legal and financial consultation, the Center launched a for-profit division offer-

ing Microsoft Office skills to non-profits, Government Agencies, Schools, corporate and small business, etc. in Westchester County, NY, who want to outsource some of their projects, while helping their neighbors-in-need. In addition to data processing, we also offer on-site computer training by our six Microsoft Certified Instructors to strengthen their staff’s keyboarding and Microsoft Word, Excel, PowerPoint and Outlook skills. We call it “Lunch & Learn.”

As Ira Minot, LMSW, Executive Director of Mental Health News Education, Inc. said, “There is a growing crisis in services and supports for adults with Autism.” According to the New York State Office for People with Developmental Disabilities (OPWDD) 2009 Medicaid billing data (OMRDD/TABS), persons diagnosed with ASD in NY have doubled in the past five years to over 20,000. We project over 40,000 persons by 2015. Incredibly, adults (21+) with ASD comprise over forty percent of the population! If CDC’s 1:110 estimate is correct, then this projection is woefully inadequate. Competitive work skills training & employment for these folks is virtually non-existent. From our Google search, it seems only Linda Fiddle, Esq., of the Fiddle Foundation has embraced this challenge.

One of our goals is to develop the ASD Employment Program into a model that could easily and inexpensively (under \$1,000) be replicated by parents, schools and vocational programs throughout the world. All it takes is one volunteer-mom with excellent office skills! (In our experience, we have found few professional educators possess the required skill set). We have prepared a “shopping list” below which reflects our current experience. We welcome your suggestions for software and learning techniques to strengthen the program.

Suggested Equipment

Suggested equipment includes: A tower or laptop computer, keyboard, mouse, headphones, monitor, and printer.

Windows 7 or XP operating system; MS Office 2007: Excel, Word, Outlook; Mavis Beacon Typing program; Data Entry and order processing programs (Computers at Work). If you’re connected to the internet, add Antivirus, Security, and Net-Nanny programs to block access to porn and malicious sites. Internet games and videos are free. Our students like LEGO & Sim City. A comfortable chair with back support and adaptive equipment, as required, e.g.: wrist rest, joystick, trackball mouse, colored keyboard, etc. We also use partitions between stations to help minimize distractions.

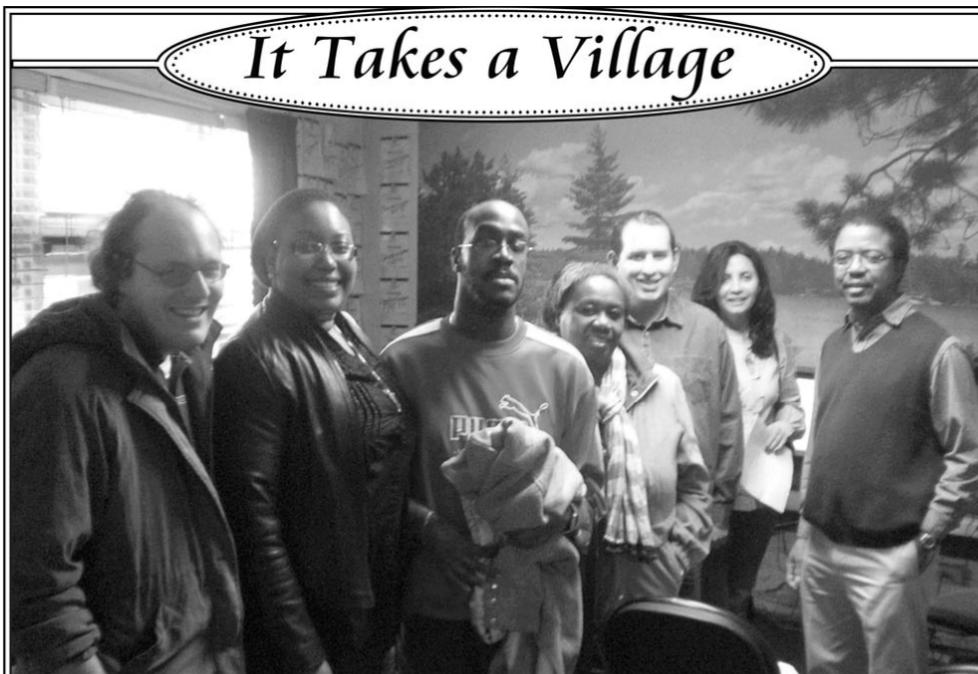
Instructive Mode

Instruction should be active, collaborative, visual and tangible. Our student and Instructor both face the screen and navigate the program together, focusing on the task. Instructors speak slowly, and use a minimum of words. We let the student control the pace and mouse. Once the student is comfortable with the program, they can practice their skills without help - depending on their stamina and interest.

Curriculum

In class, we try to use a consistent two and a half hour schedule three times per week, supplemented by as many hours of homework as the student enjoys. We start with an hour of keyboarding, a ten minute break, then an hour of Portfolio building, e.g., business cards, flyers, letter, tables, graphics, etc. in Word. Importantly, the student takes home their projects after each class and posts them on their bulletin board. After a second break, the last half hour is spent on practicing data entry and internet search skills (such as with the Google search engine). Post class rewards include snacks, downloading favorite pictures, and video games.

see *Employment on page 42*



From the left: Jon Viegner; Nicole Brown, Asst Program Mgr, RSS; Chris Nevers; Loris Nevers; Kenny Gonzalez; Monsi Arns; Steve Vernon, Dir. ASD Employ. Prgm

Examples of ASD Students' Work Skills



Tables



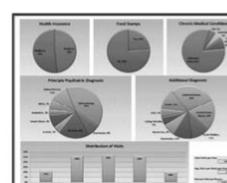
Flyers



Invoices



Data Entry



Charts



Business Cards



Internet Searches



Keyboarding



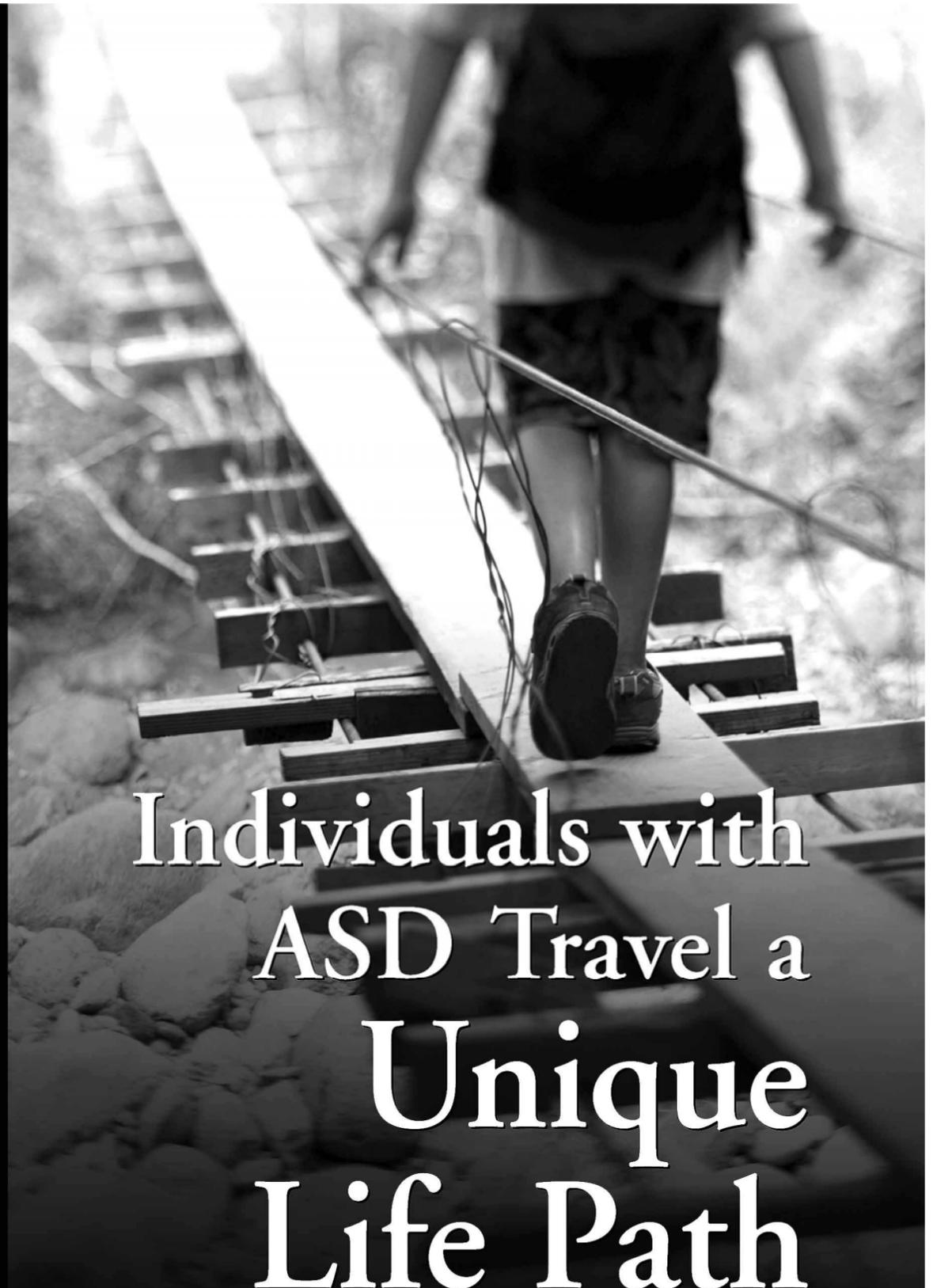
Letters

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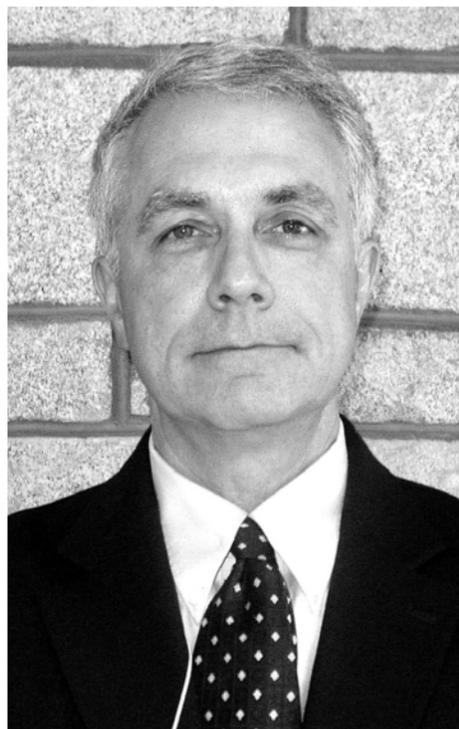
How Science and Evidence Won Out Against Auditory Integration Therapies

By Thomas Zane, PhD, BCBA
Van Loan School of Graduate and
Professional Studies at Endicott College

Autism is known as a “fad magnet” because of the plethora of treatments available to treat the condition (Jacobson, Foxx, & Mulick, 2005). Because of the varying levels of believability and evidence supporting many of these treatments, there is a need to be skeptical about any particular autism intervention until some minimal level of quality evidence exists showing that the particular treatment has demonstrated positive results. Most professionals adhere to the methods of science and scientific inquiry as the standards against which the quality of treatment evidence is judged.

Ideally, by universally adhering to common criteria for acceptable empirical evidence, professionals across disciplines would study a phenomenon and all arrive at the same conclusion as to its “truthfulness” or veracity. A conclusion about, say, the efficacy of an autism treatment would be that much more powerful given the adherence to the scientific method by professionals from varying disciplines all examining the same treatment from different perspectives.

Such a professional model is illustrated by Auditory Integration Therapy (AIT) and how professionals from different disciplines examined it and made a judgment about whether AIT should be promoted to consumers.



Thomas Zane, PhD, BCBA

Researchers have reported that persons with Autism Spectrum Disorders (ASD) show higher incidences of sensory processing difficulties than the general population (e.g., Baranek, Foster, & Berkson, 1997; Gillberg, et al., 1990). Some of these sensory problems consist of abnormal responses to auditory stimuli, which

could translate into learning and behavioral challenges (e.g., Dahlgren & Gillbert, 1989). As a result, Berard (1993) and others have proposed a therapeutic approach aimed at reducing or eliminating auditory sensory processing challenges.

Berard, a French otolaryngologist, developed the method in 1982 (Berard, 1993). Although there are variations within the field of auditory integration therapies (e.g., Samonas, 2010; Tomatis, 2010), the general method consists of the recipient listening to music that has been digitally modified in some way. The music is often played through headphones, with multiple sessions across several days (e.g., Dawson & Watling, 2000). The music is altered in some fashion, such as by dampening or limiting the peak frequencies, randomly varying the high and low frequencies on a random basis, or varying the volume. The music is modified in particular ways based upon the needs and challenges of the recipient.

The advocates of AIT claim that there is scientific evidence to support this therapeutic approach. Indeed, all of the websites devoted to AIT have references to research studies that purportedly confirm that AIT is causally related to improvements of behavior and learning. For example, at the AIT Institute (2010) website, there can be found a list of 23 research studies that purportedly support the effectiveness of AIT.

One of the first public criticisms of AIT

was provided by the American Academy of Pediatrics (AAP; 1998), which published a policy statement regarding AIT and Facilitated Communication. In unambiguous terms, AAP found that AIT had little to no quality research proving it was effective with persons with ASD. AAP concluded that its use was “not warranted.”

Two years later, Dawson and Watling (2000) reviewed the literature that existed at that time. They reviewed five studies, published between 1994 and 1997. Three of the five included a control condition. Two of these three studies found improvement in participants in both of the conditions, thus no causal relationship between AIT and improvement in participants could be believed. In another, Rimland and Edelson (1994) found improvements made by only the participants in the AIT condition, but there was a design problem in which the researchers didn’t do matching of subjects during pre-intervention.

Then, in 2003, the American Speech-Language-Hearing Association (ASHA; 2003) weighed in on the controversy. After reviewing the existing literature published on AIT, this organization adopted a policy statement stating that there was no evidence that AIT improves the behavior of persons who use this treatment. Furthermore, the policy suggests that if ASHA members chose to treat with AIT, they could be found in violation of the ASHA Code of Ethics.

see *Science on page 41*



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Toddlers from page 8

IS group received more opportunities for joint attention, affect sharing, and socially engaged imitation. The toddlers were assessed at the start and end of the intervention and again six months later.

Children in both groups made improvements in social, cognitive and language skills during the six-month intervention period. Children who received IS made greater and more rapid gains than those in the non-IS group. The researchers also noted that children in the IS group used their newly acquired abilities with different people, locations, and type of activity.

This is noteworthy because children with ASD have particular difficulty doing

so. They tend to use new skills mostly within familiar routines and situations.

At the six-month follow-up, children in the IS group showed slower improvements in social communication compared to when they were receiving the intervention, but did not lose skills gained during the intervention period. In contrast, children in the non-IS group showed reduced social communication skills at follow-up compared to their performance during the intervention period.

“This is the first randomized controlled trial to examine an intervention focused on core social deficits of ASD in toddlers, and the first to show gains in these deficits resulting from intervention,” said Landa. “Though preliminary, our findings provide promising evidence

that such a supplementary curriculum can help improve social and communication skills in children younger than 3 who have ASD.”

The researchers received additional study funding from the Health Resources and Services Administration.

References

Landa RJ, Holman KC, O'Neill AH, Stuart EA. Intervention Targeting Development of Socially Synchronous Engagement in Toddlers with Autism Spectrum Disorder: A Randomized Controlled Trial. *J Ch Psychol Psychiatry*. 2010 Dec 8. [epub ahead of print]

The mission of the NIMH is to transform the understanding and treatment of mental

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The National Institutes of Health (NIH) - The Nation's Medical Research Agency - includes 27 Institutes and Centers and is a component of the U.S. Department of Health and Human Services. It is the primary federal agency for conducting and supporting basic, clinical and translational medical research, and it investigates the causes, treatments, and cures for both common and rare diseases. For more information about NIH and its programs, visit www.nih.gov.

This NIH News Release is available online at: www.nih.gov/news/health/dec2010/nimh-08.htm.

Helping Students on the Autism Spectrum Succeed in College

By Dianne Zager, PhD, Director
Center for Teaching & Research in Autism
Pace University

Over the past few years, an increasing number of students on the autism spectrum have begun to consider college a viable option. In response to the growing interest in postsecondary education for students with disabilities, many universities are developing special college support programs. We have seen that, with adequate support, young adults with ASD can engage in meaningful academic, social, and career development programs; and that they are able to participate fully in their college community. We also have seen that these students are able to reside independently in college dorms when provided with appropriate supports. Through utilization of research-based practices based on person-centered planning, positive learning environments can be provided on college campuses. Such opportunities for academic enrichment, self-advocacy, and career development are more likely to lead to productive employment and independent living than continuation in traditional secondary programs until age 21 (Zager & Alpern, 2010, *Expanding Postsecondary Options for Students with Autism, Focus on Autism and Other Developmental Disabilities*).



Dianne Zager, PhD

Types of supports available at colleges and universities vary greatly. In determining which college will be best suited to a particular student, consideration needs to be given to the student's level of independence (e.g., personal hygiene, time management, responsibility for medication); learning characteristics (e.g., academic strengths, in-class supports, study

skills); personal traits and preferences (e.g., social competence, sensory issues, preferred area of academic concentration); and environmental preferences (e.g., rural or urban campus). This article highlights some important components of support programs to assist students and their families in selecting a college program.

Four components of successful college support programs that should be present at some level for students with ASD are (1) academic support, (2) campus-life services, (3) career development, and (4) peer mentoring. In order to effectively serve students in these four critical areas, it is necessary for support programs to create infrastructure and build capacity within institutions of higher education. Zager and Alpern (2010) found that it was necessary for stakeholders within the university to come together on an ongoing basis to plan, deliver, and readjust supports and services. Therefore, as parents and students evaluate specific programs, they should look to see whether the program is supported by the university in which it is housed. Remember that buy-in by university administration and faculty is crucial to successful inclusion and support of students with ASD at the college level.

Academic Support

When students with learning differences come to college, they usually have a list of approved accommodations that they

received in high school. The high school accommodation list is a good place to begin to plan for the delivery of college accommodations; however, continuing the same academic supports that were provided in high school may be insufficient to fulfill college level requirements. The support menu of accommodations available in high school, which might have included such supports as note takers and distraction-free testing sites, needs to be broadened for college so that it includes academic and campus-life coaches, note taking technology (e.g., LiveScribe), and flexible means to demonstrate competence in subject matter. For example, while extended time accommodations (e.g., time and-a-half) may have sufficed for students to complete tests in high school, the complexity of subject matter and length of college tests can necessitate double time or tests completed in sections over days.

In high school, students are typically well-supervised during exams, but this is often not the case in college. Recently, while proctoring a first-year student with Asperger syndrome and significant learning disabilities on a psychology exam, I read him the four essay questions. He responded that he knew all the answers, and I left him in a quiet cubicle to complete the first question. When I checked his progress 15 minutes later, he had

see *College on page 43*

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Eight Westchester NY Agencies Collaborate on Special Needs Lecture Series

By Dori Frumin Kirshner
Executive Director
Matan

Eight Westchester, NY agencies, through a generous grant from Westchester Program Services Cabinet of UJA-Federation of New York, have announced the dates for a Special Needs Lecture Series, "Building Community...One Lecture at a Time." The first lecture, "Show and Tell": *Using Visual Strategies to help your child understand, listen and follow directions*, was

held at Westchester Jewish Center on October 27 at 9:30-11:30 a.m. Ramapo for Children facilitated the interactive session.

All lectures are free of charge and are geared towards parents and caregivers of children with special needs. The collaborating organizations are: Bet Am Shalom, Congregation Kol Ami, The JCC of Mid-Westchester, Jewish Community Center of Harrison, Matan, Temple Israel Center, Westchester Jewish Center and Westchester Reform Temple. For additional information and to RSVP for the upcoming 2011 lectures, please contact Aleza Kulp at educdir@wjc.com or (914) 698-2966.

Future Lectures in 2011

March 7th - At the Temple Israel Center Rick Lavoie will do a two-part lecture from 4:00 - 6:00 p.m. with religious school teachers and 7:00 - 9:00 p.m. with parents.

April 4 - The Westchester Reform Temple will be showing the film "Rachel Is" with discussion afterwards with Tara Klein from 7:00 - 9:00 p.m. "Rachel Is" will be a two-part workshop with the follow-up with Phyllis Conley on Sunday.

April 10 - At the JCC Mid-Westchester social hall, parents will be divided up in groups to work on IEP development, goals, advocating for your child's IEP, etc. This is a perfect segue from the film "Rachel Is," shown at the April 4th lecture, where the mom is dealing with transition issues and thus stresses the importance of strong IEPs at every stage of your child's transition.

May 3 - At Bet Am Shalom Temple, Dr. Kevin Kalikow will speak on the medication dilemma.

A Different Kind of Support: Soul Support

A New Model for Meeting the Needs of Moms of Children on the Autistic Spectrum

By Judy Fiermonte, MFT and
Cynthia Hymowitz, MFT

When a child is diagnosed with an Autism Spectrum Disorder, the whole family is severely impacted. Often, the mother becomes the primary caretaker with the daunting task of researching all the therapies available, driving to appointments, cooking the special diet meals, coordinating all the services and service providers, debriefing her husband, taking care of her other children, and in some cases, working outside the home. What does this do to her relationship with her child? What does this do to her relationship with herself?

The usual gratification of reciprocal love, connectivity and responsiveness that sustains and nurtures mothers is often missing for those who have children on the autistic spectrum. The tasks before these mothers are overwhelming. Many mothers are depressed, burned out, resentful, fearful, worried, isolated and running on empty.

The Double Whammy

Most women come to parenthood with dreams of having a "normal" family and taking their place in their social, cultural



Judy Fiermonte, MFT

and family communities with the usual rituals and rites of passage. These unspoken expectations begin earlier and earlier in our achievement oriented culture; not achieving these milestones creates anxiety and fear.

The period before a child is officially diagnosed is a series of losses culminating in a diagnosis that seals the loss of hope for a "normal family." That loss can be devastating and there is often no "safe place" to express that loss without fear of being judged.

Shadow feelings of envy, inferiority,



Cynthia Hymowitz, MFT

and embarrassment can contribute to the feelings of shame and failure. These shadow feelings which occur at gatherings of families and friends are perhaps the most isolating of all and do the most to undermine a Mom's feelings of self-worth.

For parents of kids on the spectrum it can be a double whammy. Not only do they not get the life sustaining emotional reciprocity from their child, but they must suffer in silence at social gatherings (if they even dare go) and hide these feelings even from themselves.

Identifying the Needs

Both of us have children with special needs. It is through our own personal journeys as mothers of children on the autistic spectrum that we have been able to truly understand the psychological, emotional and spiritual impact this scenario *really* has on a mother.

Eight years ago, out of our own feelings of isolation, we started a peer support group with three other mothers of children with special needs. This became our "Sanctuary" as we discovered what we needed to maintain our own senses of possibility and aliveness.

Our own discoveries became the seed and inspiration for offering groups that focus on the personal needs of the mothers, rather than on the needs of the children. Our basic premise being if Mom's needs are truly met, the children will benefit in countless ways. We call our groups *Sanctuary - A Circle of Women that Nurtures our Souls*.

Attachment

In the past decade, attachment theory has become a significant model for understanding the emotional needs of children and how our lives as adults reflect our

see Support on page 34

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Asparagus Syndrome: The Newly Gourmand Life of an Impossibly Picky Eater

By Amy Gravino, BA, Founder
Asperger's Syndrome Coaching
and Other Techniques



Amy Gravino, BA

Last week, I burned the lasagna. I remember opening the oven, full of anticipation and nervous excitement, only to have my hopes dashed on the rocks at the sight of the undercooked noodles and scorched earth-colored Parmesan cheese.

Was it the glass baking pan? Should I not have halved the recipe? The questions that flooded my mind came with an even greater realization: that just a few years ago, I wouldn't even be eating lasagna, let alone going through the trials and tribulations of making it from scratch.

Like many folks with Asperger's Syndrome, my life has been the story of food sensitivities—problems with the smell, taste, and especially textures of varying dishes prevented me from having a "normal" eating experience. Scraping the cheese off pizza. Cutting the edges off of pancakes and steak. Peeling the skin from grilled hot dogs. I had a list a mile long of different things that I needed to do to different foods to make them my definition of "edible." And don't even get me started on my dissection of pre-made sandwiches!

But I never considered these things odd. It was only when others started

pointing it out—gawking at me as though a curiosity in a circus sideshow—that I became aware, and painfully self-conscious of how I ate. My own (most likely Aspie, too) father expressed a strong distaste for eating with me, citing his disgust at me using my fingers to pick things apart.

I still don't know what changed. Maybe it was going to college, being exposed to other types of food. I slowly began to try cuisine from other cultures—Japanese, Indian, Thai—foods that would have been beyond off-limits before then. And somewhere between barely being able to use a fork and nimbly picking up a single grain of rice with a pair of chopsticks, food became about more than just sustenance. It became a passion.

Stews, soups, stir-fries, casseroles, curries, quiches, tarts, pies, trifles, cakes, cookies. I have cooked and baked them all as time has gone on, delighting in turning an assortment of random ingredients into a magnificent finished product. Bringing pleasure to those who eat and enjoy my cooking has been an unexpected and welcome side-effect of this, my first-ever "perseverative interest."

One particular memory that I have is from before I really got into cooking, as a child visiting my grandparents in New Jersey. I loved making pancakes for our family, and every night before bed, I would get out the cream-colored rubber measuring bowl, the pancake mix, and all of the other tools needed. It was routine, one of the things in which I found great comfort, but more than that, it gave me purpose.

Having a sense of purpose when it comes to eating can achieve so much. Knowing that you are capable of stirring a bowl of ingredients, or chopping vegeta-

bles gives a person the sense of usefulness. The majority of my childhood was spent feeling useless, socially inept, and incapable. To get out that pancake mix and set the table made me feel as though I were exerting even a small amount of control over something in my life, and for a child with special needs, that can make all the difference.

Now, hundreds of photos of dishes that I have cooked fill albums of mine on Facebook. These dishes are the product of that control—quiet half-hours spent in my kitchen dicing carrots, sautéing onions, or kneading a ball of dough with my own two lightly-floured hands. Cooking brings me peace of mind, a calmness from truly knowing that I am useful, I am talented, I am able. It is a part of me that I can share with the world, a part that sustains and continues on, and that I hope always will.

Amy Gravino, BA, a certified coach for individuals with Asperger Syndrome, is also diagnosed with AS. She is attending graduate school to obtain a masters degree in Applied Behavior Analysis (ABA). Amy offers private services as an Asperger Syndrome college coach. She hopes to work on a college or university campus helping students with AS thrive and succeed both academically and personally in a higher education setting. To read more of Amy's writing, please visit her official webpage: www.amygravino.com.

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Interview from page 1

(CNVs) which are changes in the number of copies of a gene or portions of it and can be caused by deletions, duplications, inversions, and translocations of pieces of the genetic code. High-resolution genetic techniques like array comparative genomic hybridization (aCGH) are now able to explore large swaths of the human genome and search for differences in copy number between a given individual and what is typically expected in healthy controls. The current yield in detecting causes of autism when these kinds of techniques are utilized is approximately 15-20% and rising. These CNVs are often occurring spontaneously in the child, but may also be inherited in a minority of cases, so it is also critical to perform genetic analyses in parents.

This kind of approach to understanding the cause of autism is extremely significant for families for several reasons. First, it can provide a medical diagnosis for autism and in each case, depending on the cause, these genetic aberrations may be associated with other medical comorbidity that will be important to treat and monitor. Second, it can provide families with estimates of recurrence risk should they be considering having more children. In other words, if the mutation or deletion in the genetic code occurred spontaneously in the affected child, then the recurrence risk can be about the same as for the general population. However, if the parents have similar changes in their genetic code, it may confer increased risk for a sibling to have autism. Finally, every identified cause of autism provides the opportunity

to develop model systems (e.g., mouse models) by knocking out the causal gene and the model systems can be used to understand the neurobiology of the disorder and most importantly, to develop targeted novel therapeutics.

It is important to understand that autism is a behavioral diagnosis made based on observations of language, social cognition, and repetitive behaviors. The more we learn about the genetic causes of autism, the more we come to understand its etiology as residing in genes that regulate processes of neuronal migration, differentiation, synaptic plasticity, and the formation of neuronal networks. There are many, many single gene defects and known genetic syndromes that account for a growing percentage of cases of autism. The American College of Medical Genetics now recommends aCGH as a first line test for children with ASD (Genetics in Medicine, 2010; 12 (11): 742-745). Comprehensive clinical evaluation and genetic testing is required in children with autism to clarify underlying medical diagnoses and determine appropriate monitoring.

Q: Can you give us a general overview of our current understanding of the medical conditions associated with Autism?

A: Some of what used to be considered comorbidity can now be considered signs and symptoms of underlying medical conditions causing the autism. Several examples illustrate the issue of comorbidity and the significance of detecting causes of autism. The most well known example is Fragile X Syndrome. If you examine 100 individuals with Fragile X Syndrome,

approximately 25-40% will have an ASD. And if you look at 100 individuals with autism, 1-2% will have Fragile X Syndrome. Silencing of the Fragile X mental retardation 1 gene (FMR1) is the cause of the Syndrome and the cause of the autism in these cases. Silencing of this gene is thought to lead to excess glutamate dependent protein synthesis and results in significant impairment in learning and memory likely responsible for the intellectual disability characteristic of Fragile X Syndrome. Fragile X Syndrome is also associated with a number of medical complications, including seizures, cardiac problems (e.g., mitral valve prolapse), hernias, joint problems, and scoliosis among others. People with Fragile X Syndrome also have increased rates of attention deficit, hyperactivity, and anxiety. Rett's Disorder is another important example and a medical condition that causes autism where the precise gene, MECP2, has been identified on the X chromosome. It is critical to identify these children early as severe neurological problems may develop, including loss of muscle tone, feeding problems, apraxia, and breathing difficulties (e.g., apnea). Another example is illustrated by work in the Seaver Autism Center by our Director, Dr. Buxbaum, and colleagues where mutations in the PTEN gene were found in a child with autism and intellectual disability. Mutations and deletions in the PTEN gene also cause Cowden Syndrome which is associated with increased risk of certain types of cancers and noncancerous tumor-like growths called hamartomas. Phelan McDermid Syndrome is yet another important example of a medical condition causing autism. Phelan McDermid Syndrome is caused by mutations and deletions in the SHANK3 gene located on chromosome 22 and responsible for approximately 1-2% of cases of autism. It is associated with neonatal hypotonia, motor skills deficits and gait disturbance, and absent or severely delayed speech. Affected individuals are also at greater risk of seizures, renal abnormalities, lymphedema, gastroesophageal reflux, and arachnoid cysts, all of which require careful monitoring.

Other comorbidities common to ASD include intellectual disability, sleep disorders, gastrointestinal symptoms (e.g., bloating, diarrhea, and constipation), and fine/gross motor deficits. Less common but still significant are the presence of metabolic disorders, several of which have been associated with autistic features. Phenylketonuria, for example, has been associated with autism when uncorrected. And while rare, there is growing interest in the role of mitochondrial dysfunction in autism and in inborn errors of cholesterol synthesis (i.e., Smith-Lemli-Opitz Syndrome).

Q: Can you give us a general overview of the psychiatric conditions associated with Autism?

A: One of the reasons ASD is so challenging to treat is because there is no uniform approach that works for a majority of children. Treatment needs to be tailored to individual needs and this is particularly true for medication treatment, where the issue of comorbidity plays a significant role. In addition to the clinical triad of symptoms that characterizes ASD (i.e., language, social, and behavioral impairments), there is a wide range of associated

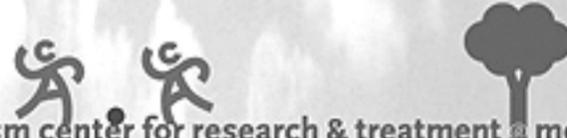
features that add to the complexity. Anxiety occurs as part and parcel of the repetitive behavior domain and is often manifested by symptoms consistent with obsessive compulsive disorder. People with autism can become preoccupied with rigid adherence to routines and engage in frequent ritualistic behaviors to soothe their anxiety but also to stimulate at times. When these routines are interrupted, some patients may erupt with impulsive aggression, which is probably one of the most common reasons families seek pharmacological treatment. Attention deficit, hyperactivity, and impulsivity are other common associated features and a frequent target for medication intervention. Although the current diagnostic criteria prohibit the concurrent diagnosis of Attention Deficit/Hyperactivity Disorder (ADHD) and ASD, ADHD symptoms can occur in a large percentage of kids with ASD and this exclusion is due to change in the next iteration of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V).

Dr. Emily Simonoff from Kings College London published an epidemiological study looking at the 3 month point prevalence of psychiatric comorbidity among 112, 10-14 year old children with ASD (Journal of the American Academy of Child and Adolescent Psychiatry, 2008;47(8):921-929). The results suggest that 70% of participants had at least one psychiatric disorder in addition to ASD and about 40% had two or more. The most common diagnoses were social anxiety disorder, ADHD, and oppositional defiant disorder. Other common comorbidity included panic disorder, obsessive compulsive disorder, and tic disorder. While psychosis and paranoia are often discussed in the context of ASD, the rates of true psychotic symptoms are probably not greater than in the general population. Patients with autism may become obsessively preoccupied with perceived injustice or wrongdoing; though it may appear paranoid, they are more likely to be misperceiving social cues or obsessively preoccupied as opposed to experiencing paranoid delusions.

At the moment, currently available medications are not reliably effective to treat core symptoms of ASD. While some medications have shown evidence of efficacy for the repetitive behavior domain (e.g., selective serotonin reuptake inhibitors), more recent studies indicate that the percentage of patients likely to respond is around 40%, and not a greater percentage than respond to placebo. The medication treatment of associated features, like ADHD symptoms or aggression, is more reliable. Stimulants (e.g. methylphenidate/ritalin) and non-stimulants (e.g., atomoxetine/strattera) effectively treat ADHD symptoms in some patients with ASD although less reliably than in typically developing children with ADHD. And second generation antipsychotics like risperidone (risperdal) and aripiprazole (abilify) are effective to treat irritability and aggression associated with ASD. Of course, medication must be used with extreme caution and certainly the more powerful antipsychotics require careful monitoring of weight and metabolic functioning, among other potential side effects.

The more we learn about the genetic causes of autism, the better we understand the neurobiology and the greater the

see *Interview on page 36*



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Strengths and Challenges of Individuals with Fragile X Syndrome

By **H. Laurie Yankowitz, EdD**
Senior Director of Family Support Services
HeartShare Human Services of NY

Fragile X Syndrome (FXS) is an inherited genetic disorder that results in a range of characteristics which include autistic-like features, such as gaze avoidance, hand-flapping, difficulty with transitions, and impaired social and communication skills. It is the most commonly known inherited cause of intellectual disability, affecting 1 in 4,000 males and 1 in 8,000 females (Dykens, Hodapp, & Finucane, 2000). Organizations such as the National Fragile X Foundation and FRAXA are working to raise awareness about FXS; however, families continue to consistently hear "Fragile *what?*" when advising physicians, clinicians, teachers, friends, and neighbors of their child's condition.

The syndrome is called "Fragile X" because the genetic mutation, which is caused by excessive repeats of the trinucleotide cytosine-guanine-guanine at a specific marker on the X chromosome, appears to be fragile or broken in that spot when viewed under a microscope. The typical number of CGG repeats is 30 – 50; when it exceeds 200, the mutation causes a protein, named the FMR-1 protein, not to be produced, which results in a spectrum of symptoms that impact cognition, behavior, and physiology. FXS affects



H. Laurie Yankowitz, EdD

males more than females because females typically have an unaffected X chromosome, so they produce some FMR-1 protein. It is common for affected females to have difficulty with math and social anxiety; some can have more extensive and severe symptoms comparable to males. Most males with FXS have mild or moderate cognitive impairment, hyperactivity and attention deficits, and a number of

difficulties with language, including articulation, pragmatics, and tangential speech. Studies indicate from 15 – 25% of individuals with FXS meet the diagnostic criteria for autism; 2 – 4 % of individuals with autism are diagnosed with FXS (Demark, Feldman, & Holden, 2003).

Knowing how FXS impacts a person promotes understanding and can provide others with tools to bring out the best in affected individuals. People with FXS have nervous systems which are highly prone to hyperarousal, identified by researchers as a core deficit influencing many other symptoms of the disorder (Belser & Sudhalter, 1995). Hyperarousal can be instantly triggered by a wide range of environmental stimuli and circumstances. These include a host of sensory sensitivities, such as light, sound, and touch. Conventional social interactions, such as direct eye contact and open-ended questioning, can also be lead to reactive episodes. The high anxiety levels that result from these triggers further impair the person's ability to speak and process information. When calm, individuals with FXS are often extremely social, known for a great sense of humor and a desire to be helpful. When their nervous systems are overwhelmed, however, they can lose control, reacting to ordinary demands with tantrums, self-injurious or aggressive behavior.

Individuals with FXS are known to demonstrate greater independence and ability in performing activities of daily

living than is typically expected of individuals who test at comparable IQ scores. Testing conditions, which typically require eye contact, sitting still and answering direct questions, exacerbate hyperarousal in examinees with FXS; for this reason, experts are concerned that their cognitive capacity is under-estimated (Braden, 2000). I have heard many families report with amazement and pride that their child will at times contribute a sophisticated bit of information to a conversation they thought was way over their head. At other times, to their frustration, they are met with confusion or no response at all when attempting engagement in a very basic dialogue.

Empirical research has established a profile for individuals with FXS which includes a spontaneous vs. sequential learning style (Kemper, Hagerman, & Altshul-Stark, 1988). Individuals with FXS are "big picture" processors – they notice everything at once, rather than first one thing followed by another. Consequently, students with FXS struggle greatly with phonetics, which requires sounding out letters in a sequence. They are much more successful at learning sight words. They are motivated by function and purpose and a desire to get things done; so integrating academics into meaningful activities that culminate in a tangible result is much more likely to lead to

see Fragile X on page 42

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Asperger's from page 22

Self-awareness is the most basic building block, and also one of the most challenging for children. It addresses the metacognitive function of self-monitoring, and the typical deficits of understanding nonverbal cues. Children with good self-awareness know how they look to others and how to use both nonverbal and verbal behaviors to send the right message to make friends. Awareness also includes awareness of others, especially of nonverbal behaviors that give critical feedback in social interaction.

Emotional self-control is critical to responding appropriately and effectively in social situations. Most AS children don't plan what they'll do in social situations; they simply react. They may be just responding to how they feel - usually angry, hurt or anxious. The child who immediately cries is often teased, and the child who lashes out gets in trouble. Unfortunately, it's fun for other kids to get a reaction, and often it's the child who reacts who gets blamed. It is vital that children learn, and practice regularly, those skills that help them maintain emotional control.

"Getting the Big Picture" is the third building block. Big picture thinking requires taking into account all the w's: who, what, where, when and why. If we understand how the parts of a social situa-

tion fit together, we know better how to react. The child has to read verbal and nonverbal cues, stay calm, think about perspectives other than his own, and use past experience to understand how all of this fits together. This kind of synthesis, seeing how the parts add up to a whole, is social cognition, and is very challenging for being able to put social behavior in context. Often this critical aspect of social skillfulness is overlooked when children are taught specific behaviors, but not how to judge when to use them. One must teach and model this kind of social processing.

Adaptability involves having a repertory of responses, like a toolbox filled with skills a child can use. This is where much of traditional social skills training come into play, and it is vital to create this repertory of skills. If a child is aware, in control, and sees the "big picture," he can better choose an appropriate skill to use in the situation. Groups can be very helpful in giving children the opportunity to role play and practice skills, but usually it's important to have an adult shaping appropriate skills through prompting in ongoing situations.

Anticipating the outcomes of social situations is a key skill. Children need to learn to ask themselves, "What might happen if I do this?" They need identify the outcome that they really want, so they can choose from their "toolbox" wisely.

They need to know when to act, and that not doing something can also be a plan. The challenge of anticipating outcomes is that it requires multiple executive functions: planning, shifting and flexibility to think forward and backward, and monitoring to consider the perspectives of others. Most social dilemmas happen over and over, so there's plenty of experience to rely on and to use educationally. It's not hard to teach children how to think through what they want to have happen, what they do or don't like, and how to make a situation work best.

The sixth building block, social recovery, helps children become more socially resilient. Everyone makes mistakes, but socially skillful children know how to bounce back and move on. Resiliency is a critical part of adaptability, and requires self-control and flexibility. Certain skills, like apologizing, taking responsibility and using humor can go a long way towards mending a relationship and making a better impression. Often AS children feel that they shouldn't apologize if they feel they didn't intend anything wrong. They need to learn that we can say, "I'm sorry" even when they haven't meant to hurt someone, which expresses concern for the fact that someone else felt hurt. Similarly, just because someone provoked you doesn't "make" you react.

The keys to using recovery skills bring

us back to self-control, seeing the big picture, adaptability based on having a repertory of tools, and being able to predict the outcome of different choices of behavior.

It is impossible to expect children to learn and implement such a broad range of skills independently; therefore, it is important that 1:1 social "coaching" help a child process situations in "real time," especially in unstructured situations such as hallways, cafeteria, recess and the bus at school, and in play dates and social situations at home. This supplements a group situation where children can practice skills and, as they're older, process situations. As any clinician who works with AS children knows, these skills are long term gradual projects, but the advantage of the "building block" model is that it helps to pinpoint which skills need to be the focus of intervention and priorities.

Dr. Marcia Eckerd is a licensed psychologist in private practice for 28 years, specializing in evaluating, treating and consulting on children with social disorders such as NLD and Asperger's Syndrome. Dr. Eckerd is on the professional boards of Smart Kids with LD and CT Assoc for Children with LD, is a resource professional on Asperger.com and NLDline.com, and writes a blog, "People Skills," for Psychology Today (www.psychologytoday.com/blog/people-skills).

Disorders from page 1

co-morbid psychiatric disorders we see in our clinical practice overlap significantly with early onset emotional dysregulation as well as behaviors that are part of the autism spectrum. Some clinicians prefer to avoid making a psychiatric diagnosis because of this overlap. However, to understand patterns of symptoms and behavioral presentations, and develop specific effective treatments targeting these clinical issues, clinicians should be rigorous in their efforts to accurately diagnose and disentangle the mental health issues that pose so many challenges for seven out of 10 people with ASD.

Common co-morbid diagnoses in children, adolescents and adults with ASD are anxiety disorders, especially obsessive compulsive disorder and social anxiety; attention deficit hyperactivity disorder; mood disorders, particularly depression and bipolar disorders; tic disorders, like Tourette's syndrome; sleep disorders and elimination disorders like soiling and bed-wetting.

The following vignettes of clinical situations provide an opportunity to understand how particular disorders may present themselves:

Attention Deficit Hyperactivity Disorder

(ADHD affects 20-35 percent of individuals with ASD): Brian is a 4 year old with a history of significant language delay. He started using single words at age 3 and a year later began repeating what others said to him. He is extremely active and unable to sit still. When in an enclosed space, he pushes furniture over, throws things and runs from one corner of the room to the other, even attempting to dart out of the room. He gets easily frustrated and has frequent tantrums when limits are set by his parents. In addition to his ADHD, he appears to be oppositional and defiant. However, this may reflect his frustration with his inability to communicate and delay in the development of receptive and expressive skills.

Obsessive Compulsive Disorder

(affects 10-25 percent of people with ASD): Maria is a 13 year old whose abrupt change in behavior led her to insist that her family's home be arranged a certain way. The chairs need to be in the exact same position next to the dining table; all the TVs in the house have to be on at the same time and all the doors closed. She has the intense need to watch the exact same TV show from beginning to end

repeatedly and if this routine is disrupted she gets extremely upset. These ritualistic behaviors were not present six months earlier. Within that time period, Maria and her family moved to a new neighborhood and she was placed in a new school. It seems that these changes were stressors that triggered the onset of these behaviors.

Social Anxiety

(affects 10-20 percent of people with ASD): Elijah is a socially isolated 16 year old who has a diagnosis of Asperger's syndrome. Over the past three months, he has found it progressively harder to be with unfamiliar people without getting markedly anxious. He now avoids all social situations, even gatherings of family and close friends. Making eye contact upsets him, so he finds some relief looking down or past people.

Mood Disorder

(affects 5-15 percent of individuals with ASD): At the age of 15, Nigel presented with a sudden onset of irritability, which last more than a month. He also began having difficulty falling asleep and staying asleep through the night. His irritability alternated with periods of giddy happiness along with brief intense periods of sadness with no apparent reason for the sudden shift. Nigel's

symptoms are consistent with a mood disorder, possibly of a bipolar type.

Tic Disorders

(affects 5-10 percent of individuals with ASD): Jenny is a 9 year old with a two-year history of an increasing frequency of throat clearing sounds, and a six-month history of jerking movements involving her head and neck. These movements have fluctuated in intensity and frequency. More recently, they have been accompanied by obsessive compulsive behaviors.

Cognitive-behavioral and intensive structured behavioral interventions and the careful use of psychotropic medication have the potential to significantly reduce the severity of these issues and improve the quality of life of the individual with ASD, as well as his or her family or caregiver.

Charles N. Cartwright, MD, is Director of the YAI Autism Center and Chief of the Premier HealthCare Autism Research and Treatment Institute. Victoria Bein, MA, MS, is Coordinator at the Premier HealthCare Autism Research and Treatment Institute. Premier HealthCare is a member of the YAI Network.

Handwriting from page 8

also included Christina Fuentes, Ph.D., now a research associate at University College London, and Stewart Mostofsky, M.D., Medical Director of the Center for Autism & Related Disorders at Kennedy Krieger Institute.

The study was supported by Autism Speaks and the National Institutes of Health.

About Autism

Autism spectrum disorders (ASD) is the nation's fastest growing developmental disorder, with current incidence rates estimated at 1 in 110 children. This year more children will be diagnosed with autism than AIDS, diabetes and cancer combined, yet profound gaps remain in our understanding of both the causes and cures of the disorder. Continued research and education about developmental dis-

ruptions in individuals with ASD is crucial, as early detection and intervention can lead to improved outcomes in individuals with ASD.

About the Kennedy Krieger Institute

Internationally recognized for improving the lives of children and adolescents with disorders and injuries of the brain and spinal cord, the Kennedy Krieger Institute in Baltimore, MD serves more

than 16,000 individuals each year through inpatient and outpatient clinics, home and community services and school-based programs. Kennedy Krieger provides a wide range of services for children with developmental concerns mild to severe, and is home to a team of investigators who are contributing to the understanding of how disorders develop while pioneering new interventions and earlier diagnosis. For more information on Kennedy Krieger Institute, visit www.kennedykrieger.org.

the lighter side of the spectrum: a mom's view

By Carrie Cariello



Dads

I had a moment's pause recently as I watched my husband Joe pass by me into our family room to hand our daughter her favorite pink blanket. Snuggling with all five kids on the couch, he looked like the same college guy I met when he was twenty and I just nineteen. Yet over the course of more than a decade we've built a life together based on love, family, and for the past six years, autism.

Like all parents, Joe and I don't always see eye-to-eye when it comes to managing our kids. With five little ones under the age of seven, tension is unavoidable. Things can get really fun when you throw a child with autism into the mix.

Statistics show that divorce is on the rise for couples in general, with a higher rate of incidence when parents are raising a child on the spectrum. Trying to navigate a world full of acronyms like of IEP, OT, and PT while managing the daily behavior challenges of a kiddo who throws massive tantrums, stims through the room like a cyclone, and tries to start the family minivan if you don't hide the keys can wear even the happiest couple down.

Joe and I have been deliberate in keeping our marriage successful in the midst of the demands of five small children, a



Joe Cariello with his son Jack

busy dental practice, and life in general. Soon after our first son was born seven years ago we instituted the weekly date night and have stuck with it ever since. We've been very practical about making sure we stay connected, keep open communication, and for the most part respect the other person's parenting. (This trans-

lates to the don't-ever-contradict-me-in-front-of-the-kids rule.)

Although we've matured as a couple from being parents in general, raising our crew still doesn't always bring out the best in us. There are moments of incredible stress when the baby has a diaper that's exploding and another kiddo wants

to eat his millionth candy bar – all while we're on display at the annual family reunion. We still butt heads over deciding if Jack's ready to start attending church, or if he should get a reprieve from eating all of his squash at dinner since, in Jack's Arnold Schwarzenegger-type intonation, "Squash is bad for me and will make me sick." Being a parent is never easy, never what we expected, and some days not even what we wanted. Autism simply adds a whole new dimension.

And it's so easy to vilify our husbands, isn't it? In most families, the man gets to trot off to work and leave the domestic mess in the rearview mirror for the day. I remember waking up to Jack's deep nasal whine when we lived in Buffalo and thinking, "I simply cannot get through another day of this." We nicknamed him Tuggy because his constant whimpering sounded just like the horn of a tugboat driving deep into my soul. There's no way Joe's schedule of filling cavities could compare with keeping Jack – and the other small children we had – happy. Never mind that the guy would walk into the equivalent of a bees hive when he got home – with Queen Bee herself in the foulest mood.

see Dads on page 38

Positive Thinking

By Jeff Stimpson
Journalist

I attended a workshop on "positive reinforcement," a theory of childrearing that's the opposite of "bribery" and sort of the opposite of "punishment," and one that my mother might have hurt her side laughing at. I did enjoy the presenter's warmth, though, and how she drew out stories – though a little "drawing" seems needed with parents of children with autism once they feel comfortable. She had me when her PowerPoint contained an example of an autistic meltdown that took place in the cookie aisle, which is my 12-year-old son Alex's favorite spot.

I learned that positive reinforcement involves planning ahead, setting and communicating rules using specific techniques, and rewarding with "reinforcers" for tasks completed, with an eye to eliminating or improving behavior you don't like. Negative threats are discouraged, as the parent often can't carry through on them.

A few of Alex's behaviors that I don't like:

Lip Diddling - Flicks his fingertips over his lips with wet little plops.

Stimming on the Couch - Lays on his back and flails his feet in the air; giggles and laughs loudly and madly.

Biting His Arm - Lightly, but in obvious anger when frustrated.



Jeff Stimpson

Turning up the Volume on "Elmo" - Speaks for itself, though to his credit he does try to do only when we're not watching him.

A typical positive exchange regarding the Elmo volume might involve me looking Alex in the eye before the TV ever goes on and calmly telling him that if the volume gets too high, we will shut off the TV immediately. I should use his name ("You remember their name when they do

something wrong, don't you?") the presenter pointed out. "Well, remember it here, too..."), or I might look him in the eye and say, "Alex, no ice cream until you help make the beds."

When he has made the bed or turned down Elmo, rewards can be "edibles" such as crackers or cookies, or "socials" such as high-fives or hugs or a "Nicely done!" (I've never liked "Good job!"). We should also pair socials with any other type of reward, the idea being, ABA-style, to gradually phase out the non-social rewards and just use the high-fives and hugs.

The method aims to avoid punishing. "We punish, don't we?" the presenter said. "We put people in prison for negative things. We turn on the news and what do we see first? Who got killed last night..."

To stop bad behavior already in progress, use "the least amount of attention," the presenter advised. No eye contact. A neutral face with no explanation." In short, Alex's laughing when I'm trying to discipline him means I'm paying too much "bad attention" to bad behavior.

Self-stimming, she confessed, was the hardest behavior to interrupt. "We all self-stim. Have you ever seen anyone just sitting and shaking their leg?" Well yes, but that's different of course from shaking your head and shrieking and kicking your feet in the air on the couch for 20 minutes during a family dinner party. Replace this behavior, she said, with some action more appropriate or incompatible with the ac-

tion. If someone flaps their hands, for instance, have them put their hands in their pockets, or have them hold something. All this takes time and patience and planning; I came away thinking that given time and patience and planning and one heap of luck we might even get Alex to sit through a family dinner party.

Another good tip for cookie-aisle meltdowns: "If you have to give in, give in quickly. Otherwise we're teaching our kids to misbehave for longer periods." (The thought does cross my mind that this method may not prepare a kid like Alex to live in the punishing world. What kind of childhood never features the phrase "Stop it!?"?)

So now we have steps: 1) Target three behaviors of Alex; 2) Identify his reinforcers (for example, one of mine might be "employment"); 3) Set up a script for consistency in phrases. We'll also tell Alex's typically developing brother Ned about five times what we're doing, since it won't sink in the first four.

Jeff Stimpson, 48, is a native of Bangor, Maine and currently lives in New York with his wife Jill and two small sons. He is the author of *Alex: The Fathering of a Premie and Alex the Boy: Episodes From a Family's Life With Autism* (both available on Amazon.com). Jeff maintains a blog about his family at www.jeffslife.tripod.com/alextheboy and is a frequent contributor to various websites on special-needs parenting.

An Adult's Struggle and Journey with a Lack of Services

By Gregory B. Wood, BBA
Adult Individual on the Spectrum

As a child I was diagnosed with infantile autism. I was placed in an institution from the age of 5 to 16 for children with developmental disorders and various degrees of mental retardation. This institution was chosen for me by my parents and medical professionals, as the public school system at that time had no program in place for a child with my challenges. I was the most advanced child in the school and was used as a role model and helper for the staff since at this residential institution the majority of students had Down's Syndrome. Programs for my diagnosis were still being developed as the medical community learned more about autism. After graduating from this institution at 16, I completed public high school and then a bachelor's degree. The professionals at the time recommended a vocational school for me but I made my own choice to take a different route.

Once I completed college I thought I had overcome all my barriers, but instead I found myself at the start of a 25-year struggle and journey. That journey was a wake-up call regarding the lack of information, support, and understanding for myself, my family, employers, and in many social areas of the needs of adults with Asperger's. I spent many years with feelings of failure, isolation and frustration.



Gregory B. Wood, BBA

The first 10 years out of college I could not hold a customer service job for an extended period of time. Every 6 months I was getting fired or laid off and during those years I had 15 different jobs. I ended up in a low paying hotel job for over 11 years. I worked long hours that included every weekend. What sustained me at this job was having a boss that recognized that I could do the job tasks that he could not. My boss had a special needs child and that influenced how he interacted with me at work.

Because my boss appreciated my skills in support of his role he had the power in the organization to advocate for my position when others would question my performance. Once my boss retired I lost his protection I had to leave the job under extreme stress, anxiety and misunderstanding of my work ethic and ability from my new supervisors.

During my years of job changes each time I got laid off I went to professionals for a diagnosis for help and answers on what was happening and how I could make changes to improve my career. In 2005 my therapist encouraged me to undergo a detailed neuropsychological evaluation. I was diagnosed with Pervasive Developmental Disorder, consistent with Asperger's Syndrome, Non Verbal Disorder. After this diagnosis I felt I finally had an answer to many years of disappointments and frustration. My family was relieved that we finally had an answer.

I started to search for rehabilitation for me as an adult. First stop was the Texas Department of Rehabilitation and their assessment of me was that I was too old and if I didn't get it by now I never would. Due to having a college degree I was denied services for re-training for a new job. I was placed in a social skills class through the agency but they determined I was not suited for the program. Due to years of heavy judgments from employers I decided to apply for social security disability to give me some form

of protection from discrimination if I returned to work or to assist in my rehab needs. It took three years to be granted disability with the help of a lawyer.

I was granted disability from some of the side effects of Asperger's, which for me is anxiety and depression. Once again I started to look at the various rehab programs in the community for rehab for adults. All the programs that are out there today are geared for children or young adults. When I ask do you know of any programs for adults the answer is always I am not aware of.

I began to implement my own program that consisted of engaging the help of various health professionals on a hit or miss basis. The modalities I tried were numerous and I was thankful for the therapist I found to help guide me and to ask questions on social concerns. In addition to the lack of treatment programs there is a lack for coverage from an insurance standpoint. All my treatments had to be paid for out of pocket.

I am termed high functioning and too old to qualify for any programs that would allow me to develop the skills to improve my life. As an adult I know from experience that I need physical rehab, social skill management support and guidance to identify the appropriate jobs for an adult with Asperger's. I've found much more information now and various chat groups but that does

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Support from page 28

own attachment history. One definition of a secure attachment is a sense of connectivity, responsiveness, and empathy going back and forth. This results in a sense of basic trust, competency and security.

As Moms we strive to create a secure attachment with our children, yet our attempts at this often lead to feelings of frustration and failure. Having a child on the spectrum often triggers the mother's own attachment wounds. Not getting the reciprocal love back from this child can reignite wounds of love gone awry in one's own history.

Feeling excluded from the social community of Moms, these feelings are experienced both within community and within oneself. It became our goal to address these attachment needs both intra- and inter-personally.

Intra-Personal Attachment Work

We have found the Moms in our groups to be neglecting their own inner child, and thereby not able to replenish themselves, which caused them to feel irritable, depressed, isolated, and depleted. They were unable to access a "good internal mother."

We offer experiences which help the Moms get in touch with their inner child and then hold that child with love and compassion. We use creative and imaginative methods to access an internal "good mother" and a connection with their intuition and "inner knowing."

Moms of "atypical" children often unconsciously experience feelings of shame. It is said that shame grows in the darkness, and as we share these feelings, the shame gets replaced with recognition. A new freedom becomes available; a freedom to tell the truth. By witnessing each other with empathy, compassion, and humor, we learn new ways to be with ourselves and each other. Feelings of self-acceptance and "goodness" replace feelings of shame and inadequacy. We call this intra-personal attachment work, helping create a "secure inner base," the cornerstone of healthy attachment.

Inter-Personal Attachment Work

Women count on other women for comfort and empathy. We often become attachment figures for each other. Our groups are designed to provide the experience of healthy attachment by being part of a community. Participants are required to attend an initial interview to be sure the group will be a good match for them and that they understand the focus of the group. We meet every other week for two hours and participants are required to make an eight-session commitment after the initial meeting. They have the opportunity to recommit after the initial eight meetings (sixteen weeks).

One way of explaining how these groups function to address attachment issues is by using the Theraplay model of attachment therapy. This model is based on four elements: Engagement, Nurture, Challenge and Structure.

Engagement

The group offers a high level of engagement. Each meeting consists of activities such as writing exercises, collage work, poetry and other creative experiences that engage thinking, feeling, intuitive and sensory processes. In addition to participating in these activities, the sharing of the experiences also engages a sense of "optimum arousal and compassion," two important elements in this model. We've added a private blog for the group and they stay empathically connected between sessions this way.

Nurture

A feminine, non-hierarchical model of compassion, safety and understanding are the core of our groups. We create a container for telling our truths, for grieving, for laughing, for crying, and for comforting.

Challenge

We challenge the Moms to see things from new perspectives. Many of our activities deal with opposites: worst and best, strengths and weaknesses, inner child and good mother, childhood traumas and loving memories. We are creating new stories and new ways to be present in our lives.

Structure

We operate on a tight timeline with no cross-talk. We start and end on time, and sharing is within a timed framework (for example, two minutes each and we use a timer with a lovely melody to signal that

her time is up). This structure provides safety and the knowledge that everyone will have her turn.

Creativity as Soulwork

The creative impulse is a life sustaining impulse. Moms of children with special needs rarely have the time to express their creativity. In our groups we do a lot of creative work as a way to bridge our inner and outer worlds and to give meaning to our inner experience. We call this Soulwork.

What We Are Finding

Something powerful is happening. The women are reporting more joy in their lives, more acceptance of their children, more compassion for themselves, a growing feeling of belonging, and less isolation. A feeling of renewal, replenishment, and inner strength is emerging in these women and it is having an impact on the quality of life for them and their families.

It appears that the group itself is becoming a community and a source for healing attachment. Each woman is being deeply listened to and understood by every other Mom in the group. Within the safety of the group and through the creative process, new strengths and resources are being discovered.

Questions for the Future

Our groups are in their infancy stage.

see *Support on page 37*

Robin's Voice: A Resilient Mom's Commentary on Autism

The Perils of Obsessions in Autism

By Robin Morris
Freelance Writer

Jack Nicholson's character in *As Good As It Gets* ultimately triumphs over his obsessive compulsive disorder, and he even gets the girl! It is a super comedy, invading the space of the confines of a man's life with crippling obsessions. The film depicts the devastating details of living with obsessions, but with a comedic twist. Whether or not Jack steps on the cracks in the sidewalk might crush his day, but eureka! Medication works for OCD!

It is a stunning realization to recognize the burden of raising an autistic child. Then comes the one two punch. There are segues and addenda to the disorder. It seems that the merry-go-round will never end. It is not in my nature to say "die", or in this case give up. My innate desire to delve and analyze is a constant.

Consequently, when our son was diagnosed, I gave the A word the cold shoulder, determined to hit the symptoms head on. The single most tenacious symptom that grabbed our son was his obsessive and often compulsive



Robin H. Morris

ive behavior. He was not loud about it in fact most of the obsessions were in his head. I called it the "movie in his mind." His memory has always been

very keen, better than mine, and he harbored infinite information on many subjects. The problem was that it interfered with life.

I was once asked, "Does the obsessive behavior interfere with his every day life?" We were advised if so, we could try medication. Finally, after much delay and procrastination, (after all, give a 12 year old antidepressants?) we said "Yes, it does impede his life, our lives, yes!" Following a 3 year dalliance with a plethora of anti-anxiety, antidepressant, anti-obsessive medications we failed miserably.

One psychiatrist advised us that in his opinion, that there was effective medication for true OCD. However, with perseverative behavior in autism, medication is a gamble at best. He explained his theory that when patients suffer from obsessive compulsive disorder, they experience a "risk avoidance sensation". They might perform ritual behaviors, as washing hands etc. to avoid being dirty. Those patients on the autistic spectrum exhibit habitual behaviors for a pleasure seeking purpose, as lining up cars etc. It made sense to me.

Approximately ten years have passed since our meeting with this

thoughtful psychiatrist. I have thought a lot about the notion of risk-avoidance vs. pleasure seeking behaviors. What strikes me is that the motivating factor seems to be about control. The person who wants the ultimate power over the direction of his or her life, and lacks rational thought, succumbs to obsessive compulsive disorder. How is this reaction different from a person diagnosed with OCD as a co-morbidity of autism? The question begs further consideration.

What did work for us, was behavior therapy. We rewarded our son's compliance. Is it a panacea? No. However, we can now talk through his obsessive road blocks.

Perhaps the only answer remains in the individuality of the person with autism. Like snowflakes our children are different. What works for one, just might not for another. Trial and error become willing participants in this endeavor.

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and Language Arts skills that require inferring and critical thinking skills; executive functions such as initiating work, organizing, maintaining sustained attention or managing shifting attention, regulating alertness and processing speed; and impulse control. It is crucial that the classroom setting is structured to meet these specific learning needs. A predictable, structured, consistent environment is so important to helping these students maintain focus and to minimize the anxiety that often accompanies these children to school. For example, at the Newmark Schools, a great deal of thought and planning goes into setting up the classrooms. Student schedules are posted on the wall, and any changes, such as pull-outs, assemblies, and field trips, are discussed and written on the board. Classroom sizes are kept small so students can effectively receive the individualized teaching they require. Specific classroom expectations are taught and reinforced on a daily basis. Not only are our students taught academics, they learn how to be in school successfully.

Social skills training is an important facet of education and clinical treatment

for these students. Although the specifics of their social skill deficits may be somewhat different, what students with ASD and ADHD symptoms share is: problematic communication with peers; trouble maintaining focus on topics that are uninteresting to them; difficulty playing games that require turn taking; interpersonal boundary violations, failure to notice or understand the social cues that communicate the intentions and emotional reactions of others, and negative interpersonal interactions with their peers. High degrees of impulsivity in young people can lead to serious social issues such as substance use/abuse, conduct disorder, driving difficulties, trouble maintaining employment and completing activities of daily living. When training these students, it is necessary to help them learn to improve their theory of mind deficits. In other words, they need to be able to take the perspective of others in social situations so that they may choose appropriate behaviors. Refusal skills and impulse control techniques are also essential.

As discussed, students with ASD often present with ADHD symptoms. Whether these symptoms are classified as a separate diagnosis, or they are dif-

ferent branches from the same tree, it is vital that an accurate, thorough diagnostic process takes place to identify the student's individual needs, strengths and weaknesses so an effective clinical and educational plan is put into place. Students who receive the educational accommodations they need have a greater opportunity to experience academic success, thereby lowering the likelihood of anxiety, depression and feelings of hopelessness.

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Therapy from page 14

teaching social norms and expectations as well as strategies for successful social interactions and relationship development. Several studies as well as anecdotal evidence support the use of cognitive behavioral therapy in autism spectrum disorders (Reaven et al., 2009; Wood, Drahota, Sze, Har, Chiu & Langer, 2009; Sze & Wood, 2007; Gaus, 2007; Anderson & Morris, 2006).

Individual Adaptation

When deciding how to adapt CBT for

use with an individual client with an ASD, it is important to assess the individual's particular strengths, weaknesses, interests, and preferred learning style. For example, many individuals with ASDs report that information presented visually is easier for them to process and retain. The CBT approach typically utilizes visually presented information and worksheets and these tools should be emphasized with the ASD population. Additionally, an individual's special interests may be used to increase motivation and facilitate the therapeutic process. When conducting CBT with youth with ASDs it is important

to adapt the components to best fit an individual's needs based on a comprehensive understanding of the individual's cognitive and developmental level, areas of strength and weakness, preferred learning style, interests and presenting difficulties. These factors help to determine where therapy needs to begin and how to best teach new skills, as well as set initial goals.

For individuals with ASDs, CBT facilitates the development of adaptive coping skills to modulate emotional reactions and reduce depressive and anxious symptomatology by focusing on increasing understanding of both thoughts and

feelings. By teaching pre-requisite skill as well as modifying strategies to best suit individual needs and abilities, CBT can be used successfully to treat co-occurring mental health issues for individuals with ASDs.

For more information about the ASPIRE Center For Learning and Development's CBT Clinic and opportunities to participate in treatment, please contact Samara Tetenbaum, PhD, Psychology Fellow at ASPIRE at (631) 923-0923 or sptaspire@gmail.com. You may also visit our website at www.aspirecenterforlearning.com.

Interview from page 30

potential for developing novel therapeutics targeted at the specific cause of the autism. Taking this sort of approach, the treatment of both core and associated features of autism will likely reach new depths in the coming years.

Q: Are there standard methods used to diagnose the various types of co-morbid conditions associated with autism?

A: Tools used to diagnose comorbid conditions in the general population can also be used in working with individuals with ASD. Using clinician, parent, or teacher ratings can be particularly helpful for tracking progress after an intervention is implemented. However, standardized tools are less helpful in refining diagnoses in complex disorders like ASD. At this time, refined diagnostic conclusions are most reliably made by clinicians with experience working with and treating comorbidity in ASD.

Q: As seizure disorders associated with autism are a big concern for parents, can you comment on the warning signs, complications, and behavioral regression that are sometimes seen with seizure disorders?

A: Seizures are estimated to occur in approximately 30% of individuals with autism and a significantly larger percentage has abnormal activity patterns on electroencephalography (EEG) without frank seizures. There is also frequently an association between behavioral symptoms of autism (e.g., agitation) and seizures. Likewise, the effective treatment of seizures in autism is often associated with behavioral improvement.

There are typically two peaks for the onset of seizure disorders in autism. The most common is in pre- and early adolescence between the ages of 10-13. The other peak is in early infancy, but when they occur this early, it is often associated with a comorbid medical condition like tuberous sclerosis, for example. Seizures may appear without warning signs or known triggers and can of course be very scary for families. But the onset of seizures does not typically have any association with the severity of other symptoms of autism. In general, behavioral regression associated with seizures is quite rare.

Estimates of regression in autism vary and were originally thought to be about 30%. However, as high-risk siblings of children with autism are now being followed, the longitudinal course of the syndrome is becoming better understood and rates of true regression appear much

lower. There is also significant controversy about the role of epilepsy and EEG abnormalities and regression in autism; some studies have reported higher rates of epilepsy in patients with regression and others have found no relationship at all.

Treatment for seizures in autism is the same as treatment for seizures in the general population. Anticonvulsants, like divalproex sodium (depakote) or carbamazepine (tegretol) are commonly used. Children with autism do tend to be exquisitely sensitive to medication in general, and the anticonvulsants are no exception. Whenever possible, treatment should be initiated at very low doses and increased slowly. The advantage to most anticonvulsants is that medication levels in the blood can be carefully monitored, although of course drawing blood can be highly distressing for some children and their families. Nevertheless, in many cases seizures are managed quite effectively, including spontaneous remission without medication treatment.

Q: Are any newly developing interventions predicted for the near future?

A: The Seaver Autism Center and several other centers around the US and abroad are working hard to understand more about the genetic basis of ASD and then using this knowledge to develop novel treatments. We have been actively recruiting patients for participation in the Autism Genome Project, and our Center has contributed hundreds of samples to this important initiative. Every affected patient and family is an opportunity to identify new causes of autism and to develop new treatments.

Our clinical team is working closely with basic scientists at the Seaver Center to develop treatments for Phelan McDermid Syndrome, a known cause of autism responsible for approximately 1-2 percent of cases. Drs. Joseph Buxbaum, Takeshi Sakurai, and Ozlem Bozdagi have created a mouse model with a deleted SHANK3 gene and found these mice to have significant deficits in the integrity of neuronal communication. These deficits negatively impact the process of what is called long term potentiation, a process that is known to underlie learning and memory. We are currently exploring the use of specific compounds to reverse the deficits in the mouse. We aim to bring such potential medications to clinical trials in children with Phelan McDermid Syndrome.

Using a similar strategy, Seaside Therapeutics discovered that a medication called arbaclofen reversed physiological and behavioral deficits in a

mouse model of Fragile X Syndrome and preliminary trials in both Fragile X Syndrome and ASD were recently completed. Press releases from the company in September, 2010 reported positive effects in both trials and our Center has recently joined a national network in a multi-centered trial of arbaclofen to treat symptoms of social withdrawal in ASD. Arbaclofen is a GABA-B agonist that inhibits release of glutamate into the synapse and reduces postsynaptic glutamatergic neurotransmission. We are very pleased to be part of this important new direction of treatment research.

In addition, our center has been very invested in exploring the utility of oxytocin in autism. Dr. Jennifer Bartz is currently studying the effect of an oxytocin nasal spray on social cognition and empathic accuracy in adults with autism and is also looking to better understand the neural circuitry underlying these deficits.

In terms of behavioral treatment, Drs. Latha Soorya and Ting Wang in our Center are working to help children improve social skills through a highly structured, manualized cognitive-behavior based curriculum designed to target non-verbal communication skills, emotion recognition, and perspective taking. Their team is also doing functional MRI before and after treatment to see which brain regions are involved in social cognition and whether brain activity patterns change with skill acquisition.

Q: How can families best cope with the associated features of autism, such as: anxiety, aggression, and hyperactivity?

A: Families need to be prepared to deal with a wide variety of associated features of ASD. Treatment usually includes a combination of therapy and possibly medication options. Therapy may occur in group or individual settings and is typically focused on behavioral change using a cognitive behavioral or a behavioral model depending on the patient's cognitive and functional abilities. With the help of a trained clinician, a functional behavior analysis can be useful to understand the antecedents to certain behaviors and associated symptoms and to develop targeted treatment plans to address the behavior. The specific intervention depends on the type of symptom that needs to be treated, but the impact of psychotherapy and behavioral treatment combined with changes in the structure of the environment can often have dramatic effects. At the same time, associated features like anxiety, aggression, and hyperac-

tivity, also may occur in the context of developmental changes (e.g., puberty), and in these cases therapy is still important to pursue, but medication may also be considered.

Parents will benefit from education and training to help them learn strategies to best manage their child's symptoms. Parents are usually the best advocate for their child and need to ensure that school and home-based interventions are implemented in the most consistent, structured, and predictable way possible across all settings where the child exists. Families can also benefit tremendously from the support of being with other families affected by autism. Autism Speaks (www.autismspeaks.org) is an excellent resource for community and support networks. In addition, support for siblings of affected individuals may be critical to explore, especially when associated features like aggression have a major impact on the entire family system.

Q: What message would you like to leave with the readers of *Autism Spectrum News* about the hope for the future in our understanding and treatment of the conditions associated with autism?

A: This is an extremely exciting time in autism research. With respect to genetic advances, we are in a phase of exponential discovery where new genes that cause autism are being identified at a very rapid pace. Larger and larger samples of patients and families are becoming available for more and more advanced methods of genetic analyses. Each new gene identified teaches us more about the neurobiology of autism and creates important opportunities for model systems. Model systems can then be used to develop novel therapeutics based on targeted molecular approaches. At the same, early detection methods are improving so that the behavioral diagnosis can be reliably made as early as 12-18 months and array CGH is being recommended for all patients suspected of having an ASD. Finally, studies of behavioral interventions, like the Early Start Denver Model (Dawson et al, Pediatrics, 2010; 125(1):e17-23) have shown the robust impact of early intervention as increasingly obvious.

For more information about any of the studies mentioned or to find out more about the Seaver Autism Center for Research and Treatment at Mount Sinai School of Medicine, please call 212-241-0961 or go to our website at www.seaverautismcenter.org.

Summer Camp from page 10

receive respite and typically-developing campers are given the opportunity to interact with and change the way they look at people with disabilities. Everyone wins.”

And both families already are looking ahead to next summer.

“I feel so lucky that my son and his best friend could both be part of this growing experience and I am so hopeful that MAC will continue this autism program in the future,” added Kirsten.

“From the moment I decided to send Michael to MAC, I’ve never regretted or doubted it – not even for one moment,” noted Mary. “Both boys are already counting the days until next summer!”

Marco Damiani is Senior Director of Clinical and Family Services at YAI Network. To enroll or learn more about the 2011 MAC autism program, please visit yai.org or contact 1-866-2-YAI-LINK.



Marco R. Damiani, MA

Support from page 34

We are receiving much positive feedback and numerous requests from women who want to participate. We want to create ways to measure the impact of these groups not only on the women, but on their families and particularly on their children. We need to see if we can create a model that can be replicated by other therapists in other communities.

We look forward to growing this model and hope to be able to address the needs of the many incredible Moms who are suffering and living in isolation.

Judy Fiermonte, MFT has been in practice for over 30 years specializing in work with children and their families. She is the proud mother of a 22-year-old who was diagnosed with Asperger's Syndrome at age 9 and is transgender male to female. Judy can be contacted by phone at (707) 528-1097.

Cynthia Hymowitz, MFT in addition to her private practice focusing on healing

from childhood trauma, has been leading groups on Creativity and Consciousness since the mid-eighties. She is the mother of a 15-year-old with high functioning autism who is her greatest teacher. Cynthia can be contacted by phone at (707) 575-9539.

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and has quickly set a new standard for science and evidence-based community education. *Autism Spectrum News* provides readers with a trusted source of strictly science and evidence-based educational articles and has a firm policy of

only accepting advertising from organizations that meet the publication's strict science-based criteria. *Autism Spectrum News* has become a “must read” and vital resource for families with children on the spectrum as well as for the treatment professionals and service providers that care for them.

Both *Mental Health News* and *Autism Spectrum News* are hardcopy quarterly newspapers that reach over 160,000 consumers, families, treatment professionals, service providers, educators, and decision makers across the country.

The nonprofit organization Mental Health News Education, Inc. (MHNE)

behind the award-winning publications provides thousands of free copies of each issue back into the community. In addition the publications each have websites where current and back issues are posted for free reading: *Mental Health News* (www.mhnews.org) and *Autism Spectrum News* (www.mhnews-autism.org).

Epilepsy from page 12

perform an EEG to rule out underlying subclinical seizures in a child with autism, even one who regresses, who does not have typical seizures. In one recent study of 22 patients referred for possible seizures had evaluations using overnight video EEG (VEEG) monitoring, 15 had “events” during the VEEG that concerned their parents, but none of these turned out to be a seizure. EEG abnormalities indicating seizure potential were detected in almost all. Thus, VEEG of children with autism reveals EEG abnormalities very frequently. But most of the time the finding does not indicate seizures.

We do not know if the abnormal EEG activity persists and if so for how long. Could abnormal EEG activity herald epilepsy? We just don't know. Does SUDEP occur in people with abnormal activity on EEG who has never had seizures? Probably not, since changes in heart rate, blood pressure, etc. during seizures likely cause SUDEP not the electrical changes in the brain. Does medication treatment in people with epileptiform activity on EEG who have never had seizures prevent epilepsy? Another question doctors can't answer yet.

Creating Awareness

In 2009, The Daniel Jordan Fiddle Foundation developed and created a public service brochure called *Autism, Epilepsy & Seizures: How to Recognize the Signs and Basic First Aid When You Do* to educate the community and generate awareness about this co-condition. The brochure is offered free of charge and can be reprinted from The Daniel Jordan Fiddle Foundation website (www.djfiddlefoundation.org) and is also available on the websites of many other autism organizations including Autism Speaks and the Autism Society of America. Linda Walder Fiddle, Founder and Executive Director of The Daniel Jordan Fiddle Foundation expressed the importance of this community resource: “Because of the prevalence of epilepsy among individuals living with autism, service providers, first responders, school personnel and the community at large as well as parents and caregivers need to be aware of this co-condition and how to identify the symptoms as well as basic first aid techniques.”

The brochure that was spearheaded and produced by The Daniel Jordan Fiddle Foundation was a collaborative effort

that included input and oversight from The Epilepsy Foundation of New Jersey, Autism Family Services of New Jersey and Dr. Ruth Nass, a member of the foundation's Advisory Board and the Nancy Glickenhau Pier Professor of Pediatric Neuropsychiatry, Professor of Child Neurology, Child & Adolescent Psychiatry, and Pediatrics at NYU Langone Medical Center. “The brochure includes a fold-out chart that can easily be displayed in all community settings and is being offered as a public service to families, schools, colleges, community centers, restaurants, fire and police stations, EMS providers... anyone who might be a first-responder that could make a life-saving difference.” According to Dr. Nass, “The brochure is an excellent starting point to create awareness, however, The Daniel Jordan Fiddle Foundation and I recommend that individuals and families discuss their questions and concerns with their own physician.”

The creation and dissemination of *Autism, Epilepsy & Seizures: How to Recognize the Signs and Basic First Aid When you Do* is an important step forward in fostering community awareness about the co-condition of Autism and Epilepsy. Ongoing research is still needed as to the causes and prevention of epilepsy in autism. In the

meantime, there are medical options available to avert tragic outcomes and these specific treatments should be addressed individually with one's physician.

Dr. Ruth Nass is a Pediatric Neurologist at the NYU Child Study Center. She is a Professor of Child Neurology, Child and Adolescent Psychiatry, and Pediatrics at the NYU School of Medicine. She specializes in autism and other developmental disorders and is particularly interested in the causes of epilepsy in autism and the management of epilepsy in autistic children. Dr. Nass also does clinical research and has published over 100 papers and chapters.

Linda Walder Fiddle, Esq. is the Founder and Executive Director of The Daniel Jordan Fiddle Foundation, a national autism organization focused on developing, advocating for and funding The Daniel Jordan Fiddle Foundation Signature Programs that provide innovative ways for adults living with autism to participate in and contribute to community life. Ms. Walder Fiddle is a prominent advocate on the national and state levels and has received numerous awards in recognition of her efforts on behalf of the autism community. For more information visit: www.djfiddlefoundation.org.

IEP from page 23

child services she needs and is appropriate for her because other children who may or may not need those services are not getting them?” Your child should receive services because they were recommended by professionals and it is appropriate for your child. Your child's recommended services should have nothing to do with what “other” disabled children in the district are

receiving or not receiving. Remember, you are your child's advocate at that meeting - you have no duty or obligation to be concerned about other people's children and what they may or may not be getting. You should focus intently on your child's needs and not allow anyone on the team to “guilt you” into accepting less for your child because it is “too expensive” or that “other children are not getting the services.” Even if that is the case, that is not your

problem as you are sitting at that meeting. The same is true for you - just because other children are receiving physical therapy does not necessarily mean that your child needs physical therapy. Ultimately, the strongest justification will be what an informed professional is recommending.

By all means, ask for what your child needs and be a strong advocate. However, always go into your IEP meetings with an open mind.

Tracey Spencer Walsh, JD (Fordham University School of Law, '94) is the Senior Counsel at Mayerson & Associates, a New York law firm dedicated to representing children and adolescents on the autism spectrum, and assisting families in accessing the education and related services necessary and appropriate for students. For six years, Ms. Walsh worked as an educator and served as an Upper School Dean of Students at an independent school in Rye, New York.

Aggression from page 16

aggression toward them. There are many other factors in the expression of aggression that will next be considered in an attempt to understand all the influences that can cause expression of inappropriate aggression that can endanger living in the mainstream and the achievement of an acceptable quality of life.

Some of the very characteristics of autism spectrum conditions can be contributory in the expression of aggression. The inflexibility of thinking and resistance to deviations in expectancy can cause an individual to become quite anxious and upset without the skills necessary to communicate distress. The difficulty with transitions that youngsters may have or the anxiety adults may experience in periods of life change can also lead to a response of some type of aggression if other skills to manage themselves have not been developed.

Sensory issues can also cause a feeling of overwhelm that may lead to socially inappropriate behavior, including aggression. A person may feel so assaulted by sensation that any escape is sought. In addition, the discomfort that sensory hypersensitivity causes can make one more vulnerable to increased anxiety. So, someone may be exhibiting inappropriately aggressive behavior arising from any number of sensations not obvious to others, but very overwhelming to the individual so affected.

Many individuals on the spectrum manifest difficulties with information processing because they are doing so in much slower time than is typical and needed to keep up with neurotypical interplay. For example, a child may be confused because he is still processing the directions for an assignment when everyone else is getting up to leave the room. Later, there may be a demand based on those incompletely processed directions. Children who have impaired processing speed may feel perpetually confused over expectations, transitions, instructions, or other's intentions causing them to feel perpetually stressed from lack of understanding.

Emotional dysregulation occurs when judgment and management strategies are overwhelmed by the strength of an emotion and coping resources cannot be marshaled. As the executive functions that underlie this ability are often less mature for individuals on the spectrum than for those with neurotypical development, many find themselves less able to handle emotional challenges than their age mates. Thus age-inappropriate emotional expression can occur with the resulting disdain of peers and alarm of teachers. Sometimes what may look like overreaction may be the inability to handle the rush of fear and anxiety that may result from an unanticipated transition, the interruption of a focused interest, or the anticipation of potential trauma on the bus, lunchroom, or gym.

Aggression of all types may be exacerbated by the social limitations inherent to those on the spectrum. An individual may be unaware of particular social rules or their nuanced application. They may have had limited opportunity to experience relational controls typically developed through frequent peer interaction. They may misconstrue others' behavior as confrontational or misunderstand social intent because of their theory of

mind limitations. The rather common experience of being bullied or teased may cause increased fear in school or work settings.

In addition to a spectrum condition, many individuals may also have an additional diagnosed or undiagnosed disorder. Individuals who have double challenges from a co-morbid condition are likely to find demanding situations even more difficult and may be unable to manage their behavior. Mood disorders, including bipolar disorder or depression, are themselves issues that can affect self-control, so the additionally vulnerable individual with an autism condition may be at sea in self-management. Individuals on the spectrum may have attentional issues that are typically associated with ADHD that may manifest as problems in activity level, impulsivity, or attentional focus. These factors can make following instructions and classroom demands even more difficult. A response of frustration can look like an aggressive action on first consideration. Before the student realizes the inappropriateness, a cascade of events has occurred. Most individuals on the spectrum struggle with anxiety, but many experience it so severely that an additional diagnosis on the anxiety spectrum could be made. For such individuals, the very intensity of their anxiety may create the impression of intended aggression or their desperate escape behaviors may result in inadvertent harm to others.

Sometimes the treatment for comorbid disorders can itself exacerbate physical or verbal aggression. A stimulant can cause a "crash" as it wears off. SSRIs can cause over-activation, especially during dosage increases. Benzodiazapines can cause agitation and aggression under certain circumstances. Some anticonvulsants can have activating effects. So even the agents used to help can sometimes be the culprits in an aggressive episode.

If direct and indirect physical, verbal, and relational aggression can be viewed in a very different framework, with etiology being carefully considered, we are much more likely to be able to help individuals on the spectrum develop effective coping techniques for the additional challenges they face. We need to be able to:

- Make an objective assessment of their behavior in context
- Consider their neurobiological assets and vulnerabilities
- Consider their social history and opportunity for opportunity to learn interactional strategies
- Assess additional mental health issues
- Develop a sophisticated understanding of triggers, precursors, cognitive differences, and individual situational stressors

With this assessment and knowledge, can blame be removed from the equation and can alternative behaviors be developed and incorporated into the individual's repertoire? Often the mere understanding of the causative elements can help those around them make effective environmental changes.

We are in a state of knowledge explosion concerning general neurobiological understanding, including that particular issues that affect those on the spectrum. The systematic evaluation of treatments is less well developed. Nevertheless, there are evidence-based interventions that can be utilized effectively to address many of the aforementioned issues.

For the central characteristics of the autism spectrum, we know that visual schedules, preparation for changes and pre-teaching can diminish the anxiety many children experience during the school day. Social stories (Thiemann & Goldstein, 2001; Gray, 2000, 2010) have been an effective anxiety reducer as they help the individual understand what is happening next and what their response could be. Cognitive behavior therapy has been utilized effectively for children and adults (Attwood & Nielson, 2008; Gaus, 2007) to help them handle their unusual thinking, anxiety, or distorted belief systems and communicate more effectively about their experiences.

For sensory issues, it is vital to educate those around them, teach individual self-awareness and management, and encourage self-advocacy from a young age (Williams & Shellenberger, 1996; Paradiz, 2009). When the individual and those in their environment realize the extent to which sensory overwhelm can lead to aggression, everyone can help diminish these kinds of stressors to beneficial result.

Likewise, processing problems can be supportively addressed through a combination of individual awareness and helpful supports. It is useful to assess when confusions occur, to clarify directions and check for understanding, and to assess executive functions through neuropsychological evaluation in order to develop an understanding of personal executive function challenges. From this consideration arises the application of helpful, individualized coping techniques (Metzler, 2010; Buron & Curtis, 2004).

Emotional dysregulation has many contributors including executive function problems, lack of relational experiences, poor problem solving abilities, and social misperception regarding others' intentions. Ladd & Troop-Gordon (2003) emphasize that adverse peer experiences have long-term consequences concerning a child's self-belief and skill development. Therefore, systematic efforts to develop relationships in and out of school can help children have experiences that improve personal control and social function (*Common Connections* at www.aspergercenter.com/articles.html). An understanding of an individual's cognitive processes informs the individual and important others about coping strategies for emotional dysregulation that might be particularly useful in challenging situations. Difficulties with shifting set, inhibition, or initiation imply different intervention approaches, so a thorough assessment of these aspects through neuropsychological assessment can be very useful.

As impaired social function is a defining characteristic of spectrum conditions and can have a causative effect of the expression of all types of aggression, it is critical that interventions and supports in this area be evidence-based and faithfully

executed. General social skills interventions can seem like a good idea, but then may have no real effect. Instruction in social cognition has been shown to be effective for typical issues including handling the unexpected, appropriate social initiating, and social problem solving (Crooke, Hendrix & Rachman, 2008). The many books of Michelle Garcia Winner offer effective curricula for teaching social thinking.

Another factor in inappropriate social behavior, including aggression of all types, is impairment in empathy. Empathic skills vary widely among those on the spectrum, but for those severely affected in this dimension, there can be frequent misreading of others' intent, opinion, or needs. This type of misunderstanding can be significantly diminished through instruction in empathic skills. Research tells us that such instruction can be effective (Pecukonis, 1990; Long et al., 1999) and there are curricula for school aged children that can be helpful in changing this kind of perception and thinking (Caselman, 2007). There are also some bullying prevention programs that include empathic thinking in their approach. However, large-scale bullying programs have had varying success (Rahey & Craig, 2002), so we need to also address bullying with the children who experience it or engage in it in a more individual way.

Finally, the issue of comorbid mental health issues and their treatment needs also to be integrated into any plan developed to address aggression. Professionals who have real knowledge of the special cognitive characteristics of those on the spectrum and how they may affect mental health can be valuable in dissecting the complicated factors in the expression of aggression and the development of individualized intervention plans. It is always important to ask potential treating clinicians what kind of experience they have in working with complex children and adults with spectrum conditions before engaging in assessment or treatment.

There is no quick solution to understanding and treating aggression of any type, but it is clearly a more complex problem than can be easily modified by behavioral techniques alone. A sophisticated understanding of the underlying and highly variable neurodevelopmental issues is critical to successful outcome. Knowledge of both the types of issues that may be generally germane must be paired with a thorough assessment of the individual's unique neurodevelopmental profile, psychosocial history, and environmental challenges. An approach that seeks explanation rather than assignment of blame is critical to an effective intervention plan. Because aggression is one of the biggest challenges for individuals on the spectrum and may have the most profound effects on quality of life, we owe them our thoughtful, informed, and cooperative best practices.

Dr. Lynda Geller is a licensed psychologist and the founder of Spectrum Services, a cooperative of independent practices and organizations specializing in the diagnosis, treatment and support of children and adults on the autism spectrum and committed to the development and proliferation of evidence-based learning, practice, and training.

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Distinguishing from page 13

whether the child's behaviors are excessive and severely restricting their general and social functioning. Therefore, diagnosing OCD in any child is challenging. This is even more difficult if the child has autism, given their inherent difficulties in self-report and often limited insight into their behavior.

Furthermore, it is not clear whether the diagnosis of OCD is appropriate for the population of individuals with autism. The link between compulsive acts and obsessive thoughts rests on the assumption of anxiety reduction. While there may be some individuals with autism whose repetitive acts serve this function, it is very difficult to reliably and confidently determine this information with this population.

From a definitional perspective, stereotypy is often viewed as less complex. In addition, it is generally assumed that it does NOT serve an anxiety reducing function. There are individuals with autism that do seem to engage in behaviors that generally correlate with those seen in people with OCD. For example, they may engage in ritualistic cleaning or fixing, or they may engage in movement sequences that are linked to certain mathematical rules (e.g., 16 repetitions of a motor action, closing and opening each cabinet 5 times, etc.). It could be that such behaviors are best described as compulsive, and that they would respond to treatments linked to that presumption. However, as noted earlier, research shows that some stereotypy is in fact socially mediated, which would argue against the hypothesis of anxiety reduction.

A better model for diagnosing OCD may be functional assessment (Iwata, et al., 1982). Functional assessment is a systematic evaluation of the variables in the social and physical environment that may both "trigger" and reinforce the obsessions and compulsions. Functional assessment has evolved out of the scientific study of human behavior, which posits that the variables influencing behavior can be found in the external environment (e.g., Skinner, 1953). The paradigm asserts that behavior is influenced by stimuli occurring prior to the behavior, and any behavior that persists must be reinforced (strengthened) by variables following the behavior. Functional assessment is the state of the art assessment strategy for a wide range of inappropriate and challenging behaviors, ranging from noncompliance to severe aggression, with a significant amount of research on self-stimulatory, stereotypic behaviors (e.g., Mace & Belfiore, 1990).

Research has shown that there are four functions that maintain behaviors – attention, escape/avoidance, tangible reinforcement, and automatic reinforcement (e.g., Lang, O'Reilly, Lancioni, Rispoli, MacHalicek, Chan, et al., 2009; Mueller, Sterling-Turner, & Moore, 2005). Various functional assessment strategies have been developed to determine which of these functions appear to apply to a particular problem behavior. The research base clearly shows that by

conducting functional assessments of problem behaviors and hypothesizing which function may be in play for a particular behavior, treatments based on that function are more successful than treatments based on a different function not selected. Therefore, functional assessment has become a powerful tool in the assessment and treatment of maladaptive behaviors (e.g., Kodak, Northup, & Kelley, 2007; Vollmer, Marcus, Ringdahl, & Roane, 1995).

The application of functional assessment to traditional OCD may provide information regarding the function of the OCD from a behavior-analytic perspective. This information, in turn, may result in treatments that are not only more effective, but also do not rely solely on pharmacological interventions (i.e. medication) as is often the case today.

Of all the functional assessment strategies in existence, functional analysis is the most powerful in that it provides the best determination of function (Iwata, et al., 1987). A functional analysis involves a systematic manipulation of antecedent and consequent events to determine covariation of the target OCD behaviors. Typically, there are five conditions, one testing each of the four functions (i.e., attention, tangible, escape/avoidance, and automatic reinforcement), and one "control" condition, consisting of a typical play or recreational activity.

A functional analysis of an OCD behavior may proceed as follows. The target behavior for this example is repetitive wiping of dark smudges from floors, walls, and tables. To test whether this behavior is motivated by attention, the clinician would set up a room with dozens of smudge marks on the table and floor. The client would sit at a table and be instructed to play with preferred materials, while the clinician sat nearby and ignored the client by pretending to work. If the client began wiping off a smudge mark, the clinician would physically stop the behavior and give several seconds of undivided attention to the client, after which the clinician would go back to ignoring the client. This process would be repeated for a set amount of time (e.g., 10 minutes) and across multiple sessions. The number of smudge attempts would then be recorded for each of the sessions.

To assess whether the behavior was reinforced by escape/avoidance, the clinician would put the client in a nonstop work context, using work materials/activities that, through interview or experience, were known to be difficult or unpleasant to the client. Identical to the previous setting, the work environment would contain numerous smudges throughout. The clinician would present work demands continuously to the client; if at any time, the client attempted to wipe off a smudge mark, the clinician would remove all work demands and materials for a brief period of time (e.g., 30 seconds). This session would continue for a set amount of time and the number of smudges would be recorded.

To determine the influence of tangible

consequences on the occurrence of compulsive smudge wiping, the clinician would provide a preferred object for the client to engage with for a brief period of time (e.g., 1 minute). The clinician would then remove the object while ignoring the client. If at any time after that the client attempted to wipe off a smudge, the clinician would return the preferred item for a brief period of time (e.g., one minute). This process would be repeated throughout the session and the number of attempts at wiping off smudges would be recorded.

To assess the influence of "automatic" reinforcement (which is the closest explanation to the current theory of OCD), the clinician would place the client in a room with numerous smudges within arm's reach, and then ignore the client for the entire session. The number of attempts at the target behavior would again be recorded.

Numerous sessions of each condition would be conducted and data would be analyzed to see if the behavior occurs more consistently in one condition than another. If so, this is known as "differentiated results" and the identified condition can be said to be serving the function that is maintaining the target behavior. On the other hand, if there is no differentiation in the data from one condition compared to the others (that is, in all conditions the rates of the OCD target behavior were consistent), then these would be labeled as "undifferentiated results" and the assumption would be that the OCD is, indeed, automatically reinforced, possibly by the reduction of anxiety.

The ability to distinguish truly compulsive behaviors from stereotypy in individuals with autism could increase the efficiency and effectiveness of our attempts to treat such behaviors. In addition, a new perspective on OCD, one that does not rely primarily on the self-report of the patient, but rather on a scientific analysis of human behavior, may produce gains in the assessment and diagnosis of the disorder. This, in turn, could lead to more effective and varied treatment options beyond the use of medication which is most commonly used today. Considering a different perspective in which the function (cause) of behavior could drive the development of interventions for OCD might allow for a variety of currently unanswered or unclear treatment questions to be answered. The first step toward this goal is the development of a functional analysis protocol that would explain this behavior from a behavior analytic perspective.

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Struggle from page 34

not address the full range of needs.

Today there seems to be more awareness in the New England area as compared to Texas. I am considering looking at a short-term training program with the new knowledge I have. But after the training is completed I struggle on

how to explain myself to a prospective employer in an interview. Today with the higher unemployment rate, age, and competition, I worry many employers may be hesitant to hire an older adult with Asperger's. So to stay involved in life I volunteer at 3 organizations making a contribution to society and I am valued and appreciated.

In my personal experience the schools I attended were a lot more flexible in meeting my special needs than many of the organizations I have worked for. I am a living example of the need for more programs and support and understanding for adults with Asperger's especially in the workplace and I do what I can to ad-

vocate for that end. My question has over the past several years has been, "What happens when a child becomes an adult?" The needs need to be addressed over a lifetime and not stop at age 21. I hope that my experience and what I have learned about living with Asperger's can be helpful to others and their families.

Science from page 26

The evaluation of AIT continued. Mudford and Cullen (2005) conducted a thorough review of both the conceptual underpinnings of AIT, as well as the research existing up to that date. They concluded that both the philosophy and logic of AIT was weak, and that the research base was both thin and poorly designed, with no obvious causal relationship proven between AIT and any improvement in participants.

Sinha, Silove, Wheeler, and Williams (2006) conducted the most recent review of the AIT group of therapies. These authors limited their search of the research to studies that used randomized controlled trials (recognized as the preferred experimental design when testing treatment efficacy; e.g., Chambless & Hollon, 1998) that included persons diagnosed with ASD. They discovered a total of six studies that met their inclusion criteria. Of these six, the authors of three studies reported no benefit of AIT over the control conditions. The three other studies showed improvement as defined by changing scores of the Aberrant Behaviour Checklist. However, this particular checklist has questionable validity, so the strength of this positive finding is in question. Sinha and colleagues concluded that there was, at that time, no evidence sufficiently powerful to support the belief that AIT was empirically proven to be effective.

Also in 2006, the AAP once again reviewed the existing literature and reexamined its policy statement concerning AIT. And once again, the organization found the research base lacking and confirmed their initial policy against recommending AIT be used. AAP updated their policy a second time in 2010 and left it unchanged.

Lastly, even some proponents of AIT recognize the limitations of the research base. After each study listed at the AIT Institute website (2010), a comment from the Institute critiquing the strengths and weaknesses is posted. Of the 23 studies listed, only one study suggested any positive findings of AIT using an acceptable research design. The remaining 22 studies were considered problematic due to a variety of potential methodological problems, such as small number of subjects, no control group, or the use of unreliable survey data (AIT Institute, 2010).

Conclusion

Autism treatment is fraught with strategies and tactics that vary in terms of their quality and evidence of effectiveness. The standards of science and the scientific method are the models that should be followed when critiquing autism treatment to determine if a particular therapy has evidence of effectiveness. In the case of AIT, there is no empirical base demonstrating efficacy. This conclusion is made even more compelling by the process that was used. Over a period of 12 years, investigators from around the world and different disciplines read the extant literature and evaluated that research against criteria exemplified by good science – use of quality experimental design; operational definition of important terms; adequate reliability and validity; and replication of results. These independent researchers arrived at the same conclusion again and again – no compelling evidence that the use of AIT results in any significant improvement of the recipient. Furthermore, organizations (ASHA; AAP) that had professional interests in this therapeutic strategy independently studied the research existing on AIT and, finding it weak, issued formal policy statements explaining to its constituents how the evidence supporting AIT was not compelling and should not be considered an effective therapy.

However, there are still those who continue to apparently use AIT. Green, Pituch, Itchon, Choi, O'Reilly, and Sigafoos (2006) conducted an Internet survey of parents of children with ASD, to learn what treatments exist and which ones parents admit using. The authors categorized the treatments by type, such as medications, educational/therapy, and alternative therapies. The results showed that almost half of the respondents indicated they were using a "physiological" – based treatment, which included specific treatments such as sensory integration, conductive education, and auditory integration (AIT). AIT was the 3rd-most cited treatment in this particular category.

However, the professional community has come to the conclusion that AIT has no credible evidence to support the belief that such procedures result in any positive and measurable impact of any aspect of ASD. This skepticism cuts across researchers, educators, and professional organizations. It presents an interesting example of how, by adhering to the methods of science and understanding the criteria for quality evidence, the professional communities

can speak with one voice about a particular treatment in question. There are many other therapies currently being used for which these same standards, and the same investigatory protocols, could be applied. Hopefully, this will be done so that in the future, consumers will be able to select from a menu of treatments that all have an empirical basis of support.

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Employment from page 24**Work Skill Metrics**

Measures of the student's progress towards acquiring real world work skills include: Keyboarding - 25wpm, 95% accuracy; Data Entry (3 line address labels) - 10 labels in 10 minutes, 100% accuracy; Typing a document - business letter, typing a handwritten letter, typing a table in Excel and charting it and creating a schedule in Outlook. The Portfolio demonstrates the student's skills in a powerful way to employers, family and friends. Dr. Temple Grandin credits her portfolio of completed projects with launching her own career (*Thinking in Pictures*, 2006).

Internship

Once the student has completed their work skills training, they begin

their paid internship, working from one to ten hours per week. Assignments can vary in length and complexity, e.g., mailing labels, data entry, scanning documents, sales lead research on the internet, etc.

Both monetary and in-kind payments are earned according to the work performed, and SSA disability regulations. Vocational and Government Benefits Counseling is on-going. Future work sites could include the Customer's workplace and the Interns home - wherever the student feels most comfortable and productive.

Enrollment

The spring semester of the ASD Employment Program at the Center for Career Freedom begins February, 2011. There are five student/intern positions available. There are no fees. The pilot

program is currently supported, indirectly, by New York State Office of Mental Health Reinvestment funds. Eligibility is limited to adult (21+) residents of Westchester County, NY who are passionate about the computer. Keyboarding skills (15 wpm) are a plus. There is a two hour skills assessment and interview given on Thursday afternoons in January of 2011 at the Center. Interested parties should call Steve Vernon, Director, at (914) 288-9763 to schedule an appointment. To learn more about the Center for Career Freedom and the ASD Employment Program, please visit our two websites: www.freecenter.org, and www.economicsofrecovery.org.

To insure future ASD program funding, we are circulating a Parent/Teacher Petition. We have several hundred signatures so far. Please ask Steve to email you one.



**Steve Vernon, Director
ASD Employment Program**

Sensory from page 16

behaviors to social deficits and reported significant associations between the two domains, in particular over-responsiveness and stereotypy, possibly suggesting a shared neurobiological mechanisms for over-responsive sensory symptoms and repetitive behaviors, a fact that may have implications for both diagnosis as well as intervention. In addition, recent data by Lane et al 2010 presented a "clear predictive association" between sensory processing deficits and communication skills and maladaptive behavior, supporting the use of sensory based interventions in the treatment of communication and behavioral difficulties in this population. Lastly, Ashburner et al (2008) documented that a pattern of sensory difficulties that included auditory filtering deficits, sensory under-responsiveness, and sensory seeking behaviors was associated with academic underachievement. Specifically, children with ASD who found it difficult to process verbal instructions in a noisy environment or were focused on sensory-seeking behaviors, were more likely to underachieve academically, again highlighting the need for therapeutic intervention for sensory difficulties.

Occupational Therapists with training in Ayres' Sensory Integration Theory aim to understand each child's sensory needs in different environments and the function of sensory seeking behaviors. Although sensory seeking behaviors often relate to

sensory differences in children with autism, one should keep in mind that such behaviors also have the potential to result in extra attention by the child's caregivers and therefore may be used by the child as a communication tool or to seek such attention. For example, a child may bite his hand not as a way of seeking sensation but as a way of protesting a change in his routine. This issue highlights the need for multidisciplinary approach to sensory issues and collaborations between occupational therapists and behavioral consultants can be particularly fruitful.

Once sensory-based maladaptive behaviors are identified, one is confronted with the need to make appropriate therapeutic recommendations. In a review of sensory interventions, Baranek (2002) identified pilot studies of sensory integration intervention with children with autism and reported that although sensory integration interventions were associated with improvements in social interaction, purposeful play, and decreased sensitivities, the studies included small sample size and lacked control groups, so that the evidence to support such intervention still remains weak and requires further research. Sensory-based interventions, such as those that provide therapeutic touch, have been proposed to decrease maladaptive behaviors, hyperactivity, self-stimulation and stereotypic movements, and possibly improve attention and focus. Two randomized controlled trials have examined the effects of massage on children with

ASD. Field et al. (1997) compared a group of boys with ASD who received massage for 2 days a week for 4 weeks to boys with ASD who played a game for the same amount of time. The children who received massage showed decreased aversion to touch, off-task behavior, and stereotypic behavior. However the study lacked standardized measures. Escalona et al. (2001) compared children with ASD who received massage by their parents every night for a month to a control group whose parents read to them every night. The children who received massage demonstrated less over-responsivity, impulsivity and stereotypy, and improved on-task behaviors. Therapy approaches that use the auditory system (e.g., therapeutic listening and auditory integration training-AIT) to improve organization of the central nervous system have recently become more controversial. In a Cochrane systematic review of AIT, Sinha et al. (2004) reported that the evidence for AIT effectiveness was weak and inconclusive.

A "sensory diet" is one of the most commonly used tools by Occupational Therapists to help children maintain the just-right state needed for optimal function. It is called a "sensory diet" because, like a nutritional diet, the child may need main "sensory meals" as well "sensory snacks" throughout the day to maintain a just right state. The sensory diet uses sensory-based activities to modulate arousal and alertness levels that are carefully chosen by the occupational therapist to best meet each child's sensory

needs both at home and school. While there are few studies that focus specifically on sensory diets, there are several studies that evaluate various components that may be included in a sensory diet, but controlled research is still lacking.

Most scholars recommend the use of sensory-based interventions as one component of a comprehensive intervention that uses a variety of methods to promote performance (Baranek, 2002; Greenspan & Wieder, 1997). Although some positive benefits from sensory-based treatment have been documented, it is still not clear how these interventions affect the child's overall functional and educational outcomes. Future research studies need to include measurement of both effects on physiological markers and core symptoms and global functioning, to elucidate the mechanisms by which sensory-based interventions may influence outcomes in children with ASD.

In summary, sensory differences in children with ASD have now been well documented. However, sensory deficits do remain an under-investigated symptom domain in ASD. We are in urgent need for research both to understand the nature of sensory deficits in ASD and to provide evidence-based interventions.

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Fragile X from page 31

success than drill and practice exercises. A Fragile X mind might think "but I just said that!" and see no point in repeating themselves. Hyperaroused by the uncertainty of an open-ended question and unable to access his/her knowledge, the student with FXS is much more likely to provide a correct response if asked to fill in the end of a sentence. For instance, "When Peter wakes up from his dream, he....." is more likely to set the stage for a correct response than the question "What happens when Peter wakes up from his dream?"

World-famous clinicians Tracy Murnan Stackhouse, MA, OTR, and Sarah Scharfenaker, MA, CCC-SLP, have worked with hundreds of children with FXS using sensory integration techniques to improve speech and

attention. Empirical evidence for these methods is lacking; however, families who attend national conferences and communicate on the Fragile X ListServe frequently report success with these techniques, which include the use of joint compression, weighted vests, "heavy work," chewy textures, and vestibular stimulation (such as swinging). For more information, see their website at www.developmentalfx.org.

Since the identification of Fragile X Syndrome as a single gene mutation, a great deal of research has ensued to understand the function of the FMR-1 protein and the biochemical ramifications of its deficiency (Hagerman, 2002). Several new drugs are approaching clinical trial status, targeting these mechanisms to correct for syndrome-specific neurological aberrations. A path leading to pharmaceutical treatment that alleviates the symptoms of FXS

based on biomolecular intervention is being actively pursued, with the potential for FXS to be the first known cause of intellectual disability to be successfully treated with drugs (for more information, see www.fragilex.org and www.fraxa.org).

Carriers of the mutation have between 50 and 200 repeats of the CGG nucleotide. About 20% of female carriers experience Fragile X-associated premature ovarian insufficiency (FXPOI), which can result in early menopause. About 33% of male carriers are susceptible to a condition called Fragile X-associated tremor ataxia syndrome (FXTAS) when they are over 50 years of age, which resembles Parkinson's disease. Decisions about whether or not to have relatives of individuals with FXS tested and if or when to tell siblings about the condition are yet another aspect of Fragile X Syndrome with which

families must contend.

Resources for those interested in Fragile X Syndrome include The National Fragile X Foundation (www.fragilex.org), FRAXA (www.fraxa.org), an international listserv for family and friends of people with FXS sponsored by Emory University and FRAXA (LISTSERV@LISTSERV.CC.EMORY.EDU), and HeartShare Human Services of New York (www.heartshare.org).

HeartShare administers a contract funded by the New York State Office for People with Developmental Disabilities to provide information, referral, consultations, and staff training to support people with Fragile X Syndrome and their families. For more information, contact the Senior Director for Family Support Services at HeartShare, Laurie Yankowitz, at (718) 422-3271.

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typed only two lines because his anxiety had caused him to become “stuck.” In high school, this student’s accommodation list had not stated that someone needed to be with him for tests because someone was always with him. However, in a more independent and open college environment, we needed to take into account that this student required a coach to help keep him moving, record his answers, and to empower him to demonstrate his knowledge and competence. The young man was able to demonstrate his superior grasp of the material and received a 92 on the test.

Strategies utilizing Universal Design for Learning will help college faculty to reach, engage, and assess all the learners in their classes. It is important for applicants to consider the level of understanding and commitment of the faculty at a particular college in meeting diverse learner needs, as well whether the special program actively supports faculty. Entertain questions such as, “Do professors have access to staff with expertise in autism?” and, “Does the special program teach faculty to accommodate instructional needs of students with autism spectrum disorders in their courses?”

In degree bearing programs, college curriculum cannot be modified (i.e., diluted) for students with disabilities. The academic integrity of college degree programs must remain intact for all students. Maintaining academic rigor is possible through the provision of individualized supports whereby the role of the academic coach may vary by necessity from student to student. Many students may require the coach to assist them with organization and time management. Others may need their work scaffolded and broken into approachable chunks. Some may need their coach to accompany them to classes through transition periods and/or until appropriate college behaviors are acquired and firmly established.

Supervised study sessions with access to academic coaches for several hours daily can meet academic needs in several ways: Such programming can make efficient use of coaching time by having coaches available to groups of students, combining coach expertise in a complimentary manner, accommodating student schedules that are often very full with classes and extracurricular activities, and providing a gathering place that reduces isolation. In addition to study sessions, individual customized tutoring is essential because students in support programs often have information processing challenges that may cause them to miss important information in class; or they may have executive function issues that affect their organization and time management. Academic coaches need to ensure that assignment deadlines are being met and that students are prepared for tests.

The current definition of academic success may need to be revisited so that attainment of an undergraduate degree is not necessarily the ultimate goal for every college attendee. Rather, it is important to realize that education is about individual growth, increased independence, growth in social competence, career preparation, and self-determination. Educating students among their right-age peers on college campuses can contribute to these vital outcomes.

Campus-Life Inclusion

As postsecondary programs have grown, an increasing need has emerged for colleges to provide housing accommodations for students with learning and behavior differences. Services to support students with disabilities in university housing should foster independent living skill development. There are typically three tiers of available college support programs: (a) specialized programs in which students with disabilities are housed and instructed in proximity to each other, (b) inclusive programs for

students who need minimal support and are able to self-advocate and navigate their college system to obtain support when needed, and (c) inclusive programs in which students receive varying degrees of intensive supports on a routine basis. The type and level of support is critical so that students may benefit from safe and enriching experiences. Program staff, parents and students should take into account the amount of support required and received in secondary school when selecting a college program. For students that have had one-on-one aides throughout high school, it can be helpful to wean the student from the aide before transitioning to a university.

Career Preparation

We know that postsecondary educational experiences lead to better employment and adult living outcomes for individuals with disabilities (Winsor & Butterworth, 2007). The severity of the problem caused by inadequate preparation for integrated employment and adult living becomes clear when one considers that only 22% of adults with developmental disabilities are currently participating in integrated employment. The Olmstead decision, President’s New Freedom Commission on Mental Health (Executive Order 13263, 2002), and Developmental Disabilities Assistance and Bill of Rights Act of 2000 address weaknesses in services to support independent living and employment. The Americans with Disabilities Act of 1990 provides a framework to address the need for supports to fully include all persons in their communities. It is imperative that college programs prepare students with ASD for productive employment. It is not enough to earn a college degree. Students need to be prepared to be contributing members of their community. Support programs should provide access to supervised internships and varied community-based training experiences so that when students graduate

from college they have been exposed to varied career options and are ready for graduate school or a career.

Peer Mentoring

Individuals with ASD often require encouragement and assistance in the social interaction arena. Students may come to college and live in a residential hall, but if they remain in their dormitory room engaged in computer games and other solitary activities, they will miss a significant slice of college life. A valuable resource at colleges is the student population. College students, who volunteer as peer mentors, have reported that the experience was rewarding and growth producing. In fact, these peer connections are two-way relationships in which all parties benefit and learn. Students on the spectrum may have special strengths and interests that are channeled into the peer connections, so that, for instance, a student who enjoys watching sports and knows a great deal about baseball statistics may provide excellent company for a fellow sports enthusiast. A theater buff makes an excellent companion with whom to go to movies and plays.

Summary

When evaluating college support programs, four essential concerns are academics, campus-life, career development, and peer mentors/connections. If you are considering a program but find it lacking in a certain area, you may be surprised to find that the staff may be receptive to your requests to include a new service. This is a time when programs are growing and we need your input.

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relationship with her father he thought he may never have with his young daughter.

Sarah’s Story

Sarah enrolled in Hillside services through its early intervention program, which provides treatment to children from birth to three years old who have developmental delays. Most children who enter early intervention services, exhibit signs of developmental delays in at least one area: cognitive, physical (fine and gross motor, vision and hearing), speech and language, social/emotional and adaptive and are eligible for further evaluation, as was Sarah. It was through this further testing that Sarah was diagnosed with ASD.

Sarah first started working with Hillside therapists at three years old. At that time, she would often act out with sudden verbal outbursts, bite others, and pull out her own hair. She also had trouble sitting still for long periods of time, a behavior that greatly impacted her family’s tradition of having dinner together.

Using behavioral modification strategies, Sarah’s therapists developed a struc-

tured routine involving positive reinforcement and repetitive training to strengthen desirable behaviors. In addition, when Sarah would display undesirable behaviors or “act out,” her therapists would distract her with a toy. The objective of this practice was to remove behavioral triggers from Sarah’s environment and teach her a new behavior in response to the same trigger. Within a few weeks of utilizing this technique, Sarah was “taught” to grab a vibrating teething toy to satisfy her sensory need instead of biting herself or others or pulling her hair. Through repetition, therapists have helped Sarah to find new ways to cope and self-calm.

Using careful behavioral observation and positive reinforcement, Sarah’s therapists also taught her how to sit still for longer periods of time. One step at a time, therapists would encourage Sarah to increase the duration of time she sat at a table reinforcing the behavior through “play,” with puzzles or string beads that she enjoyed. Sarah can now sit at a table and eat meals with her family.

To further ensure Sarah’s treatment would be successful, her therapists worked closely with her school and family to organize therapeutic and home envi-

ronments for consistency. The rewards and consequences for her behaviors both desirable and undesirable also needed to be delivered in the same manner across both environments.

At the time of enrollment, Sarah was in an integrated classroom with typically developing three year olds and children with developmental disabilities. By age five, Sarah had successfully transitioned into a regular education kindergarten classroom with typically developing children her own age and was supported by her therapists offering supplemental services. Now at age six, Sarah remains in a regular education program with typically developing children and has reduced the level of supplemental services needed for her successful functioning. She now requires only 10 hours of supplemental and home-based services, in comparison to the more than 40 hours of service she received during her early intervention program. This spring, her therapists will most likely reduce their level of support to 5 hours.

Adrienne and Sarah’s stories are just two of many at Hillside Family of Agencies. Using Applied Behavior Analysis, Hillside has been able to work with hundreds of children with ASD to

increase their independence and improve social functioning. Applied Behavior Analysis has been proven as an effective treatment modality in Hillside’s service delivery and will increasingly be practiced by the organization to improve the quality of life for a broader population of youth, not just those with ASD, in years to come.

For more information on ABA or services for youth with autism spectrum disorders at Hillside Family of Agencies, contact Dan Lesinski by email at dlesinsk@hillside.com.

Hillside Family of Agencies (www.hillside.com) is a family and children services organization that provides child welfare, mental health, youth development, juvenile justice, special education, and developmental disabilities services across central and western New York and in Prince George’s County, Maryland. Hillside Family of Agencies is comprised of affiliates Crestwood Children’s Center, Crestwood Children’s Foundation, Hillside Children’s Center, Hillside Children’s Foundation, Hillside Work-Scholarship Connection, and Snell Farm Children’s Center.

AUTISM SPECTRUM NEWS



Helping families understand and cope with a child on the spectrum can only be achieved by providing them with information that is based upon the best scientific research and medical evidence.

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