

Autism and Mental Health Services

Medication Treatment of Co-Occurring Illness in Autism Spectrum Disorders

By Russell H. Tobe, MD
Director, Outpatient Research Dept.
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One of my first mentors in psychiatry said early in my career: “when a disorder impacts an organ in the body, other problems and challenges often follow suit within that same organ.” This is apparent in many areas of medicine: a leg deformity related to a prior growth problem may lead to joint erosion and pain of that same leg or the first heart attack weakens the heart in a manner such that the second is often more severe. This rule applies to the brain. Certain types of brain infections or tumors increase risk for seizures which can further damage neurons and interrupt their function. Accordingly, it is intuitive that the neuronal differences that are in place for individuals with Autism Spectrum Disorders (ASDs) may also elevate risk for the development of other psychiatric disorders. Conversely,



disorders that may damage the brain, such as certain infections, environmental exposures, or seizures, also impart added risk for development of ASD. Finally, though no causal relationship between the con-

ditions may be evident, ASDs can share common risk factors and neurobiology with other psychiatric disorders. Given these factors, co-occurring illness (comorbidity) with ASD is frequent; treatment of

distressing and impairing symptoms related to comorbidity is often necessary. This article will review the most common disorders associated with ASDs, rare but severe disorders, and their treatments.

Medical Comorbidity

Depending upon the population, the rate of identifiable genetic disorders in ASD can vary but is typically in the range of 10-20% (Shishido, 2014). These rates have and will continue to increase as technology advances to permit rapid and cost-effective pathways to identify new alleles that play a role in ASD. Indeed, the rate of identifiable genetic contributions to ASD pathophysiology has prompted several organizations, including the American Academy of Child and Adolescent Psychiatry, to recommend genetics evaluation for all children diagnosed with an ASD (Volkmar, 2014). More commonly associated genetic disorders associated with ASDs

see Co-Occurring on page 14

Anger and Autism Spectrum Disorders: A Clinician's Perspective

By Grazyna Kusmierska, PhD
Psychologist
Premier HealthCare

Psychology defines anger as a complex psychological phenomenon, a syndrome consisting of emotions, related thoughts, physiological reactions, and behavioral scripts or action tendencies that define the way in which the person acts when angry (e.g. Berkowitz & Harmon-Jones, 2004; Deffenbacher, 1999; Kassinove & Sukhodolsky, 1995). Anger is commonly and frequently experienced (Averill, 1983), and it has an adaptive value: It signifies lack of satisfaction with the current state of affairs and could mobilize a person to take steps to change this situation. It is the poor regulation of anger that often leads to problematic outcomes, could cause an individual's and family's distress, and calls for treatment.

People with autism spectrum disorders (ASD) have more reasons than the average person to feel angry. In addition to

typical triggers of anger, such as feeling provoked or intentionally mistreated by someone, they often struggle with communication and processing problems, sensory overload, transition difficulties, social rejection, difficulty meeting expectations in school, at work, and in their families (Gaus, 2007), all contributing to frustration and angry feelings. A recent study by Samson, Huber, and Gross (2012) indicates that people with Asperger's syndrome and high functioning autism report higher level of negative affect (defined as feeling nervous and upset) and more difficulty identifying, describing, and regulating their emotions than typically developed individuals do. Other studies (e.g. Fitzgerald & Bellgrove, 2006; Hill, Berthoz, & Frith, 2004; Konstantareas & Stewart, 2006) and clinical experiences confirm these results.

Clinicians often see individuals with ASD referred for counseling to improve frustration tolerance and anger management. The referral sources usually expect that through participation in individual counseling or an anger management group, the person will

learn how to control his or her outward expressions of anger and better manage frustration. However, this can be particularly challenging when a person with ASD is not able to make use of therapy sessions, for example, because he or she does not have sufficient verbal and processing abilities or refuses to participate in sessions. Even when a person is able and willing to verbalize his or her experiences and work with a therapist on coping strategies, there is a limit as to how much can be done by focusing on the individual. People typically experience anger in a situational context, mostly in relation to others (Buckley, Winkel, & Leary, 2004). In my experience, conceptualizing anger as related to an issue that exists in a person's environment, and work with a system in which the person with ASD functions, in addition to individual or group counseling, brings faster and more lasting results.

Work on Coping Strategies

As previously stated, anger consists of emotions, related thoughts, physiological

reactions, and behavioral scripts. According to Berkowitz and Harmon-Jones's model (2004), all those components are interconnected: Activation of one of them affects the other parts. For example, physical discomfort could increase physiological arousal and evoke angry feelings and thoughts, which may or may not be related to the discomfort. On the other hand, decrease in activation of one of the components affects the other parts as well. For example, relaxation, which brings down the physiological arousal typical for anger experience, reduces the intensity of angry feelings and decreases angry thoughts.

The interconnectedness of anger components has a great impact on the therapist's ability to help people with ASD to manage anger. The therapist has a choice to work on physiological reactions, thoughts, feelings, or behavioral scripts, and she can tailor work on coping strategies to the needs of a person that he/she serves. It is difficult to treat people who cannot verbalize their

see Anger on page 18

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AUTISM SPECTRUM NEWS DESK

Adults with Autism May a Have High Burden of Health Problems

By Jessica Wright
SFARI.org

Adults with autism may suffer from various health problems, ranging from psychiatric conditions to motor symptoms that resemble Parkinson's disease, according to two studies presented Thursday at the 2014 International Meeting for Autism Research in Atlanta.

Some of the conditions may stem from people with autism feeling like outsiders in society, says Lisa Croen, director of the Autism Research Program at Kaiser Permanente, an integrated healthcare delivery system in California. Croen led one of the studies, which documents the health status of more than 2,000 adults with autism.

"From our experience, inclusion and feeling part of society really does impact on health status," says Croen. "It's very important to include adults with autism in all sections of society."

The findings are also of concern given the rising numbers of children diagnosed with autism, the researchers say. They highlight how little is known about adults with autism, many of whom may be misdiagnosed with other conditions.

"There is almost no literature on older



Lisa Croen, PhD

adults with autism in the field, so we have virtually no knowledge base," says Joseph Piven, professor of psychiatry at the University of North Carolina at Chapel Hill, who presented the second study.

Piven and his colleagues pursued a "boots-on-the-ground approach," sending queries to nearly 14,000 households and contacting several health agencies in North Carolina. After three years of searching,



Joseph Piven, MD

they found 20 men with autism who were over 50 years old.

"I think the main finding is how hard it was for Joe Piven's group to find people," says Catherine Lord, director of the Center for Autism and the Developing Brain at New York-Presbyterian Hospital. Lord has followed children with autism over long periods of time, but was not involved in either new study.

Hidden Adults

Most of the men in Piven's group have markedly low intelligence quotients: 40 percent have IQs under 35 and about 60 percent have IQs below 50. This is probably because to be diagnosed with autism decades ago - when there was much less awareness about the disorder - they would have had to have severe symptoms, says Piven.

One of the men in the study was among the first group of 11 people to be diagnosed by Leo Kanner in 1943. Some of the others received a diagnosis for the first time during the course of the study and had instead been diagnosed with disorders such as schizophrenia or bipolar disorder. "One of the big stories here is that there are people out there who are misdiagnosed. We just can't find them," Piven says.

A 2012 study found, for example, that about 10 percent of adult patients in a state psychiatric hospital have undiagnosed autism.¹

Of the 20 men in Piven's group, 17 look older than their age, with a stooped posture, and about half have at least one symptom associated with Parkinson's disease, including tremors, slow movement and rigid gait. About one-quarter of the group has two or more of these symptoms.

One of the men was already undergoing

see Adults on page 27

Autism Science Foundation Announces 2014 Grant Recipients

By The Autism Science Foundation

The Autism Science Foundation, a not-for-profit organization dedicated to funding autism research, has announced the recipients of its 2014 annual pre and post-doctoral fellowships as well as the recipients of its first undergraduate summer research grants.

Pre and Postdoctoral Research Grants

Five postdoctoral and four predoctoral grants will be awarded to student/mentor teams conducting research in autism interventions, etiology, treatment targets, biomarkers, language development and animal models. "The autism community has demanded more research to understand what is causing autism and to develop better treatments" said ASF president Alison Singer. "We are proud to be able to increase our research funding in response to this national health crisis and we are especially grateful to all our donors and volunteers who have come together to support autism research and make these grants possible."

"ASF attracts outstanding applicants across the board, representing a broad range of perspectives on autism science"

said Dr. Matthew State, Chair of the ASF Scientific Advisory Board and Chairman of the Psychiatry Department at the University of California, San Francisco. "These projects show great potential to move the field forward."

The following projects were selected for 2014 funding:

Postdoctoral Fellowships

Dr. Boaz Barak/Dr. Guoping Feng:
Massachusetts Institute of Technology

Characterizing and Manipulating the Social Reward Dysfunction in a Novel Mouse Model for Autism

Goal: Provide treatment-facilitating insight into the pathophysiology of autism

Dr. Shweta Ghai/Dr. Gordon Ramsey:
Emory University, Marcus Center

Identifying Biomarkers for Early Diagnosis of Prosody Disorder in ASD using Electrolottography

Goal: Improve vocal and language development in children with ASD

Dr. Katherine Kuhl-Meltzoff
Stavropoulos/Dr. James McPartland:
Yale University

The Effects of Oxytocin on Social Learning in Individuals with ASD

Goal: Understand who may or may not benefit from oxytocin treatment

Dr. Julia Parish-Morris/Dr. Robert Schultz:
University of Pennsylvania

Developing Automated Algorithms to Assess Linguistic Variation in Individuals with Autism

Goal: Design effective, personalized interventions for pragmatic language deficits

**Dr. Aarthi Padmanabhan/
Dr. Vinod Menon:**
Stanford University

Social Motivations and Striatal Circuit Development in Children and Adolescents with Autism

Goal: Determine windows of brain plasticity during which intervention may be especially successful

Predocctoral Fellowships

Alexandra Bey/Dr. Yong-hui Jiang:
Duke University

The Role of Shank3 in Neocortex Versus Striatum and the Pathophysiology of Autism

Goal: Determine whether and how specific brain regions control specific ASD-related behaviors

Nick Goeden/Dr. Alexandre Bonnin:
University of Southern California

The Impact of Maternal Inflammation During Pregnancy on Placental Tryptophan Metabolism, and the Downstream Consequences on Fetal Brain Development

Goal: Understand the impact of prenatal inflammation and infection on fetal brain circuits and ASD development

Erin Li/Dr. Alexander Kolevzon:
Seaver Autism Center,
Icahn School of Medicine at Mt. Sinai

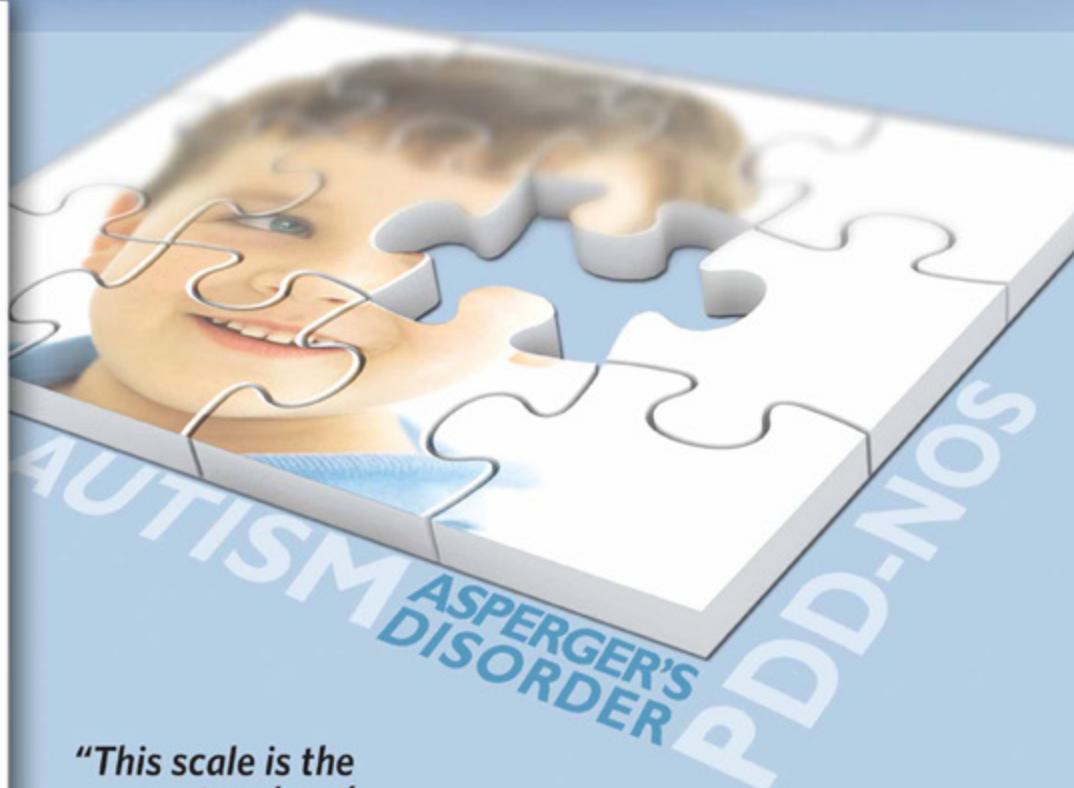
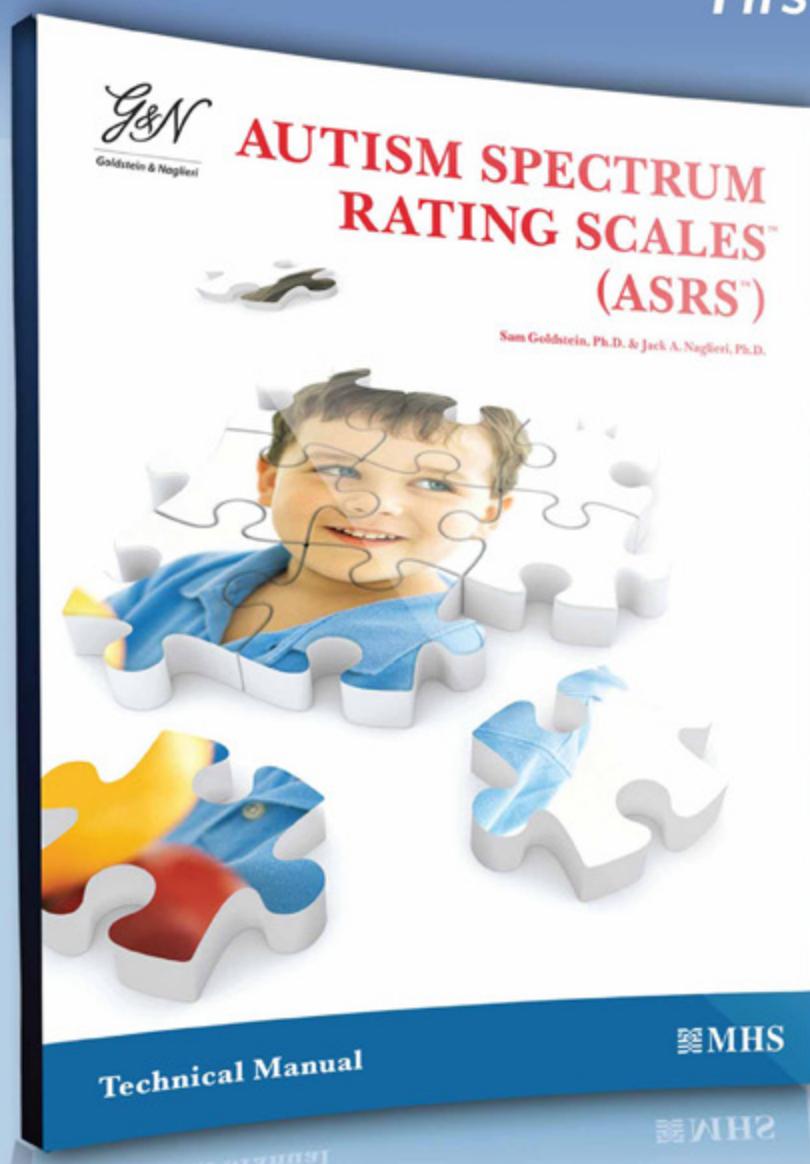
Mapping the Neurobehavioral Phenotype in

see Grant Recipients on page 29

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-Kirsh, Aimee A. Assessment With Aimee, The Ohio
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It Takes Brains to Solve Autism

By The Autism Science Foundation

The Simons Foundation, Autism Speaks, the MIND Institute and the Autism Science Foundation have announced the launch of the Autism BrainNet, and encourage individuals with autism and their families to register to become tissue donors at www.takesbrains.org. Autism BrainNet is a consortium of academic sites funded to collect, store and distribute brain tissue resources necessary for researchers to understand the underlying neurobiology and genetics of autism.

The pace of autism research has been significantly hindered by a severe shortage of human brain tissue. Important discoveries have already been made thanks to generous donations of brain tissue from individuals with autism. This type of research could lead to a better understanding of the disorder, its treatments and its causes. To date, research has shown that the brains of people with autism seem to be structurally different — possessing different numbers and sizes of neurons — and appear to show increased inflammation compared with the brains of typically developing individuals. In addition, shared changes in gene expression have been identified in the brains of people with autism. However, none of these findings have received adequate replication, in part due to a lack of adequate samples.

The following institutions will join as inaugural members of Autism BrainNet and will be collection and storage sites: Harvard University/Beth Israel Deaconess Medical Center in Boston, Icahn School of Medicine at Mount Sinai in New York City, the University of California, Davis MIND Institute in Sacramento, and the University of Texas Southwestern Medical School in



David G. Amaral, PhD, and Robert H. Ring, PhD

Dallas. Additional sites worldwide are expected to join in the future. Each site will adhere to standard protocols for clinical data and brain acquisition, preparation, storage and distribution to researchers.

Autism Speaks' Autism Tissue Program (ATP) will transition to Autism BrainNet. Resources from the ATP will continue to be made available through Harvard University. Communication with ATP donor families will continue through Autism BrainNet, and ATP registrants will be added to the Autism BrainNet database to receive updates on the new program and news about general brain research.

Dr. David Amaral of the University of California, Davis MIND Institute will serve as director of Autism BrainNet. "Studies on brain tissue represent the best way for researchers to gain a deeper understanding of the genetic, cellular and molecular

causes of autism spectrum disorder," Amaral says. "This research takes us important steps closer to effective treatments that will lessen disability for affected individuals."

"Human brain structure and function is the key to understanding behavior — and identifying differences in the brains of individuals with autism is essential for advancing our understanding of autistic behaviors," says Marta Benedetti, senior scientist at the Simons Foundation Autism Research Initiative. "Autism BrainNet will provide the material needed to identify and understand these differences, and will greatly advance our understanding of and the ability to treat autism. Autism BrainNet will also allow researchers to replicate previous findings using new, better-characterized and larger sets of tissue."

"Since it was launched in 1998, the Autism Speaks Autism Tissue Program has

been committed to providing the rare and precious resource of brain tissue to many highly qualified scientists," said Autism Speaks chief science officer Robert Ring. "The launch of Autism BrainNet enables us to continue this mission and expand the number of available collection sites, and represents an unprecedented investment ensuring that researchers have access to the brain tissue they need to answer the big questions about autism."

Educating families affected by autism is essential to growing Autism BrainNet's tissue resources quickly. *It Takes Brains*, Autism BrainNet's outreach program, encourages families affected by the disorder to register with Autism BrainNet in the event that brain tissue donation is someday relevant to their family. Registrants will receive updates about the ongoing progress of Autism BrainNet.

"My 16-year-old son, Grayson, was a brain tissue donor," says Autism BrainNet family participant Valerie Hund of Livermore, California. "I would encourage any family to register to be donors. Although we could not have anticipated losing our son to a seizure, for us, in that moment, we gave back and did something that felt right — not even knowing that brain tissue is so in demand. So now Grayson can be a pioneer in helping make this next quantum leap in research. Out of something bad, something good came about."

"Most people think brain tissue is included when you register as an organ donor, but it's not," says Alison Singer, president of the Autism Science Foundation. "Every family raising a child with autism needs to think about registering to donate brain tissue in case of a tragedy. Brain tissue research is the best hope we have for understanding what causes autism and developing new and better treatments for individuals with autism."

Autism Science Foundation Hosts Autism Community's First TED-Style Talks

By Meredith Gilmer
Community Relations Associate
Autism Science Foundation

On April 10, 2014, the Autism Science Foundation celebrated its fifth anniversary by hosting a Day of Learning and an Evening of Celebration at the Yale Club of New York City. For the Day of Learning, ASF presented the autism community's first TED-Style Talks, which were given by nine experts in the autism field. At this sold-out event, over 250 scientists, parents, individuals with autism, and other stakeholders gathered to listen and learn about autism spectrum disorders.

TED-Style Talks are short, powerful presentations that usually only last about 15 minutes. They are intended to share information in a concise and inspiring way, often encouraging the audience to take action after the presentation is over. This format allowed for this event's attendees to hear from many experts in the autism field in just one afternoon.



Dr. David Amaral speaks to over 250 attendees about "Why It Takes Brains to Solve Autism" at the Autism Science Foundation's TED-Style Talks

The topics presented at ASF's TED-Style Talks touched on a variety of subjects that are relevant to individuals in the autism community. The day's first presenter was Dr. Tom Insel, Director of the National

Institute of Mental Health. Dr. Insel gave a talk entitled, *From Four Kingdoms to One Community for Autism*, presenting autism as an illness, an injury, an insight, and an identity, and calling on the audience to act

as one community. He noted that it is crucial for everyone to work together in order to advance the science and to improve the lives of those with autism.

Dr. David Amaral of the University of California, Davis and the Director of Autism BrainNet also touched on the need for community support. Dr. Amaral presented *Why It Takes Brains to Solve Autism*, informing the crowd that fewer than 150 physical brains have ever been studied in the history of autism research. In order to advance the science, researchers depend on brain tissue donations from the community. Anyone who is interested in learning more about the crucial gift of brain tissue donation can visit www.TakesBrains.org.

Another speaker who added his own perspective to the day's proceedings was Paul Morris, a 26-year-old adult with high-functioning autism. Mr. Morris shared *Growing Up with Autism*, his personal account of some of the struggles and triumphs he has experienced. He inspired the crowd as he spoke, inviting them into his life's story.

see TED-Style Talks on page 31



THE MATTHEWS,
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AND THEIR SONS
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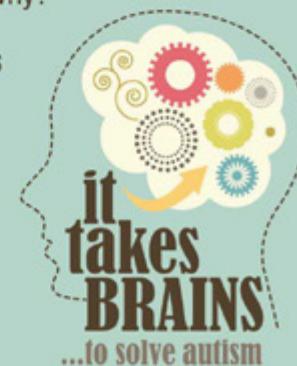
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Visit **TakesBrains.org** to learn more and see how your entire family can help build a better tomorrow.



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Autism and Comorbid Mental Health Issues: Challenges and Issues for School Teams

By Vanessa Tucker, PhD, BCBA-D
Professor of Special Education
Pacific Lutheran University

Children and youth with ASD (Autism Spectrum Disorder) represent a variable and growing population in the K-12 school system who may be served under IDEA (The Individuals with Disabilities Education Act: 2004). ASD is, according to the DSM V (Diagnostic and Statistical Manual of Mental Disorders, 5th Ed.; American Psychiatric Association, 2013) a neurological disorder characterized by deficits, social-communication and the presence of restrictive and repetitive patterns of behavior. It is a difficult disorder to neatly classify as individuals are highly heterogeneous in their symptoms, delays and strengths. Schools may identify children to receive services under IDEA in the eligibility category of Autism at any age provided that there is evidence of an adverse educational impact. The diagnosis of ASD is often not the only issue the family and school team has to contend with. A large percentage of children, youth and adults with ASD present with one or more other disorders, termed "comorbidity," including sleep disorders, seizures, tic disorders, ADHD, gastrointestinal disorders, obsessive compulsive



Vanessa Tucker, PhD, BCBA-D

disorder and others (Hanson, E., Cerban, B.M., Caccamo, L.M., Bacic, J. & Chan, E. 2013; Manion, Leader & Healy, 2014;). The presence of one or more comorbidities is quite common in this population (Manion et al., 2014; Manion & Leader, 2014) and presents a number of issues worthy of discussion for educational teams. The focus of this particular article is on ASDs with comorbidities of mental health disorders.

Eligibility

The public school system is federally mandated to serve any child with a disability between the ages of 3 to 21 provided that the disability (or disabilities) present(s) such an impact that accommodations alone cannot adequately ensure progress in the general education curriculum. School systems operate under IDEA and determine an area of eligibility based upon best fit when evaluating a child for special education. Teams can and do struggle when more than one disorder is identified. Eligibility categories serve multiple purposes for educational planning and service delivery including identification of prevalence, better definitions for research purposes and deployment of resources. The child with more than one diagnosis may be the "square peg in the round hole" when it comes to identification and eligibility for services. For example, a young adult may present with diagnoses of ASD and Bipolar Disorder. In this case there are two possible IDEA eligibility categories to choose from: ASD and ED (Emotional Disturbance). Teams in this case must grapple with identifying the category that best fits the student and move beyond the label toward adequately addressing adverse educational impact and academic/behavioral needs in the IEP. In some cases

a team could qualify the student under the IDEA category of MD (Multiple Disabilities). Ultimately the team should select the category for eligibility that represents the best fit and look toward creating written plans and specially designed instruction that address the multiple and varied needs of each child. The category opens the door to services and ensures the continued entitlements. The paperwork and plans that follow are the true guides to creating a package of services that address all needs related to ASD and any impairment areas that create an adverse educational impact.

Comorbidities: Addressing Needs Through Collaboration and Training

Comorbidities with ASDs in children and youth bring up a number of important issues for school teams during the educational planning and intervention phases and suggest the need for greater collaboration and training. School teams typically approach each child from a strength and needs-based perspective related to the disabilities creating the adverse educational impact. All interventions should be designed to increase functional capacity to cope with the social and academic demands of school and are tied to the underlying

see *Challenges on page 26*



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Advocating for a Student-Centered Approach in Special Education

By Vicki Ofmani, MEd, LDT-C
Supervisor/SLE Coordinator
The Forum School

Autism Spectrum Disorder is on the rise. Autism Spectrum Disorder is on the rise? While pondering over information found on the National Institute of Mental Health website (www.nimh.nih.gov), one cannot help but fluctuate between statement and question. The latest edition of the diagnostic manual (DSM-5) now includes Asperger's Syndrome under the ASD umbrella, broadening the category ever further. In addition, greater awareness is, thankfully, bringing with it earlier diagnosis. We all look at genetics, vaccines, environmental factors – none of which has led us to a cause for the disorder which is now estimated to touch approximately 1 out of every 88 of the children we love (National Autism Association, 2014).

Perhaps it is human nature to search for a cause so that we may point to and blame something in particular. However, through years of teaching and caring the truth seems to be that some things really don't matter... and a few things matter very much.

The label or classification matters little unless you are looking for government funding. Autistic, Communication Impaired, Multiple Disabilities, Emotionally Disturbed, Cognitively Impaired, Other



Vicki Ofmani, MEd, LDT-C

Health Impaired, or Specific Learning Disability – finding how to teach the child is what comes first. The challenge comes from the balance that must be struck. The teacher must be demanding yet patient; energetic but calm; firm, sure and always flexible. The difference is striking. And, paramount to all else, there must be respect

for the child as an individual. It has been said that from the seeds of trust integrity blooms. The teacher must see the strengths students possess and facilitate their growth, acknowledging the partnership between student and teacher which can only exist within an environment of trust.

Keeping the balancing act is not easy, yet it is necessary to foster the independence and generalization of learned behaviors and academic skills. The basis of humanistic design is the individual. Therefore, looking at each child with their individual characteristics, needs, tendencies, expectations, strengths and successes is central. Since every child with ASD is different, no single education plan should be mass produced. We see this when we look at a deficit model; we should also be open to this when looking at attributes. Teachers have heard the phrases and have used the classroom design of both student and teacher centered instruction. Special Education screams out to be focused on the learner. This really should be more than a matter of semantics. The focus must be on what the child is doing in the classroom rather than focusing on what the instructor is doing or covering in the paradigm.

Teaching styles and teaching strategies obviously affect student learning. Please consider the shift which may occur when instruction changes from being teacher-centered and content-driven to becoming learner-centered and learning

process-driven. The teacher remains as a skilled facilitator throughout the process. The learner's role changes from that of being a passive recipient or empty receptacle into that of an active learner engaged in the procedure.

Shifting the focus places the teacher along side the students during the learning development. Children construct knowledge through repetitive gathering and integrating of information. General skills of inquiry, communication, critical thinking, and problem solving are addressed and advanced. We all know how important it is to read and write and understand the use of mathematics (and a calculator). Those soft skills, however, are as, if not more, important as the 3 Rs (reading, writing and arithmetic). Rather than answers being "right" or "wrong," learners are exposed to the idea that they can learn from their errors and, thus are able to generate better questions. In addition, generally, student-centered instruction is considered interdisciplinary in nature of collaboration, cooperation and mutual support.

Formative assessment is one effective way a teacher can be clear about the intended learning goals for a lesson (www.education.com/reference/article/formative-and-summative-assessment/). This means focusing on what students will

see *Student-Centered on page 26*

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Psychiatric Hospitalization and ASD

By Sophia Francis-Stewart, MD
Katherine Cody, PsyD
and Natalia Appenzeller, PhD
Fay J. Lindner Center for Autism
and Developmental Disabilities

Admission to a psychiatric inpatient unit can have varying outcomes for a patient. The success of the admission is determined by the patient's ability to function after discharge. During the course of treatment, it is important to prepare the patient for life after hospitalization. All members of the team, including family members, residential staff, and the outpatient team in conjunction with the patient himself play a significant role in determining whether or not the transition will be successful. For patients with ASD/DD there are some key components that, if in place at each juncture of this process, will help increase the likelihood of this success.

At Admission

It is important to have an understanding of the circumstances that resulted in the hospitalization including (but not limited to):

- Behavioral Triggers
- Environmental Triggers (changes in environment)



- Medical Triggers (medication changes; other medical concerns)

Prevention of these triggers in the future can help to decrease the likelihood of readmission to an inpatient unit in the future. In recent years the criteria for admission have become much more stringent; only patients that have psychiatric symptoms that meet specific criteria as outlined by the DSM-5, or whose functioning has deteriorated to a point that they pose a threat to themselves or others, are typically admitted psychiat-

rically. Accordingly, only those who have severe psychiatric symptoms are admitted.

Coordination of treatment between the patient's outpatient team and the hospital treatment team is critical to success, allowing for ongoing monitoring of the patient's treatment and progress and taking into consideration the patient's strengths and needs.

During Hospitalization

Patients intellectual, emotional and psychiatric functioning and feelings about the

hospitalization will affect their ability to participate in a successful discharge plan. Some people with ASD/DD experience hospitalization as desirable because of the increased attention and structured group activities. Hospitalization can create a sense of belonging and comfort which can result in reinforcement of the behaviors that resulted in the hospitalization. But other patients can experience the hospitalization in a negative manner or as a "punishment." They could be resentful of family members/caregivers who facilitated the hospitalization, and become uncooperative/unmotivated during their stay, prolonging discharge and adversely affecting what happens following discharge. Regardless, the ultimate goal should be a collaborative process of all parties involved for successful treatment and discharge.

Successful hospitalizations should always include the following:

- Establishing clear treatment plans with concrete goals
- Implementing motivational systems and positive reinforcement for expected behaviors and progress toward treatment goals
- Establishing a positive sense of progress for the individual to facilitate the

see Hospitalization on page 34

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Treating the Adolescent with ASD: The Quest To Establish Selfhood

By Shuli Sandler, PsyD
Clinical Psychologist
Spectrum Services

In our society, adolescence is thought of as a time of self-discovery and identity formation. It is a time when the individual is not quite a child anymore, but is certainly not an adult; it is the transitional period between the two. During the span of roughly seven to ten years, or in some cases longer, the child grows up to become a man or woman. The famous developmental psychologist, Erik Erikson, summarized various developmental stages across the lifespan. According to him, the conflict during that stage of life is "identity versus role confusion." His idea is that the adolescent is trying to navigate his or her place in the world, try and fit in in a unique and personal way, with the ultimate goal of forming a stable sense of self over time. While some of Erikson's ideas have been challenged more recently, I think the goal of adolescence reflecting the process of identity formation rings true for most, if not all, adolescents to some degree or another. In seeking to establish this unique identity, which can be an ambitious undertaking, the adolescent may reject beliefs or ideas that were previously accepted (Hamman & Henricks, 2005). In addition, he or she may actively challenge parental figures who previously served as role models. Ad-



Shuli Sandler, PsyD

olescence can be thought of as a potentially stormy time where one's relationships with parents and caregivers may be quite difficult as the adolescent searches to define and understand him or herself. He or she may find the need to pull away to establish an identity that may be similar to or differ-

ent from the parents. The storminess of that time period is really a reflection of the adolescent's need to discover this sense of self.

Individuals with Asperger's Syndrome typically have average to above-average IQ's with deficits in social reciprocity, perspective taking, and executive functioning, and they often lack independence in daily living skills. As such the individual with Asperger's is often living with significant discrepancies between various areas of strength and weakness. For example, an 11 year old with Asperger's Syndrome may present with verbal abilities that are equivalent to those of a 17-year-old and social skills that are equivalent to a 3-year-old (Volkmar et. al 2000). It can be quite confusing and complicated living with such a large gap, and put the individual with Asperger's in a difficult situation. It's very hard to be gifted in certain areas, while challenged in others. As such, the child with Asperger's typically relies on parents, caregivers, and therapists to help them compensate for various areas of social and emotional weaknesses. In my practice, I often encounter parents (typically mothers) who have spent years serving as their child's "blackberry" to compensate for their child's deficits in executive functioning. Children with Asperger's often rely on their parents out of necessity to help them navigate these complicated, confusing, and even alien social aspects of the world that can feel virtually incomprehensible.

When children with Asperger's become adolescents this can prove to be quite a difficult time. On the one hand, they may struggle with the developmental pull to "grow up," to develop a sense of autonomy and self-definition that is age appropriate with their peer group. At the same time, because of their difficulties with socialization, executive functioning, and daily living challenges, they are forced to remain dependent on their parents, at least for a longer time than their neurotypical peers. This conflict creates yet another discrepancy for them, the age-appropriate developmental desire for independence with the reality of the need for continued dependence. This pull can feel irreconcilable and leave the adolescent with Asperger's and the parents feeling hopeless, depressed, anxious, and guilty.

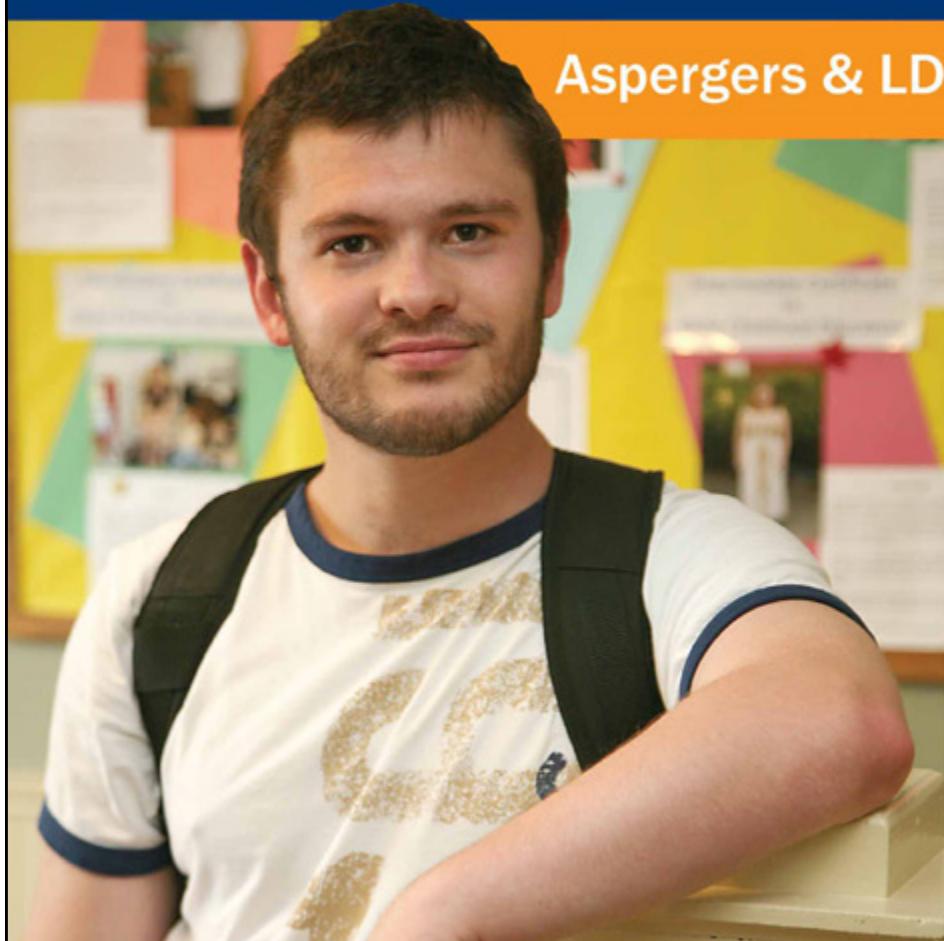
How do we support these adolescents in their quest for independence while acknowledging the reality of the fact that they do require continued dependence on parents, teachers, and therapists, which may not be the case for their neurotypical peers? Below are some suggestions and guidelines that I have found to be helpful in working with this age group and their parents.

Acknowledge the problem - Understanding that the storminess, moodiness, anger, and confusion are actually a normal part of

see *Selfhood* on page 24

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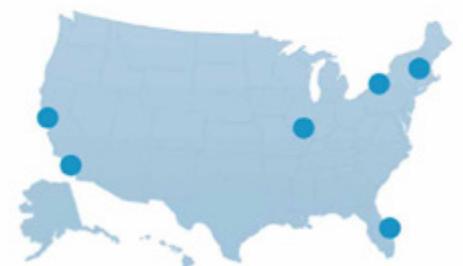
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PEERS: A Parent-Supported Evidence-Based Social Skills Intervention for Adolescents with ASD

By **Karina G. Campos, PsyD**
Clinical Psychologist
NYU Child Study Center

Martin is a 14 year-old boy who has recently starting expressing increased levels of anxiety, particularly about his impending transition into high school starting this fall. Martin was diagnosed with ASD as a younger child and finding a place among his peers has always been an obstacle. Although he has one friend he occasionally spends time with—mainly by playing video games and exchanging ideas about shared interests—he often complains that he does not have many friends at school and that he is not very much liked by his peers. Kids at school have previously called him “weird” and have not readily invited him into their groups or cliques. Distressed that he will continue to feel this way in high school, Martin is beginning to shut down and avoid many of the daily school social interactions. His parents are concerned that his ostracization will persist and, as a result, he will feel increasingly down and insecure about his relationships and identity.

A misconception exists whereby, because individuals with Autism Spectrum Disorder (ASD) are challenged in the area of social development and skills, they do



Karina G. Campos, PsyD

not need socialization and friendships (Sicile-Kira & Sicile-Kira, 2012). People with ASD are indeed more socially isolated, but it is often not out of their own personal doing or desire. They will frequently express wanting to befriend others, and can experience intense disappointment when they are having difficulty doing so.

This appears to especially be the case for those individuals with higher functioning and cognitive abilities who often have a better understanding of their inabilities (Grynszpan et al., 2011; Tse, Strulovitch, Tagalakis, Meng & Fombonne, 2007).

The capacity to establish lasting friendships emerges as critical in the middle and high school years when young people increasingly rely on their peers, rather than their families, for social support, validation, and feedback concerning their burgeoning identities (Mitchell, Regehr, Reaume & Feldman, 2010). Typically developing children usually learn via natural exposure and observation, as well as from specific feedback from their parents, teachers and peers about what constitutes appropriate social skills and good friendship behavior. Since children with ASD have difficulty naturally picking on these skills from their daily environment and interactions, they appear to require much more direct, structured and frequent feedback regarding their social behavior (Laugeson, Frankel, Mogil & Dillon, 2009). Thus, making and sustaining friendships often continue to evolve as common areas of struggle for young people with ASD (Laugeson, Frankel, Gantman, Dillon & Mogil, 2012).

Specific social deficits in persons with ASD often involve “poor social communication, impaired social cognition and a lack

of understanding of social cues” (Laugeson et al., 2012, p. 1025). That is, these young people will have: trouble engaging in reciprocal conversation, including taking turns and flexibly changing topics (Klin & Volkmar, 2003); problems with understanding and expressing emotions and empathizing with others’ feelings (Krasney, Williams, Provencal & Ozonoff, 2003); and a strained understanding and ability to pick up on nonverbal and subtler forms of communication—for example, changes in voice inflections and gesturing (Weiss & Harris, 2001).

As children enter adolescence and the complexity of social communication expands with the pressure to fit in and be accepted, deficits in the aforementioned areas tend to become even more pronounced in these young individuals with ASD and to those in contact with them (Tse et al., 2007). Unsurprisingly, perhaps, this commonly results in peer rejection and subsequent feelings of loneliness, depression, anxiety, and isolation (Bauminger & Kasari, 2000). As adolescents progress into adulthood, these social complications can permeate other important social areas of life, including the ability to navigate college, dating and seeking and maintaining employment (Mitchell et al., 2010). Given that social difficulties continue on into

see *PEERS* on page 28

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Video Games and Kids – How Much is Too Much?

By Paul Weigle, MD
Psychiatrist and Medical Staff President
Natchaug Hospital

Although video games have been a part of American culture for over 40 years, their influence in the lives of youth has grown exponentially in recent years, particularly for those on the Autism Spectrum. The Kaiser Family Survey found that, between 2000 and 2010, the average amount of time that 8-18 year olds spend playing video games quadrupled to an average of one hour per day for girls and two hours per day for boys. Those whose parents did not set rules on how much they are allowed to play video games spend twice as much time doing so. Evidence confirms that children on the Autism Spectrum spend twice as much time playing video games as their typically developing peers. Video games have come to dominate the free time of many autistic children and teens, leading parents and health professionals to wonder about their long-term effects. There are undoubtedly some advantages to youth engaging in this hobby. When kids are busy playing video games, they are typically content, physically safe, and don't appear to require much parental attention. Video games can enhance eye-hand coordination and visual attentions skills, and educational video games can be effective teaching tools.



Paul Weigle, MD

However, a growing body of scientific research confirms what parents and mental health professionals have long suspected; that too much gaming can be a serious detriment to our children's health.

For example, numerous studies indicate a negative correlation between time spent playing video games and academic success. In other words, the more kids play on their Xbox or the Nintendo, the less likely they are to earn good grades. The reasons

for this are complex, but the primary effect appears to be that excessive video game habits displace activities with academic value and those that teach patience and delayed gratification, such as reading for enjoyment or devoting adequate time to homework. In my psychiatric practice, I often care for youth who are able to perform well on their schoolwork at school, where video games are not a distraction. However when these youth are at home they are so motivated to play video games that they consistently fail to complete homework. This is particularly evident in the case of children who performed well academically until they were given a computer or video game console, after which their grades quickly deteriorated. Some research evidence indicates that playing video games excessively over months may weaken a child's academic skills, particularly the ability to concentrate.

Video gaming can also interfere with a child's sleep habits, particularly if played in a child's bedroom or before bed. Access to video games in the bedroom is strongly associated with inadequate sleep, which can in turn lead to problems with learning, memory, depression, and hyperactivity. Children on the Autism Spectrum are particularly vulnerable to this effect, and are more likely to have behavioral problems if they have a video game console in their bedroom, especially those who have no consistent rules on how much they are al-

lowed to play. Playing video games before bed also significantly increases the amount of time it takes a child to fall asleep, partly because youth often resist turning the game off when instructed, but also because the activity is mentally stimulating and promotes wakefulness. I frequently evaluate children who habitually play handheld video games (on a phone, tablet or Nintendo DS) in bed at night, leading to severe sleep problems which can only be reversed after parents confiscate these devices at bedtime.

In the wake of an increasing number of school shootings such as the tragedy at Sandy Hook, there is a significant concern about the effects violent video games play on vulnerable youth. Research reassures us that most youth who play violent video games do not go on to act out violently. However, younger, impressionable, or unsympathetic children who play violent video games excessively are at risk to develop more aggressive thoughts and behavior problems over time. Aggressive youth tend to prefer violent video games and play more, which can lead to more aggressive thoughts in a harmful cycle.

Can video games be addictive? Although most children and teens play video games in moderation, some habitually spend excessive time playing, causing significant problems in their lives. Video game addiction is not yet an official psychiatric

see *Video Games* on page 30



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Autism Treatment: Addressing the Changes and Challenges

**By Christopher Dennis, MD, MBA, FAPA
Chief Medical Officer, Commercial Division
ValueOptions, Inc.**

This past March, it became clearer than ever that the scope of autism is changing. With new estimates from the Centers for Disease Control and Prevention (CDC) identifying that 1 in 68 children in the U.S. are now affected by autism, a nationwide conversation ignited on how to address the pervasiveness of a disorder with no verified cause and no known cure.

Of course, this same conversation has long been going on within the autism community, where prevalence exists not as statistics, but as people—more specifically, our children, our students and our patients. Though autism is the fastest-growing developmental disability in the U.S., it currently receives about 5 percent of the research funding of many less prevalent childhood diseases (Autism Speaks, n.d.).

The simple logistical demands of obtaining autism treatment are astounding, particularly for working parents: more than 50 percent of caregivers report the need to reduce or stop work entirely, while more than 25 percent report spending more than 10 hours a week to provide or coordinate special care for their child (Kogan, Strickland, Blumberg, Singh, Perrin & van Dyck, 2008). Another 33 percent of caregivers



Christopher Dennis, MD, MBA, FAPA

report financial burdens related to autism health care costs—in fact, working mothers forfeit anywhere from \$3,000 to \$5,000 in lost productivity each year (Rich, 2011). When you consider that autism costs families an annual average of \$60,000 (Autism Speaks, n.d.), any reduction in income can be devastating to both the continuation of

treatment and the family budget as a whole.

Even caregivers insecure financial situations encounter enormous psychological demands. Families of children with autism experience significant levels of stress and exhaustion, incur more parental medical issues and expenses (Rich, 2011), and have higher rates of divorce.

Autism has remained a challenge for families largely because the quality of autism assessment and diagnosis is extremely variable and often poor, while the quality of autism treatment is often non-specific and ineffective. So how are we working to change this?

Modifications in Autism Diagnosis

One of the major concerns of autism treatment has been in ensuring treatment is accurate from the onset, which means examining our historical diagnosis of autism and adapting it to present day needs.

Previously, patients would have received an individual autism-related diagnosis—autistic disorder, Asperger's disorder, childhood disintegrative disorder or pervasive developmental disorder—but researchers found these diagnoses were inconsistently interpreted and applied. For some patients, this resulted in a less clear understanding of the individual case, and ultimately, a less effective treatment plan.

The American Psychiatric Association (APA) addressed these concerns with the

latest update of the *Diagnostic and Statistical Manual of Mental Disorders*, DSM-5, by rolling these individual disorders into a single diagnosis called autism spectrum disorder (ASD). This modification is meant to provide patients with a more consistent—and in some cases, an earlier—diagnosis. As the ASD diagnosis includes original significant diagnostic criteria, children identified with an autism disorder before the introduction of DSM-5 will not need to be reevaluated unless there is a determined clinical need.

An ASD diagnosis now requires deficits in two core domains: social communication and interaction (a lack of interest in peers, for instance, or difficulty displaying nonverbal communication cues such as facial expressions); and restricted, repetitive behavior patterns (such as developing an inflexible routine, or responding adversely to certain materials or sounds). As autism-related symptoms vary in intensity from person to person, ASD is classified into three levels of severity based on the amount of required support.

Additionally, DSM-5 also introduced the diagnosis of social pragmatic communication disorder, which is given to children who experience difficulties in social communication and interactions, but who do not display the restricted and repetitive behavior patterns associated with autism. While not

see Treatment on page 32

Co-Occurring from page 1

include tuberous sclerosis, fragile X, neurofibromatosis, Angelman's, Prader Willi, Williams syndrome, Down's Syndrome, and 22q11 syndromes, including Velocardiofacial and DiGeorge Syndrome. Currently, biological interventions directed at some of these identified genetic mutations are underway. The other advantage of genetic testing in ASD includes evaluating risk for other medical conditions associated with that same genetic disorder as well as guidance for family members considering having children. While it is beyond the scope of this article to review associated medical conditions for each of these disorders, and others not listed, it is clear that early identification of these disorders permits rapid evaluation and treatment of potentially serious conditions that may be associated with these alleles, including seizures, cardiovascular defects, and ophthalmologic disease, amongst others.

Psychiatric Comorbidity

Given the broad inter-individual differences with respect to the numerous domains in the diagnosis of Autism Spectrum Disorder, it continues to be challenging in drawing a clear boundary between symptoms that exist as the direct result of ASD and those stemming from other neuropsychiatric disorders. This is not at all surprising as most of these conditions are syndromes with some overlapping symptoms – not at all atypical for medical conditions. This is reflected in the new DSM-5 criteria which now permit for the diagnosing of other psychiatric disorders, along



Russell H. Tobe, MD

with ASD. That brings a clear advantage in planning treatment of impairing symptoms associated with common ASD comorbidities. However, it also brings with it the possibility for polypharmacy. Generally I apply four rules of thumb when approaching medication treatment of co-occurring illness in ASD:

1. Individuals with ASD are more likely to respond to pharmacological and other interventions when co-occurring symptoms form a constellation that closely approximates the standard diagnostic criteria for a disorder for which the medications are indicated.

2. Individuals with ASD may have more challenges in managing medication side effects. This may be related to difficulty in communicating those side effects as well as individual differences in medication metabolism
3. Individuals with ASD may respond to low doses of medicine quite nicely
4. Individuals with ASD who respond to low doses of medicine do not necessarily respond to higher doses and may even do worse

Attention-Deficit/Hyperactivity Disorder

Attention-Deficit/Hyperactivity Disorder (ADHD) is commonly comorbid with ASD. Attentional symptoms and hyperactivity were also amongst the first symptoms described (Kanner, 1943). Interestingly, until recently, the DSM did permit individuals with ASD to receive a diagnosis of Attention-Deficit/Hyperactivity Disorder (ADHD) (APA, 2000; APA, 2013). This was largely related to a still ongoing debate about whether ADHD and ASD are truly separate conditions or a part of a separate subgroup of disorders that share both features. Despite this debate, rates of ADHD symptoms in individuals with ASD are high; it is estimated that 20-50% of individuals with ASD can independently meet ADHD diagnostic criteria (depending upon which specific ASD population is being studied) (Hanson 2013).

While joint attention (one's ability to engage in a shared area of focus with another individual) is best managed with behavioral and educational intervention, treatment of

“classic” ADHD symptoms such as sustained attention in the context of ASD with stimulant medications may be as effective as treatment in individuals without ASD (Kylkylo, 2012). However, rates of medication discontinuation due to side effects are higher relative to treatment of ADHD in individuals without ASD (RUPP, 2005). Other medication interventions such as atomoxetine have also been shown to be helpful in treatment of ADHD symptoms in the context of ASD (Harferterkamp, 2012).

Obsessive-Compulsive Disorder

Rates of Obsessive-Compulsive Disorder (OCD) have been reported to be as high as 37% in ASD (Leyfer, 2006). Given that restricted and repetitive patterns of behavior (such as inflexible adherence to routine or fixated interests) are one of the two major symptom domains in DSM-5 ASD diagnostic criteria, clarifying a diagnosis of OCD in this context can be challenging. This is particularly challenging if language limitations impair the ability of an individual to outline intrusive and irrational thoughts that are common in OCD. Symptoms of OCD (such as intrusive thoughts of contamination leading to repetitive hand-washing routines) can occur within the context of ASD and may be responsive to medication intervention. However, repetitive and restrictive behaviors are significantly more common in ASD and the effectiveness of medications in their treatment is less clear. Prior studies of selective serotonin reuptake inhibitors targeting these repetitive and restrictive

see Co-Occurring on page 27

Addressing the Need for a Behavioral Medicine Approach for Children with ASD

By Michael J. Cameron, PhD, BCBA-D
Chief Clinical Officer
Pacific Child and Family Associates

When a child with autism spectrum disorder enters a doctor's office, are they being treated with the same care and attention as a child not on the spectrum?

In many cases, going to the doctor's office can be a daunting experience. It can be frustrating for families to spend the time and energy to get medical help for an ongoing issue, like gastrointestinal problems, only to be told "it's just behavioral and we can't help."

Contrary to what some in the medical profession might believe, these issues are real for families. According to research from the University of California:

- 55% of children with autism have a sleep disturbance
- 45% of children with autism have a gastrointestinal disturbance
- 10% to 60% of children with autism have epilepsy
- 70% of children with autism have a co-morbid psychiatric disorder such as an anxiety disorder



Michael J. Cameron, PhD, BCBA-D

(Statistics from Daniel Geschwind: Program in Neurogenetics, Department of Neurology, Center for Autism Research and Treatment, Semel Institute, David Geffen School of Medicine, University of California)

Although there's a statistical concurrence between many secondary conditions and autism, the dangerous linear thinking in the medical community still exists. When a doctor's reflexive response is "it's autism, therefore it's behavioral and not a medical issue," they do a disservice to

the child and his or her family. The family leaves feeling frustrated and hopeless, and the patient is no better off.

Towards a Behavioral Medicine Approach

In contrast to the medical treatment that many children on the spectrum experience, a behavioral medicine approach allows medical professionals to uncover the true causes of disturbances and find solutions that work for families. The goal is to promote health in order to produce good behavior and learning outcomes and promote behavior change to produce health changes, not just sweep the possibility of a health diagnosis away simply because ASD is involved.

By using an integrated knowledge from multiple sciences, we're able to bring that knowledge to bear on the health issues of those with autism spectrum disorder. The techniques bridge behavioral and biomedical sciences in order to reach solutions that help children and families cope.

The Case of Alex

Alex, a boy on the ASD spectrum, had uncontrolled emesis. His regular vomiting made it difficult for him to be accepted by his peer group at school, and at home his family dreaded mealtime and constant clean up. He was non-verbal, so he was unable to report his discomfort.

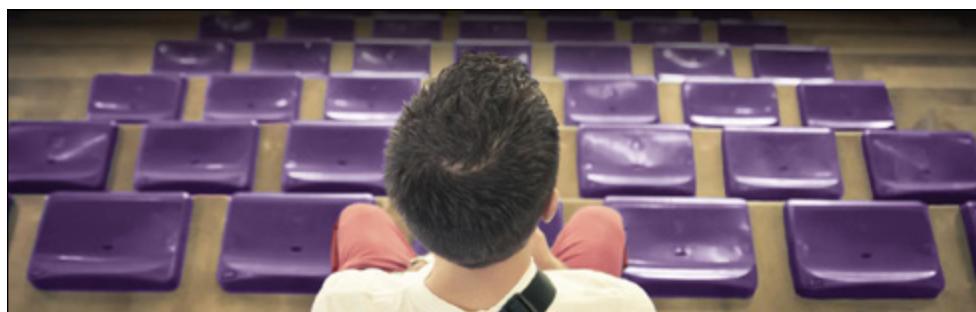
After being informed of what was a behavior problem by the medical community, his mother referred him to my clinical team and we used a "scatter plot" to identify the commonalities in his emesis incidents. We took a computational behavioral medicine approach and systematically excluded and included foods to identify what might be causing the constant emesis.

Through a series of changes, we discovered that Alex wasn't vomiting on purpose – as had previously been suggested. He had a reaction to histamine-rich foods which were then eliminated from his diet. When the offending foods were gone, his emesis disappeared as well.

The Next Steps for the Medical Community

Alex is not alone – there are hundreds of children just like him. By adopting a computational behavior medicine approach for children with ASD, the medical community can start being a true ally to their patients and their families. The prevalence rate of common issues like gastrointestinal disturbance, emesis, disruptions in sleep/wake cycles and psychiatric disorders means that primary care physicians are going to see more and more of this in their patient population. It only makes sense to shift to an interdisciplinary approach.

see Behavioral on page 27



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SAP and Autism at Work

By Bonnie Squires
SpArc Philadelphia

Autism has been very much in the news recently, especially since the report indicating that the level of autism has now been estimated at one in sixty-eight children. And Laura Princiotta, who serves as the CEO of SpArc Philadelphia, a family of organizations which deal with intellectual and physical disabilities in adults, took particular note. The Arc of Philadelphia, under her direction and that of Tanya Regli, executive director of The Arc of Philadelphia, was selected by The Arc of US for a pilot program with SAP Americas, the giant international technology corporation, with headquarters in Newton Square, Pennsylvania, to put forward candidates on the autism spectrum who have technology skills.

Using their network of contacts in the community, the SpArc and Arc officials put out the word and attracted more than a dozen adults on the autism spectrum with technology skills. After an innovative interview process where candidates were able to demonstrate their abilities in non-traditional ways, five candidates were selected to work with a staff member who had been trained by Specialisterne, an organization led by Thorkil Sonne, a Danish man (now re-located to the state of Delaware), who is also the parent of a child with autism.



Bonnie Squires

Sonne devised a four-week training program for SAP candidates using Legos, to work as a team and create a robot. Laura can tell you all about how exciting it was to see the five candidates who usually have difficulty with eye contact and with inter-personal relationships, working together as a team.

The assignment was for the team of five candidates to come up with a theme for their robot and then build it. The team decided to focus on senior citizens, learning that the average intake of pills each day for a senior

is seven. And they were able to design a robot which dispensed the pills on a signal. So the team passed with flying colors.

On May 1, there was a huge launch of the Autism at Work initiative by SAP, working with their partner, Specialist People and Specialisterne, outlining the corporation's commitment to hire people on the autism spectrum and try to guarantee that they would succeed at their jobs.

The SAP national vice president, Jose Velasco, in charge of the Autism at Work initiative, flew in from Texas for the day-long symposium. Jose himself has two young adult children, both on the autism spectrum, although technology is not their major interest. The Special People concept builds on people with autism who have demonstrated skills which can be used in a whole range of ways by a technology company such as SAP. What may be viewed as a weakness by others is viewed as a strength here - like focusing intently on something and doing repetitive work. Several of the five candidates recently hired have earned college degrees.

One of the speakers on May 1 at SAP, Stephen Shore, Ed.D., who is a professor at Adelphi University, had been diagnosed with autism at a young age. Fortunately, his parents had refused to accept the medical professionals' recommendation that he be institutionalized. The parents found a way to communicate with him, and ultimately discovered how bright and talent-

ed he was. Dr. Shore shared his growing up, the way he "focused" on taking things apart and putting them back together again, like watches and bicycles - which led him to a satisfactory job while in high school working at a bicycle repair shop.

SAP and Thorkil Sonne know there is a huge untapped pool of talent around the world - people with autism. Tens of thousands of jobs are not filled for lack of qualified candidates, but SAP, Sonne and The Arc believe that people with autism could fill those jobs, fulfilling their potential and becoming taxpayers.

Anka Wittenberg, SAP Chief Diversity Officer, based in international headquarters in Germany, spoke about the need to devise a new system for hiring perfectly competent employees but whose autism prevents them from going the usual route of interviews and the usual team-work requirement. She explained that the program has been successful for the past two years in India, Ireland, Canada, and in the U.S. SAP in Palo Alto, California, recently "on-boarded" their first hires with autism. Now Newtown Square has joined those ranks.

SAP has committed to hiring people on the autism spectrum as 1% of their workforce around the world by the year 2020. How exciting! And SAP has also trained mentors and buddies on the teams which will support the new hires - such a large number of SAP

see SAP on page 26

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When an ASD Diagnosis Isn't the Whole Answer - A Diagnostic Perspective

By **Kate Palmer, MA, CCP, CAS**
and **Lindsey Pfundstein, BA, AC, QMHP**
GRASP

Receiving a diagnosis of ASD or Asperger's Syndrome can be intense, emotional, and validating for an individual and his/her family. For many, it can begin a journey of self-discovery and understanding concerning one's past experiences. Even in the best-case scenario for an ASD individual to come to terms with his/her strengths and weaknesses, possible sensory integration difficulties, relationship challenges, Executive Functioning issues, and potential employment concerns, it takes a great deal of time and guidance from one's network of support. With the proper treatments, network of support, and guidance, there can be marked improvement in challenging areas which increase independence and quality of life. But, what happens when an ASD diagnosis doesn't demonstrate improvement with an individual's issues and challenges? There are many instances where an ASD diagnosis does not provide the answers many are looking for due to possible misdiagnosis, co-occurring psychological and/or physiological issues, family dynamics, health and nutritional deficits, or meeting academic and residential service needs. Although this may initially seem a daunting issue to raise, solutions exist that



Lindsey Pfundstein, BA, AC, QMHP and Kate Palmer, MA, CCP, CAS

address this issue while still providing the much needed, appropriate care and treatment for individuals diagnosed with ASD or Asperger's Syndrome.

As Directors of GRASP, a nonprofit agency providing services, education, and programming for teens and adults on the

Autism Spectrum and their family support systems, we work with up to 150 ASD individuals per month in our support group program format. As Certified Autism Specialists, and over 30 years combined experience in the Autism and Mental and Behavioral Health fields, we are trained

to recognize behaviors and symptomology consistent with the current criteria set forth by the Diagnostic & Statistical Manual of Mental Disorders (DSM). However, historically speaking, there have always been considerable overlaps of symptomology observed with Autism (Grinker, 2007; Becker, 2012; Frith, 1991; see also Kanner, 1943, Asperger, 1944). Schizophrenia, trauma disorders, PTSD, and Personality Disorders all have similarities to the Autistic Phenotype. And, as the DSM-5 states in the introductory section, "we have come to recognize that the boundaries between disorders are more porous than originally perceived" (American Psychological Association, 2013). This issue has created some concerns as to the best approach to treatment for the population we are trained to support. As we continue to provide services to our members, we have over time noticed some inconsistencies in a number of individual's psychological, physiological, and sociological profiles regarding the known, and accepted, ASD criteria. Following are several specific case examples from our groups can be cited as reference to these inconsistencies.

"John," age 28, attended one of our groups for nearly two years. He had official co-occurring diagnoses of Schizo-Affective Disorder and Asperger's Syndrome. His behavior was consistently disruptive,

see Diagnosis on page 30

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The Importance of Resolving Psychosocial Stages for Adults with ASD Who Have Committed Criminal Acts

By Lino Faccini, PhD
Chief Psychologist
Brooklyn DDSO
NYS OPWDD

A majority of adults with an Autism Spectrum Disorder (ASD) do not commit criminal acts. Those adults with an ASD who do commit criminal acts represent about 1.5% of all individuals with an ASD (Ghazziudin & Ghazziudin 1991) to 2.3% of all individuals with an ASD in special forensic hospitals in the United Kingdom (Scragg & Shah, 1994). These adults with an ASD are considered to have autism-based deficits (Baren-Cohen, 1995; Howling, 1997; O'Brien, 2002) or psychopathology (Palermo, 2004) that contribute to the commission of the criminal acts. Also, Eriksonian Psychosocial deficits have been suggested as another set of factors that mediate the connection between an ASD and criminality (Faccini, 2014). This article presents the developmental framework of "reconstructive therapy" and discusses its need in regard to therapy with adults with a high functioning ASD and criminal acts.

Adults with an ASD face the same stressors and challenges of resolving the most basic of human developmental milestones. Not only do adults with an ASD try



Lino Faccini, PhD

to positively negotiate psychosocial tasks, as identified by Gilson 1987, but also need to resolve essential Eriksonian Psychosocial stages to develop a substantial quality of life. Gilson (1987) identified 14 psychosocial milestones that an individual with an Intellectual Disability or an ASD may encounter as they age. In encountering these "milestones" the person would undergo experiences that would stress their abili-

ties and own self-concept. Essential psychosocial milestones, as defined by Gilson (1987) encompass the following: an individual's symptoms first being diagnosed as consistent with an Intellectual Disability (ID) or ASD, dealing with the birth of siblings, commencing school, dealing with adolescence, puberty, sexuality, and having one's sibling's development and accomplishments surpass one's own. Additionally, finishing one's schooling and education, coping with an out-of-home-placement, the aging of one's parents, possible loss of staff/friends/peers, and the development of medical illness and even mental illness are also identified as stressors. Other stressors that a person with an ID or ASD may encounter includes a higher risk of one's own victimization, social stigma, possible trauma and even the substantial stress of congregate living.

Many will notice that the developmental milestones identified by Gilson (1987) are also those that many of us must negotiate throughout our lives. However, there are another set of developmental tasks, as identified by Erik Erikson, that are as basic to the developmental of a coherent sense of self, and a fundamentally satisfying life. These developmental stages are identified as the development of a sense of self-value, autonomy, pride, identity, intimacy etc. According to Dr. Jerome Schulte (personal

communication, 2007), the developer of reconstructive therapy, "within each phase of therapy, the individual is presented with contradictory 'forces' that pull at the person. The goal is to withstand, negotiate and personally resolve these contradictory forces towards personal growth." A positive resolution of these stages would contribute to a sense of positive self-worth, trust in oneself to manage one's life as well as trust of others and that goodness in one's life can last. In addition to these tasks are also those involving taking initiative in engaging in activities that add meaning to one's life, developing pride in one's accomplishments, a coherent identity, and a capacity for closeness and intimacy with others. However, their substantial negative resolution contributes to a deficient sense of self-value such as a sense of worthlessness, an ongoing sense of doubt in not being able to be oneself, exert self-control, and make important decisions for oneself. Furthermore, one can be nagged by a sense of guilt over inappropriate actions or the lack of relevant actions and left with a sense of inferiority that one cannot direct one's life towards the fulfillment of one's goals, or a good life. It may be at this point in one's development, that a person may resort to manipulation and the control of

see *Criminal Acts* on page 34

Anger from page 1

thoughts and feelings, but they can benefit from relaxation strategies (Taylor & Novaco, 2005). Their angry feelings can also be decreased by introducing the opposite emotion (as suggested by Dialectical Behavioral Therapy, Linehan, 1993). For example, they can engage in an activity that makes them feel good or happy, such as watching a comedy show or playing with pets, to decrease their frustration. These simple techniques could be used preventively, to reduce overall stress level, or as coping strategies. It cannot be expected, however, that all people on the spectrum will use these strategies without being reminded or encouraged. That is why work with the person's support team is crucial.

One anger management strategy is to identify angry thoughts and challenge them. This work is possible with some people with ASD and not possible with others. Cognitions that evoke anger include blaming and labeling others and deeming their behavior to be wrong and intentional. For example, a person with Asperger's syndrome who is sensitive to the smell of cigarette smoke, becomes outraged around smokers. He says to me that he thinks that smokers are "a menace to the society" and that they "always blow smoke in my face, to spite me and to make me sick." Cognitive therapy could be used to help this individual identify and challenge his unhelpful thinking styles, such as black and white thinking, labeling, mind reading, or over-generalizing. It is also helpful to ask a person who is angry at smokers to think about someone they like and respect who also happens to smoke. This technique introduces an element of complexity to the black and white thinking of people on the



Grazyna Kusmierska, PhD

spectrum and helps to decrease their anger with behaviors or attributes of others.

People with ASD have difficulty seeing situations from the perspective of others. My patients with Asperger's often say, "I don't know how people operate." This limited ability to understand what is going on with others, what do they think, and how do they feel, causes a great deal of misunderstanding of the motivation or intentions of others. Interpersonal situations become, therefore, ambiguous and easy to misinterpret. Difficulty reading social cues adds to the confusion and frustration that many people with ASD experience when interacting with others. Anger management with people with ASD needs to focus on improving their perspective-taking and challenging errors that they make while attempting to read minds of others.

There are many other coping strategies that could be used to help people with ASD manage their anger and use its energizing aspect to their advantage. These include assertiveness and problem-solving, strategies that are crucial in modifying anger-evoking situations. Again, working with the system in which the person exists could increase a person's chances to use these skills effectively.

Situation Modification

Any work on behavior modification starts with an assessment. In anger management, anger logs are used to identify situations that anger the person (anger triggers), and specifics of the person's response. Completing anger logs is often difficult for people with ASD and typically staff or family members assist in compiling them. The logs provide information which is used to determine situational and behavioral patterns of anger.

Once the conditions related to the person's anger are identified, work on changing them could start. Counseling could help a person with ASD to find a solution that would modify the situation in order to remove the anger trigger and to advocate for the change needed to stop feeling angry. This aspect of anger management is crucial; It would be unwise to expect any person just to adjust to the existing situation and suppress or otherwise control those angry feelings if the situation continues to trigger that anger. It would also be unwise to expect that all situations could be changed, but many of them need to change in order to prevent triggering the person's anger. Unfortunately, change is difficult. Many people with ASD can and do advocate for their needs,

but many of them also state that caregivers or other authorities dismiss their best efforts to resolve their anger triggers and that they eventually either give up or act out because others "don't listen." Therefore, the clinical work is more useful when anger is conceptualized as resulting from an issue that exists in the system, not necessarily within the individual, and work includes a system, such as a family, program, or residence.

Conclusion

Both coping strategies and situation modification are needed when helping people with ASD to manage anger. Special considerations need to be given to the unique characteristics of people on the spectrum and anger management techniques that are used with the general population need to be modified to utilize strengths and address difficulties related to those characteristics.

Grazyna Kusmierska is a psychologist at Premier HealthCare, a health care practice serving people with intellectual and developmental disabilities and their families throughout New York City. For more information about psychological and other services available through Premier HealthCare, visit YAI.org or call 212-273-6182.

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see *Anger* on page 23

Social Problem Solving: Best Practices for Youth with ASD

By Michael C. Selbst, PhD, BCBA-D and Steven B. Gordon, PhD, ABPP Behavior Therapy Associates

Joey, age 9, has been diagnosed with an Autism Spectrum Disorder (ASD), and due to his high functioning has been mainstreamed into a fourth grade classroom with a shadow. His challenging behaviors typically center on his peer interactions in spite of adequate academic performance. When in a group situation he becomes very argumentative when his ideas are not used, becomes very bossy on the playground, and has run out of the classroom when things do not go his way. Megan, age 14, has also been diagnosed with ASD. She isolates herself from her peers and rarely initiates or responds to greetings. Conversations are almost non-existent unless they are focused on her favorite topics of anime or fashion.

Children with ASD described as above typically have significant social skills impairments and often require direct instruction in order to address these deficits. They often have difficulty in many of the following areas: sharing, handling frustration, controlling their temper, ending arguments calmly, responding to teasing, making/keeping friends, complying with requests. Strong social skills contribute to the initiation and maintenance of positive relationships with others and as a re-



Michael C. Selbst, PhD, BCBA-D

sult contribute to peer acceptance. Social skills impairments, on the other hand, contribute to peer rejection. The ability to get along with peers, therefore, is as important to self-esteem as the ability to meet with academic success in the classroom. This article will review the domain of social skills, the assessment of social skills, the importance of social problem-solving and



Steven B. Gordon, PhD, ABPP

a social skills curriculum which incorporates evidence-based practices to address this very important area.

Social information processing (SIP) is a widely-studied framework for understanding why some children have difficulty getting along with peers. A particularly well-known SIP model developed by Crick and Dodge (1994) describes six stages of

information processing that children cycle through when evaluating a particular social situation: encoding (attending to and encoding the relevant cues), interpreting (making a judgment about what is going on), clarifying goals (deciding what their goal is in the particular situation), generating responses (identifying different behavioral strategies for attaining the decided upon goal), deciding on the response (evaluating the likelihood that each potential strategy will help reach their goal and choosing which strategy to implement), and performing the response (doing the chosen response). It is assumed that the steps outlined above operate in real time and frequently outside of conscious awareness. Numerous studies have shown that unpopular children have deficits at multiple stages of the SIP model. For example, they frequently attend to fewer social cues before deciding on peers' intent, are more likely to assume that peers have acted towards them with hostile intent, are less likely to adopt pro-social goals, are more likely to access aggressive strategies for handling potential conflicts, evaluate aggressive responses more favorably, and are less skillful at enacting assertive and prosocial strategies.

Deficits in social skills are one of the defining characteristics of children with ASD. These impairments manifest in making and keeping friends, communicating feelings

see *Problem Solving on page 31*



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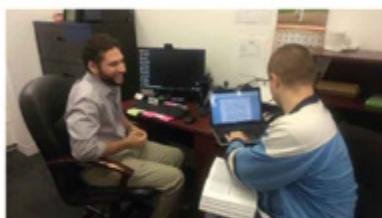
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Unique Collaboration for Youth with ASD

**By Bernadette Murphy Bentley, MPA
Autism Resource Specialist
Tufts Medical Center**

Despite the abundance of supports available today to help young people with Autism Spectrum Disorder (ASD), many youth are still struggling behaviorally. In most cases families do everything they are advised to do by professionals, but their children are still getting suspended from school, causing problems at home, and are unable to participate in many activities of daily life. Some of these youth have been placed in psychiatric hospitalizations, and others have been involved with the juvenile courts.

With up to 70 percent of people with ASD meeting diagnostic criteria for at least one emotional or behavioral disorder, a team at the Floating Hospital for Children at Tufts Medical Center in Boston devised an innovative approach to address the behavioral health needs of this population. In 2011, they proposed the creation of a joint program between the Tufts Divisions of Child Psychiatry and Developmental-Behavioral Pediatrics to integrate care for these youth so that they could experience success in all aspects of their lives.

A private philanthropist saw the merits of the novel endeavor and provided a substantial gift to launch the Tufts Autism Behavioral Consultation (ABC) Program in De-



**The Tufts Autism Behavioral Consultation Team:
Christina Mulé, PhD, NCSP, Eric Goepfert, MD,
Erik von Hahn, MD, and Bernadette Murphy Bentley, MPA**

ember 2012. The philanthropic donation was critical: the unique interdisciplinary and comprehensive nature of the ABC Program requires significant clinician time that is not reimbursed through insurance plans.

The mission of the Tufts ABC Program is to improve the emotional and behavioral functioning of youth ages 6-22 with ASD

at home, in school, and the community through a family-centered, interdisciplinary approach informed by empirically validated behavioral and psychotherapeutic practices. The ABC team includes Erik von Hahn, MD, Developmental-Behavioral Pediatrician; Eric Goepfert, MD, Child/Adolescent Psychiatrist; Christina Mulé, PhD,

NCSP, Fellow in Clinical Psychology; and Bernadette Murphy Bentley, MPA, Autism Resource Specialist.

Focusing on youth with ASD for whom standard medical, therapeutic, and educational treatments have not been working well, the Tufts ABC team collaborates with the family, the school, the pediatrician, in-home and private therapists, and all other providers to determine possible causes for the youth's challenges. Using a modified Multi-System Therapy (MST) approach over three to ten visits, the team then integrates treatment with all of the involved professionals to develop the youth's needed skills and to improve functioning. After a maximum of ten visits, care coordination is returned to the child's community medical providers to carry on integration of treatment.

What does the service look like? One of the key contributions of the Tufts ABC Program is in how the team works with the youth's service providers and provides extensive telephone consultation and case management, in addition to face-to-face meeting time. Although the program always start with the child and his or her family, ABC team appointments can include siblings and grandparents; teachers and school therapists; staff from the Department of Developmental Services and other state programs; educational advocates and

see Collaboration on page 31

Dianne Zager Joins MHNE Board of Directors

**Staff Writer
Autism Spectrum News**

At its June meeting, the Board of Mental Health News Education, Inc. (MHNE), publishers of *Autism Spectrum News* and *Behavioral Health News* elected two new members: Dianne Zager, PhD, Michael C. Koffler Professor in Autism at the Dyson College of Arts and Sciences of Pace University, and Kimberly A. Williams, LMSW, from The Mental Health Association of New York City (MHA-NYC). Ms. Williams' election to the MHNE Board will be announced in the *Behavioral Health News* fall 2014 issue.

Dianne Zager, PhD, is the Michael Koffler Professor in Autism at Pace University in New York City and is president of the International Council for Exceptional Children's Division on Autism and Developmental Disabilities. She founded one of the nation's first college support programs for students with autism, has consulted with school districts across the US to develop high quality educational programs for students with autism, and has over 30 years of experience directing graduate and post-graduate programs to train school personnel in autism. She has worked with students with autism and related learning differences from the early childhood level through postsecondary



Dianne Zager, PhD

education as a special education teacher, administrator, teacher trainer, researcher, and advocate.

Dr. Zager has devoted her career to teaching students with significant disabilities, preparation of school-based professionals, and research in disabilities - most especially autism. She is pleased to join the board and looks forward to being an active and involved board member. As a new member

of the board, she will work to continue the practice of providing evidence-based information that responds to real-life needs of individuals with mental health issues, especially those on the autism spectrum; so that information may be shared among consumers, families, educators, clinicians, and related service providers in the field.

"I am committed to continuing and promoting the philosophy and ideals of Mental Health News Education, Inc., which foster dissemination of scientific research-based practices that have potential to improve services and quality of life. It is my hope that I will continue the tradition of sharing evidence-based information to improve and increase successful community integration and accessibility to needed services."

Dianne's history of service and leadership at the regional and national levels includes serving as President of the Northeastern Educational Research Association and President of the New York State Council for Exceptional Children. She is an advocate for individuals with disabilities and their families. She has served on editorial boards of national and international educational journals, and was founding editor of *Focus on Autism and Other Developmental Disabilities*, currently one of the most widely read autism journals in the U.S. In addition, she has been editor of *The Educational Researcher*. Awards received include the American Academy

of Child and Adolescent Psychiatry Furman Fellowship, Leo Doherty Educational Research Service Award, New York City's Department of Education District 75 Service in Leadership Award, and the Thomas Donlon Award for Educational Leadership and Mentoring from the Northeastern Educational Research Association.

Dr. Zager received her BS in Special Education/Psychology from Boston University, MS in Education from Boston University, and PhD in Educational Research from Hofstra University. The fourth edition of her text, *Autism Spectrum Disorders: Identification, Education, and Treatment* will be published in by Routledge/Taylor & Francis. She recently was senior editor on a text titled, *Educating Students with Autism Spectrum Disorders: Research-Based Principles and Practices* with Michael Wehmeyer and Richard Simpson, published by Routledge/Taylor & Francis. *Educating College Students with Autism*, written with Carol Alpern and Barbara McKeon, was published in 2012.

Dr. Zager has gained national recognition for her work in integrated behavioral experiential teaching, and transition to adulthood and employment for persons with autism. She has presented over 300 papers, keynote addresses, and workshops across the US; and has authored numerous books, chapters, and research papers on topics related to education of students with autism spectrum disorders.

Technology and Autism: The Backbone of Effective Collaboration

By Maria F. Wynne, PhD, BCBA-D
Executive Director
Wynne Solutions LLC

It is an exciting time to be working in the field of autism. The amount of research being conducted on autism diagnosis and treatments now cuts across many disciplines and specialized fields. At major conferences, it is not unusual to hear about breakthroughs from geneticists, psychologists, behaviorists, neurologists and a host of other disciplines. The challenge we face is enormous, but the brainpower that is marshalled on our side is growing exponentially. I can see clear signs of optimism in the collective progress we are making.

What is even more exciting to me is that the insights of researchers in (apparently) unrelated fields is beginning to give insight to the work of others. In my research on the comparative efficacy of different video modeling techniques, for example, I have consulted with neurologists, linguists, audiologists, psychologists, speech pathologists, educators and even parents. Each has added critical insight to my work because each possesses a unique lens through which to help me analyze and process my findings.

I feel fortunate to have the multi-faceted background I do—it gives me a powerful impetus toward collaboration, and a perch from which to see what the future of care may look like. Fifteen years ago,



Maria F. Wynne, PhD, BCBA-D

I began working as a clinician in several cutting-edge therapy programs in private pay homes. Within a year I was supervising those programs and coordinating teams of specialists. From there, I went on to obtain my doctorate in special education and was able to work directly as an educator in special education classrooms, while also teaching at a university. I followed that with over a decade in a large clinical setting, advising parents and overseeing school district programs where speech

therapists, occupational therapists, BCBA's and teachers all worked together.

I have seen the view from the research bench, from a clinician's viewpoint, from the teacher's desk, through a school administrator's eyes and from within a family's home that has been affected by an autism diagnosis.

If we are to look at the future of autism care, it is a future that harnesses the unique contributions and perspectives each one of those players brings to a child's life. Just as in the research world, no one discipline has the answer.

Luckily, we live in a world that is increasingly interconnected through technology. As I bring my practice into the future, I have embraced many of the new and powerful tools that are available online and I have seen how much easier collaboration becomes.

I'd like to discuss what I see as the most promising trends in autism care: 1) the increasing willingness of specialists to collaborate and 2) the power technology can bring to our practices. I will discuss these by giving practical examples.

Collaboration and Flexibility Are the Keys to Success

While I conducted studies in grad school my advisors always told me to stay away from "treatment packages" as we would never know what specific part of the treatment package was working (unless of course we could set appropriate controls). In a per-

fect world, that would be true. And, as BCBA's we should strive to bring the rigor of the scientific approach to everything we do.

But we don't live in a perfect world. We live in a world where budgets are strained, where (in many rural areas) clinical expertise is simply not available, where challenging home environments may have students who have difficulty transitioning into a classroom. As a teacher, I saw this every day. In some cases, I may not have had full control of the process. Often, there were so many interventions happening at once, I was not at all equipped at the time to use my savvy ABA skills that had worked so well in university settings. There were many variables to evaluate and different clinicians or team members tied to specific pieces of an individual student's program. It was not possible to isolate treatments. I had to work with my colleagues and do the best with the data we had, and combine our skills to find consensus (or something close to it) so we could move forward.

I have worked in many settings. I have worked in settings where speech therapists and BCBA's saw each other as rivals. I have worked in settings where parents viewed administrators as enemies that would be threatened or sued. I have also worked in environments where a spirit of flexibility and teamwork were present. These collaborative environments always resulted in bigger gains and observably happier children.

see *Technology on page 29*



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Bringing Autism Insurance Mandates into Compliance with the Affordable Care Act

By Cari Brown, BS
Advocate

When care isn't taken, grave problems can arise when a state's autism insurance mandate is brought into compliance with the ACA. Starting in 2014, "dollar value" limits for essential health benefits are not allowed per the Patient Protection and Affordable Care Act, more frequently called the ACA or "Obamacare." Seeing as how many states with autism insurance mandates have dollar value limits specifically written into the law, a unique and varying process is taking part across the nation.

Some states are allowing insurers and/or individual families deal with this new language. Other states, such as Colorado, are in the process of changing the mandates either by passing new laws or the state's regulatory authority issuing new bulletins or regulations.

Each process can be wrought with problems: insurance companies far too frequently look more toward the immediate bottom line rather than what is most effective treatment course over the long term; families frequently lack the knowledge and resources necessary to effectively appeal their cases; and federal law is open to interpretation. Additionally, when these chang-



Cari Brown, BS

es are brought about, families, clinics, and even advocacy organizations can misunderstand why these changes are happening, and, perhaps more importantly, what can be done about it.

State by State

It's important to note that not every state will need to make changes to their autism

insurance mandate. The qualifying criteria must be met:

1. Obviously, the state must have an autism insurance mandate
2. This mandate must be an essential health benefit in that state. Most of the time, this also means that individual plans will be required to carry this coverage.
3. The autism insurance mandate must have a "dollar value" limit. As will be examined later, exactly what qualifies as a "dollar value" limit is up for debate.

Below is a list of the states that meet these three criteria. As a result, they may experience changes in the future to their autism insurance mandates depending on that state's legislature and regulatory authority:

Arizona, Arkansas, Colorado, Connecticut, Delaware, Illinois, Kentucky, Louisiana, Maine, Missouri, Montana, Nevada, New Hampshire, New Jersey, New Mexico, New York, Rhode Island, Texas, West Virginia, Wisconsin

Case Study of Colorado

Colorado was one of the first states to undertake the process of bringing their au-

tism insurance mandate into compliance with the ACA. Planned years in advance, the Colorado Division of Insurance was given authority to make the conversion in HB 13-1266. Specifically, in the HB 13-1266 the Colorado Division of Insurance was charged to create a rule that would "... require coverage of a number of services of visits that is actuarially equivalent to the dollar limit of the benefit as it existed prior to the effective date of this paragraph."

A study was ordered by the State of Colorado from Wakely Consulting to determine the actuarially equivalent level of visits to the old dollar limits. The table on page 29 details the report's findings.

Initially, the Colorado Division of Insurance intended to use the exact numbers produced by the Wakely Consulting Report in the new regulation. In other words, under the new regulation, children 0-8 years old would receive just 4.4 hours of ABA therapy per week and children 9-19 years old would receive just 1.48 hours of ABA therapy per week. However, under the old dollar limits, children could expect to receive at least 2-4 times as much therapy.

In order to prevent this significant loss, the autism community in Colorado banded together; with a loud voice they communicated together; with a loud voice they

see *Insurance on page 29*

Autism Paradox and the Broken (Special) Education System

By James O. Grundvig
CEO and Founder
Cloudnician LLC

YouTube and the Internet have provided a boost for my 14-year-old autistic son, where his public school has failed to educate him. Technology has empowered Fridrik to explore his curiosity, while expands his intelligence.

Using the 1990s cartoon series *Dexter's Laboratory* and its 78 episodes as an audiographic template - knowing every line of dialogue from every episode - Fridrik taught himself Russian in a week. He compared the Russian dialogue of the characters with the English lines he knew from his mind's database. Never once did he open the American version to compare (www.wikipedia.org/wiki/Dexter's_Laboratory).

Fridrik took the mouse and broke down each Russian word into syllable and then into sounds bites. Over and again, he broke down the Russian sounds into a mathematical form that he understood. By the second week, he laughed at the Russian jokes and humor.

I asked, "Fridrik, do you understand Russian?"

He looked at me with a confident stare, and replied, "Jaaa." For non-verbal Autism Spectrum Disorder (ASD) children, *ja* is easier to say than *yes*.

Over the past couple of years using other



James O. Grundvig

cartoons he saw as a child, Fridrik taught himself Spanish - his mother tested him - and has a working knowledge of Japanese, German, and French. Russian and Japanese are about as far from Western languages as one can get. But when broken down into mathematical bits, they appear easy for him to handle. It also helps having a photographic memory to go with his audiographic database.

Rosetta Stone language program watch out. He and some of his peers don't need you.

A Broken Special Education System

Unlike being force-fed the basics in math, speech, and behavior at a third grade level in his New York City public school program, where Fridrik is one of six ASD children in class, the curious boy has ventured on his own in terms of education. Technology, from the iPad and mobile apps to "tech talk" devices that help them communicate, has been a key enabler for parents and special educators to interact with autistic children today compared to the ASD kids in the 1990s, when the neurological disorder exploded into a full blown epidemic.

For school having an Individual Education Plan (IEP), designed from the top down by the U.S. Department of Education, hasn't helped him or his teachers grasp his deficits or even know about his unique gifts. For the record, Fridrik has had five teachers the past four years in the same Manhattan special ed public school (www.wrightslaw.com/info/iep.index.htm).

With the IEP the only tool for new teachers to learn about Fridrik and his classmates, each fall semester his homework began with the same dumbed-down items: counting coins, reading elementary school books, matching shapes and sizes. Bored out of his mind, he silently protested, tuning out his teacher. No one at school knew how smart he was; nor did they realize he had taught himself to read. Today, his verbal comprehension is at high school level.

In math, he excels making mincemeat of

complex, multi-step problems in seconds. Give him a new math theorem once, and unleash the savant in him. *Rain Man* can't wear his size 11+ shoes. Fridrik has one advantage over kids with Asperger's: he feels empathy and understands other human emotions.

Math at the Speed of Light

Today, Fridrik cranks through math problems that college graduates take for the GMAT exam, answering questions as fast as people watch the colors change on a traffic light.

Part of the problem with his IEP centers on information gleaned from test taking, and test taking only. They appear to be the only metric to measure intelligence in special ed kids. Yes, my son blows through math problems with all types of complexity, but he doesn't test well. That's because another part of his brain - Obsessive Compulsive Disorder (OCD) - prevents him from answering questions.

With the regiment of a drill sergeant, Fridrik needs a track runner's starting gun. In his case, his mother sits next to him and taps his wrist to get him to glance at a problem - a paragraph of words, radical exponents, square roots of fractions squared by fractions, any kind of geometry. In less than a second, he looks up and away. It takes him longer to write the answer than

see *Autism Paradox on page 33*

Autism and Bipolar Disorder

By Jessica Hellings, MD
and Andrea Witwer, PhD
Ohio State University

In individuals with Autism Spectrum Disorder, establishing an additional diagnosis of Bipolar Disorder can be very challenging. In the article below, Dr. Jessica Hellings and Dr. Andrea Witwer of the [Autism Speaks Autism Treatment Network](#) discuss a study they conducted in 2013 that helped identify true bipolar disorder symptoms in individuals with autism. The article outlines some behavior changes that may indicate that something more than ASD is going on with your child.

For those of you not familiar with bipolar disorder, it's a mood disorder once known as "manic depression." Persons with bipolar disorder alternate between a frenzied state known as mania and episodes of depression. While some individuals experience only the manic episodes, many affected individuals rapidly alternate between these two states and experience great irritability.

As with other psychiatric disorders, studies suggest that bipolar disorder may be relatively common among children and adults with autism. Some studies have found that as many as 27 percent of those with autism also have symptoms of bipolar disorder. By contrast, its prevalence in the general population is around 4 percent.



Jessica Hellings, MD

However, we believe that bipolar disorder is mistakenly over-diagnosed in those with autism. In part this is because some of their symptoms can overlap.

It's particularly challenging to diagnose psychiatric disorders in individuals who have language impairments or intellectual disabilities – as do many of those with autism. When diagnosing typically developing children and adults, we can ask them about their emotions and experiences. Yet we know that many individuals with autism have trouble expressing themselves or



Andrea Witwer, PhD

understanding such questions. Even mild language difficulties can make it difficult to relate thoughts and feelings.

For these reasons, traditional methods of assessing psychiatric disorders can be inappropriate for many of those with autism. It's particularly important for the doctor to get to know the individual and his or her family and environment before attempting such a diagnosis.

The challenge is to distinguish symptoms of a mood disturbance from those of autism or attention deficit hyperactivity disorder

(ADHD). ADHD is even more commonly associated with autism. Its symptoms can include extreme frustration and difficulty controlling emotions, as well as hyperactivity, distractibility and impulsivity.

In a [recent study](#)¹ of children with autism (ages 7 to 17), we found that nearly a third had frequent episodes of "elevated mood." Just over 60 percent could be described as "very irritable." Just over half talked excessively. Other common symptoms included excessive activity such as pacing (43 percent), accident proneness (44 percent), distractibility (43 percent) and a tendency to "get in trouble" (47 percent). Sleep disturbances were also common.

The point is that all these behaviors could be considered symptoms of bipolar disorder!

Yet clearly these children did not all have bipolar disorder. In many cases, their "mania" symptoms were, in fact, symptoms of autism. ADHD symptoms also overlap with these behaviors.

In our study, we found we could tease apart the symptoms of true bipolar disorder from those of autism by looking carefully at when the symptoms appeared and how long they lasted. An example would be a teenager with autism who has always been high-energy, happy and socially intrusive. She shouldn't be labeled as manic just because she talks to strangers and makes inappropriate comments. By contrast, let's

see [Bipolar Disorder on page 28](#)

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The Regular Tiger: A Father Deals With His Son's Obsessions

By Jeff Stimpson
Journalist

A little past 10 on a Tuesday night my 16-year-old son Alex jackknifes up in his bed, throws down his blanket, looks at me, raises his arm and moans, "Tiger."

"I don't have it, Alex. Did you have it in here?"

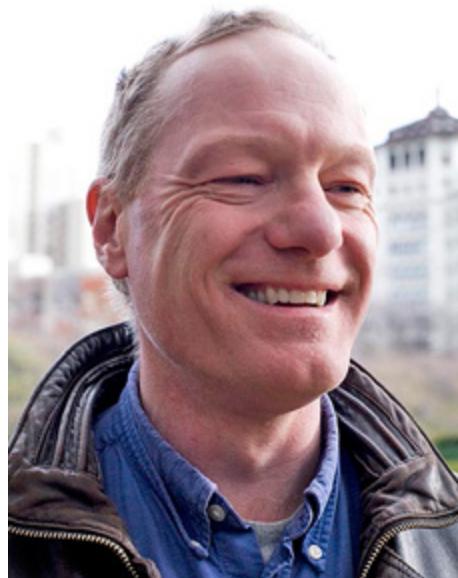
Does he mean the \$5, four-inch tiger or the \$4, four-inch one with his (her?) head turned slightly to the right? Or the little one from the dollar set that also contained a little plastic lion, a jaguar and – ha ha – a zebra. A food chain for a dollar. Sometimes Alex's thing for plastic animals is a real riot.

Sometimes. "Tiger? Aw, tiger."

TIGER! He's on his feet and lifting his mattress to peer under the bed and around the bedframe. It's pushing 11:00 pm. "Aw tiger, tiger. A-ba-ba-ba!" Alex (PDD-NOS) usually uses more words than this.

So do I. "Alex, I don't have it and I don't know where it is. You have to take care of your things, Alex. Where did you last have your tiger?"

"Ti-GER!" He's back out to the living room, where I find my wife Jill shoving her face under the couch and doing her part to erase what's normal in our household. "I've gone through all the regular tigers," she says. We offer them to Alex. This one? This one? "Aw, tiger." Back to the bedroom



Jeff Stimpson

where starts craning under the radiator next to his bed.

"Alex, we will find it tomorrow. You have to go bed now. Here-" I switch on a flashlight and hand it to him. Alex has never used a flashlight. What a good parent to turn this into a teaching moment.

"Tiger..."

Alex has a ton of plastic animals – too many to keep straight, Jill thinks – standing at attention along the edges of almost piece of furniture in our apartment. The two-inch-

long elephant on the edge of the dining room table. The pigs on the hutch, flanked on one side by the lion and on the other by the lioness. The big elephant, the rhino and the turtle. The plastic cat, the plastic salamander and otter and aardvark and chickens. Animals detailed down to the ruffles in the fur and the shine of the eyes as they stare at you.

Mental health? I don't know. All we tell anyone who asks is that somewhere among those animals is Alex's idea of order.

Those with ASD may develop obsessions for several reasons, according to Great Britain's National Autistic Society (www.autism.org.uk/living-with-autism/understanding-behaviour/obsessions-repetitive-behaviours-and-routines.aspx), including:

- Obsessions may provide structure, order and predictability;
- Special interests may be ways to start conversations and interaction; and
- Obsessions may help people relax and feel happy.

Fine but does it have to be when the school bus is coming? On more than one school morning Alex demanded a lost plastic animal (*Rhino!* 'potomos!) minutes before his bus pulled up. "Alex, come on!" "potomos!" In the lobby his hand would shoot up and he'd bolt for the elevator back to our apartment. If we even made it to curb-

side on those rotten mornings, he'd wriggle back off the bus and sometimes lay flat on the actual pavement of East 108th Street.

Repetitive behaviors and restricted interests are among autism's core symptoms, according to a study cited by Autism Speaks (www.autismspeaks.org/what-autism/treatment/treatment-associated-psychiatric-conditions). The symptoms of autism's version of obsessive compulsive disorder often fool therapists and doctors unfamiliar with autism.

"A distinguishing hallmark of OCD is that the compulsive thoughts or behavior cause anxiety," the citation reads. "Persons with autism are not generally bothered by their repetitive behaviors and restricted interests. Just the opposite, these behaviors and interests tend to bring comfort and enjoyment."

To some. Wednesday: I turn on the coffee and wake him up. Maybe he forgot all about it overnight.

"Tiger? Tiger." His arm is up as his eyes still squint with sleep. What'd Jill once say about this? *Life comes to a halt.*

"School, Alex, then tiger. You'll find it when you get home. Mom's working from home today and she'll look for it." Did he toss it out the window, I wonder? I show him the plastic cat, the big tiger, the little tiger, the other big tiger. Wrong. Wrong and wrong. You can't fool him. Can't reason with him, either. "Aw tiger-" I actually get him into his hoodie, out the door and down

see *Obsessions on page 28*

Selfhood from page 11

growing up and adolescence. The surge of hormones, the ever-changing physical bodies, confusion about roles, and the challenging quality of the teenager are actually developmentally appropriate responses to a difficult developmental time. Sometimes parents are surprised when they call me up in a "crisis" because their child is acting more challenging and difficult. My response may be reassuring them that they are acting like a developmentally appropriate 15 year old, and it is in fact good news. Sometimes the Asperger's diagnosis has become the lense through which every behavior is viewed, but the child is also a teenager and tolerating some of the typical adolescent behavior can be quite healthy for the child. The child may also be uncomfortable with the instability of this time so education about puberty and adolescence can be helpful as well.

Encourage independence whenever possible - Even though there may be some real difficulties in social skills and independent life skills, I think it is important to challenge adolescents to be independent, at whatever their level. I always tell parents that the goal is to create a gap that is wide enough for the child to stretch to step over, without falling into a chasm. It may be difficult to teach a teenager with Asperger's to do laundry, help with the dishes, drive a car, take public transportation into the city, or set up a sleepover with a friend or family member, but it will be more worthwhile to expend the effort in teaching him or her how to do these

skills independently rather than doing it for the child. Every child is different so what he or she is capable of will vary depending on age and abilities. Praise and reward independence whenever possible. The sense of self-esteem the child feels when being independent can be quite amazing.

Accept and support failure as part of life

- Individuals with Asperger's often have poor frustration tolerance and difficulty with cognitive flexibility. As mentioned previously, the chasm between strengths and weaknesses can be enormous. A child may wonder, "how come I am such a reading whiz, but I can't seem to figure out what to do during recess?" As a result, the child may shut down and resist taking risks. As parents, teachers, and therapists, we are in a unique position to encourage taking risks, and accept that failure is a natural part of life. Adolescence may be a ripe time to explore this issue, by giving the teenager permission and encouragement to fail at things, as they try and figure out who they are, and what they are good at. I often give families homework that as they sit down around the dinner table they all have to share an example of something they failed at during the day. This allows the adolescent with Asperger's to experience their challenges in a universal way, and learn to persevere despite facing very real challenges.

Find an area where the child can shine

- Individuals with Asperger's tend to have an area of stereotyped interest that they can spend hours reading and talking about. Perhaps the child can get involved in a club

or activity that reflects that interest where he or she can feel like the star. A child who loves a specific topic may be able to create a blog with help of a parent, and write about whatever interests him or her. A child who loves to sing can join a choir, and a child who likes to act can join a drama or improv group. These experiences can help the child feel good about him or herself.

Let the child exercise some autonomy

- Many children with Asperger's are incredibly reliant on parents and caregivers, as they should be. These adults in their lives can literally serve as their lifeline. As they mature, they may be ready to take on some more responsibility with decision making and be ready to exercise more autonomy. The adults in their lives can serve to support that initiative and help them talk through different options, rather than knocking down ideas, or only presenting one option. I know an adolescent boy with Asperger's who literally could not take himself away from his ipad. It provided him with security that he felt he could not give up. After being threatened by his parents that they would take it away altogether, he created a contract between himself, me, and his parents, that outlined appropriate parameters of the use of his ipad. We talked through the pros and cons of each of the clauses until he, I, and his parents were satisfied with the terms and compromises regarding when he could use the device. Rather than have us tell him what to do, in which case he may feel forced and end up rebelling, we gave him the power to exercise his own initiative in this regard, which

he has owned ever since.

Adolescents with Asperger's, like everyone, struggle to develop a sense of identity and feel empowered and successful in their lives. In giving them the space and support to engage in this difficult, yet rewarding journey, we are giving them life skills that will reap benefits across their lifetime.

Shuli Sandler, PsyD, is a clinical psychologist licensed in New York and New Jersey. She received her doctorate from Long Island University - C.W. Post Campus in 2007. She works with children, adolescents, and adults in individual, couple, and family sessions, as well as psychological testing. Among her areas of focus in her practice are children and adolescents with Asperger's Syndrome, as well as those who are experiencing a variety of difficulties in school, and young adults struggling with issues of achieving independence. Dr. Sandler has offices in Spectrum Services, located in midtown Manhattan and Teaneck, New Jersey. She can be reached at shulisandlerpsyd@gmail.com.

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The Lighter Side of the Spectrum ~ A Mom's View

By Carrie Cariello

Remember the Kayak

Carrie Cariello and her husband, Joe, live in New Hampshire. They have five children; four boys and one girl. Their second son, Jack, has autism. (No, their daughter, Rose, is not the youngest. The youngest is Henry, a child born nine months after the urologist canceled Joe's appointment.)

"Saturday. Saturday is Miss Jennifer's wedding."

"I know Jack," I said. "It's going to be on a lake so we have to be extra careful—" "She is a favorite person. To me."

Usually when people say they want our five to come to formal events, I smile and shrug my shoulders and say politely, "Really, don't feel pressure to invite them. It's okay." But inside I'm shrieking, "Are you crazy? WHY WOULD YOU DO THAT?!"

If we do get invited to a wedding *en masse*, I try to make excuses as to why the kids can't make it. "Oh, they're all busy! Baseball and soccer and stuff. Henry joined the Peace Corps so he'll be abroad. But put Joe and I down for the tenderloin. And what kind of cake are you going to have?"

But this time, I made an exception, because Miss Jennifer was getting married.

We met her six years ago at Picture Peo-



Jack with Jennifer on her wedding day

ple, and right away she started to babysit for us. She cleaned up messes and helped potty train Henry and read The Chocolate Surprise during her weekly visits. She was amazing, and eventually, Joe stole her to work at his office.

But she remains a special part of our family, especially for our son Jack.

his shirt untucked anyway.)

As we pulled into the lake house, we gave the talk; the instructions for the day. Keep quiet during the ceremony, do not touch the bride or her dress, and no fingers on the cake.

We did not, however, have the prudence - the foresight - to warn about a kayak.

(Note: this is called foreshadowing. It's meant to keep you excited and engaged throughout my narrative.)

Jack's been really tough for us lately. I'm not even sure how to describe his behavior. He's impulsive and determined and a little belligerent. He has this new independent streak going on, but not a lot of judgment to temper it.

Basically, he's a 10-year old boy with autism.

And he tends to look, well, how shall I put it? He looks very *special* in these situations. I feel bad saying that but it's true. Those of you with non-special children may find that inappropriate, and those of you with special kiddos in your life may be offended, but I don't know any other way to describe it.

For one thing, he can't seem to control his body. The excitement of the day takes over; so much to touch and see and smell

I always want us to look together for these things. I bought the matching plaid shirts and we combed the matching hair, but somehow, somehow, on the ride there, the hair started to stick up in weird places and the plaid shirts crumpled and untucked.

(Except for five-year old Henry. His pants wouldn't button so we had to leave

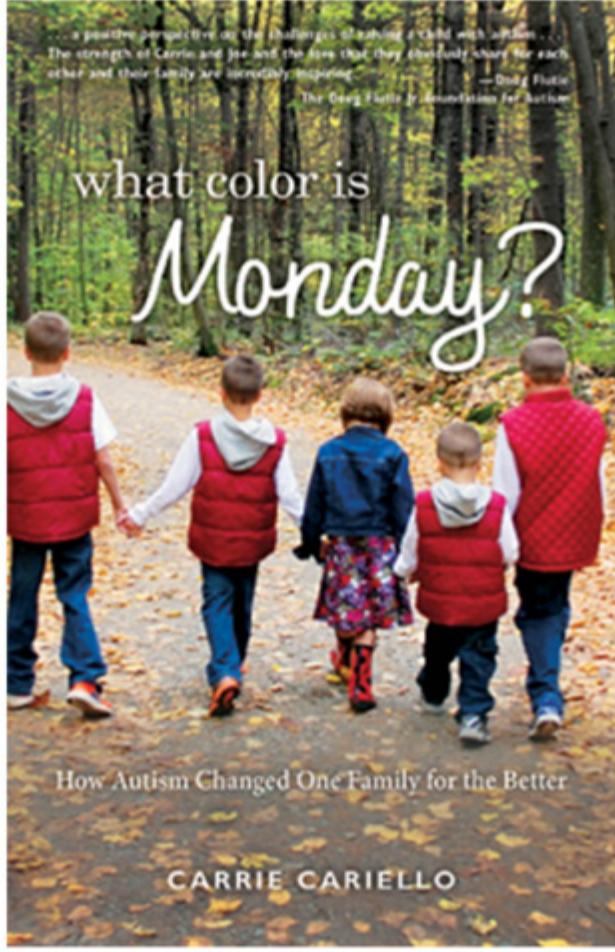
see *Kayak* on page 32



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a positive perspective on the challenges of raising a child with autism... The strength of Carrie and Joe and the love that they abundantly share for each other and their family are incredibly inspiring. —Dana Rubin, The Giving Family Foundation for Autism

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Challenges from page 8

core symptoms of ASD within the scope of the educational professionals' practice. These cases become complicated when more than one disorder is creating adverse educational impact and blur the lines of what educational professionals can address.

For example, consider the dilemma a school team finds themselves in with the following scenario. A teenager diagnosed with ASD presents with multiple challenges that create a barrier to successfully accessing the general education curriculum. He has a hard time getting in assignments due to disorganization, will often day dream in class, does not seek out the help of his instructors and seeks his smart phone video game apps at any opportunity. His grades have plummeted, engagement has dropped significantly and everyone is struggling to compete with the reinforcement the phone provides in all subjects. Complicating this scenario is the fact that this teenager is diagnosed with Bipolar disorder and presents with the behavior of cutting, specifically to his arms, chest and legs. This youth recruits attention from peers by showing the wounds in social settings. As school pressures mount the team notes that he engages in more cutting behavior as well as demonstrating more emotional variability in the school setting. He receives outside therapy to address cutting behavior as well as anxiety and depression. This therapy is cognitive-behavioral in nature and is delivered in tandem with medication interventions from a psychiatrist. In this complicated case there are multiple confounds and issues to work through—not all of which can be attributed solely to ASD. In this case the youth has mental health needs which also adversely impact his education and access to the general education curriculum. An approach designed to address his core deficits

Student-Centered from page 9

learn as opposed to what they will produce, which is often where teachers are tempted to start. To achieve maximum transparency and buy-in for learners, we share the learning goal, or actively create it with the child, at the beginning of the lesson. This especially holds true when dealing with teaching appropriate behavioral skills or social interactions. In addition, the indicators of progress toward the learning goal are determined in collaboration with the child. These indicators serve as signposts for both teachers and learners regarding progress and provide stress reduction.

Within this trusting environment, clarity about goals and indicators are certain and teachers gather evidence of emergent learning. There is no single way to collect formative evidence because formative assessment is not a specific kind of test. For example, teachers can gather ev-

SAP from page 16

employees volunteered to participate that the executives were overwhelmed.

"Jobs" is the magic word these days, and The Arc of Philadelphia is working with the right companies and programs to make sure this happens. Government agencies and officials are also very excited about the program and participated in the May 1 event at SAP. You knew how important this initiative must be when you saw the list of representatives of elected officials

of ASD alone will not suffice.

School teams in a situation like this case are faced with a number of challenges. They are responsible for building skills that are required for success in school including organization, self-advocacy, staying on task and avoiding distractions in order to be engaged with academics. They are also responsible for addressing the social-emotional needs that this young man brings to the table. The outside mental health providers are addressing his cutting and internalizing behaviors both therapeutically and medically. School teams should be encouraged, in situations like this, to develop a collaborative relationship with the child's outside therapists in order to develop a coordinated approach. This might involve securing permission to share information, meeting to exchange treatment plans, developing an understanding of therapeutic approaches and implementing generalizable strategies as appropriate. For example if the therapist is working on developing approaches for him to use when he feels like cutting, the school team can, as appropriate, implement similar strategies, cues and prompts in the school setting. Outside therapeutic and medical information can and should be a part of this child's functional behavior assessment, behavior intervention plan and possibly as part of a health care plan if side effects from medications are an issue. Ongoing communication with all parties can assist with generalization as well as sharing of progress (or lack of) with the interventions that are put in place.

School teams can benefit from specific training to address prevention and intervention strategies for ASDs as well as comorbid mental health conditions. This training may include reviewing or learning specific hallmarks of the disorders, prevention tactics, intervention strategies and oth-

er behavioral supports. Teams need time to not only gather new ideas but to plan and work through how interventions will look in a typical school situation. They can also benefit by ongoing collaboration with outside mental health professionals by reviewing their strategies and considering how they could inform their approach in the school setting. Districts can and should support their instructional staff in ASD issues by including content covering the common comorbidities and their manifestations in children and youth as an ongoing component of professional development.

Discussion

ASD as a disability category and area of special education is unfortunately not a neatly wrapped box into which we can place all children and youth. The needs of this population are highly variable and confounded by the presence of comorbidities. School teams are in a position of decision making when evaluating and finding children and youth eligible for special education under IDEA. They may struggle when determining eligibility based upon the categorical nature of the process. School teams are counseled to consider a best fit approach in order to create eligibility, to consider the MD category if needed and available, and to expand upon the child's needs accurately within the IEP paperwork and plans. In other words, the category should not limit the team from addressing all areas of need within the IEP and behavior plans. School teams will find that interventions designed for children and youth with ASDs may not be sufficient for dealing with mental health issues that are commonly found in this population. Collaboration with outside agency professionals is critical to creating a coordinated approach that can improve service delivery

Would you drive in a car only using the rear-view mirror?

We need to look ahead, to be alert, prepared, and ready to act. A strong home-school allegiance connects the child's behavioral and academic school work with their interests in and concerns for the home and community. Working with the family develops an understanding of the world they live in. The real-world allows for learning what is most important or what really makes the most sense based on practical real-life needs and the implementation of common core standards across different environments. We look to experience a steady and purposeful progression from one level to the next in all areas: Academics; Behavioral Growth; Life Skills; Recreational Skills; Communication and Social Interactions.

Educators frequently are looking for "the" new strategy, a shiny "new" material, or "solutions in a box" to improve learning for the students with ASD for whom

who attended - from Senators Casey and Toomey's offices, to state senators and state representatives.

Governor Jack Markell of Delaware, where Specialisterne is now based, gave an inspiring speech at the opening of the day-long launch. Perhaps most important was the fact that Governor Markell called the Autism at Work initiative at SAP an "employee-powered movement" - not just from the top down. He also talked regarding the best thing about having served as chair of the Council of Governors, when he

was able to set his goal for his year-long term as promoting the hiring of people with disabilities.

And Governor Markell, as well as most of the other speakers, insisted that the hiring of people on the autism spectrum is good business sense and not "charity." He urged that hiring people with nontraditional skills be part of the overall workforce development initiative. Bravo to him and to SAP!

Bonnie Squires is a communications and government relations consultant for SpArc

and generalization of skills. Training is a necessary ongoing process in order to increase instructional staff's knowledge and skills in ASD as well as comorbid conditions. School teams do need to remember that in most cases the ASD label does not adequately explain the intricacies of each child or youth, and to remain open to other factors including mental health needs when engaging in educational planning and service delivery.

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we care so much. I'm just not sure there is anything to purchase. Shifting the focus to looking for strengths, concentrating on soft-skills such as positive attitude, curiosity, following the rules, honesty, and self-direction to name a few and aligning with families may be the key.

Once the changes are implemented the cycle begins. This is what professional development is all about. To learn to teach the skills that will lead to greater independence and a higher quality of life for each of our students by enabling them to be successful. It is a cycle of action and reflection.

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Philadelphia, The Arc of Philadelphia and SpArc Services, the family of organizations which offers programs and services to adults with intellectual and developmental disabilities in the Philadelphia region. She hosts a weekly radio show, "The Marketing of Business," as well as a weekly local cable access television interview show, "Bonnie's Beat" at Radnor Studio 21. She can be reached at her website, www.bonniesquires.com. The Arc of Philadelphia can be reached at 215-229-4550 and the website www.sparcphilly.org.

Co-Occurring from page 14

behaviors have demonstrated mixed results in symptom improvement (Hollander, 2012; King, 2009).

Other Common Co-occurring Disorders

Treatment of other common co-occurring disorders has been less studied rigorously in treatment trials. Major Depressive Disorder and subclinical depressive symptoms in ASD are estimated to occur in approximately 10% and 24%, respectively. Rates of specific phobia vary between 30-45%. Individuals with ASDs may have other anxiety disorders such as generalized anxiety disorder and separation anxiety, at rates in the range of 3 to 12% (Leyfer, 2006). Given the paucity of research on pharmacologic treatment of these disorders within the context of ASD, careful consideration of risks and benefits of medication use should be considered along with clear plans for measuring treatment progress and side effects.

Psychotic Illness

Psychotic illnesses, such as schizophrenia, are characterized by some level of a loss of reality testing. Symptoms may also include, "hearing voices that others don't hear" (hallucinations) or strongly believing things to be true that are not (delusions). Clinicians who are unaccustomed to working with individuals with ASD and are unfamiliar with developmental contributions to their symptoms, particularly for those individuals who also have intellectual disability, may falsely characterize a developmentally typical experience such as an imaginary friend or "self-talk" as symptoms of psychotic illness. Therefore caution is required when considering a diagnosis of psychosis in the context of ASD. However, though epidemiologic data are mixed and limited by

Adults from page 4

treatment for Parkinson's disease, and the researchers referred two more for therapy. This is a possible prevalence of 3 in 20, which is much higher than the 1 in 1,000 rate of Parkinson's in the general population, notes Piven.

However, the results are preliminary, he cautions, and may be affected by the men's medical history. Drugs for epilepsy, which commonly co-occurs with autism, can cause motor deterioration, for example.

Lord notes that many older adults with autism have spent time in institutions, where they might have received strong courses of drugs.

Motor deficits are also a common feature among children with autism, says Stewart Mostofsky, director of the Laboratory for Neurocognitive and Imaging Research at the Kennedy Krieger Institute in Baltimore, who was not involved in the study. Slow movement and rigid gait are more common than tremors, he says.

"It's certainly possible that at least some of these features were present for many, many years, and possibly even in child-

Behavioral from page 15

Establishing clinical decision protocols for systematically examining the causes of common presentations is essential. With protocols in place, physicians can be empowered to assist families and discover the true causes of these disturbances. Enlisting

the lower prevalence of psychotic illness, individuals with ASD can experience psychotic illness; further, several genetic loci associated with ASD (such as 22q11) have also been associated with schizophrenia (Shishido, 2014). But, for now, the clinical significance of these findings remains unclear. Nonetheless, irrespective of diagnosis, principle pharmacologic treatment of psychotic symptoms includes the neuroleptic class of medications. This medication class also includes the only two medications approved by the Food and Drug Administration for any use in ASD (albeit for the specific indication of treatment of irritability and aggression associated with ASD).

In summary, ASD represents a broad phenotype that can vary along numerous dimensions (functional, cognitive, social, etc.). There are also broad inter-individual differences in the types of co-occurring symptoms and disorders. While as many as 70% of individuals may have comorbidity with their ASD (Leyfer, 2006), the ways in which these co-occurring disorders are diagnosed and the populations of individuals with ASD in which they are studied vary. Therefore, at the moment, it may be best for clinicians to apply the standard DSM-5 criteria to symptoms when they appear and to then consider appropriate, evidence-based treatments for disorders when the diagnostic criteria are met. If a co-occurring disorder is identified, individuals with ASD are often more sensitive to medication side effects, may respond to lower doses of medication, and may do no better or even worse at higher doses. Clear pathways for measurement of treatment response and side effects should be outlined prior to medication initiation and adhered to during treatment in order to assist in the ongoing assessment of benefit versus risk while minimizing the probability of escalating doses and polypharmacy.

hood," Mostofsky says.

There may also be an underlying genetic overlap between autism and Parkinson's disease, says Emanuel DiCicco-Bloom, professor of neuroscience at the Robert Wood Johnson Medical School at Rutgers University in New Jersey. A family of chemical messengers called monoamine neurotransmitters, which include serotonin and dopamine, are implicated in both disorders.

Health Registry

Piven and his colleagues are collecting detailed life histories for each of the participants, aiming to understand how the disorder manifests throughout a lifetime. In contrast, Croen's study began with medical records to find and study a large number of adults with autism. She and her colleagues found 2,108 adults with autism enrolled in Kaiser Permanente.

They compared these adults - about 1,000 of them are over 30, and 300 are over 50 - with ten times as many controls matched for age and sex.

Overall, the adults with autism are more

clinical expertise from providers like Pacific Child and Family Associates helps families identify the right treatment plan for each individual. Better yet, they accept insurance plans that help both financially and emotionally for the family, while giving peace of mind in knowing that individuals and families are receiving the highest

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that leads to social deficits.

These individuals were diagnosed with autism only after their dementia set in, he says. "I think when you dig into these databases, you're going to find all this crazy stuff."

For more reports from the 2014 International Meeting for Autism Research, please visit <http://sfari.org/news-and-opinion/conference-news/2014/international-meeting-for-autism-research-2014>.

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Having a frustrating experience at the doctor doesn't have to be the reality for families dealing with ASD.

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quality protocols and dedicated care that those with ASD need.

Until those protocols are in place, families need to be proactive. Be prepared to hear that a child's issues are related to ASD, and not a medical condition. Fuel yourself with questions about what could be the cause, and continue to be your child's advocate.

Bipolar Disorder from page 23

say the same teenager abruptly started going without sleep for days in a row, while having more tantrums than usual. This may represent a true manic episode.

Not surprisingly, the symptoms of bipolar disorder in someone with autism are likely to look different than they would in others. They commonly include “pressured speech” (rapid, loud and virtually nonstop talking), constant pacing, an abrupt decrease in sleep and increased impulsivity leading to aggression.

Psychiatrists often prescribe psychoactive medications to treat bipolar disorder. Lithium is one of the most common treatments. Unfortunately, lithium often produces significant side effects. They can include thirst, excessive drinking and bed wetting, shaky hands and even life-threatening toxicity. This is of particular concern with individuals who have communication difficulties, as they may not be able to alert caregivers to

the side effects they’re experiencing.

Studies suggest that anti-seizure, mood-stabilizing medications such as valproic acid may be a safer treatment for those with autism. We’ve also seen success with a combination of a mood-stabilizing medicine and a low dose of an antipsychotic medication. The atypical antipsychotics risperidone and aripiprazole are both FDA-approved to treat irritability in children with autism ages 6 and older. However both tend to produce significant weight gain and diabetes risk. Therefore, their use requires close monitoring. (For further guidance, please see our recent blog on “Behavioral Medication Side Effects.”)

In addition to medication, researchers at our ATN center (Ohio State and Nationwide Children’s Hospital) are evaluating a family treatment intervention that combines education and psychotherapy to help individuals with autism and mood disorders. Early results suggest that this type of intervention decreases mood severity in

children, while improving family interactions and access to appropriate healthcare.

If you or your child has autism and you’re concerned that it may be complicated by a mood disorder such as bipolar disorder, we recommend that you seek assessment from a mental health provider with experience in autism spectrum disorders and co-occurring psychiatric disorders.

Editor’s note: Specialists working within Autism Speaks Autism Treatment Network (www.autismspeaks.org/science/resources-programs/autism-treatment-network/tools-you-can-use/visual-supports) are dedicated to combining cutting-edge research with the delivery of comprehensive “whole person” care for children and teenagers with autism. To find the ATN center nearest you, please visit www.autismspeaks.org/science/resources-programs/autism-treatment-network/where-can-i-find-atn-location. ATN clinicians are also dedicated to sharing their autism expertise with pediatricians and other

medical practitioners in their regions.

This article was originally published on autismspeaks.org and is reprinted with permission. You may view the original article, published May 22, 2014, at www.autismspeaks.org/blog/2014/05/22/mental-health-awareness-month-autism-and-bipolar-disorder.

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Obsessions from page 24

to the lobby where we sit to wait for the bus.

“It is the intensity and duration of a person’s interest in a particular topic, object or collection that marks it out as an obsession,” another Autism Speaks article adds.

Find it tomorrow, mom will look all day, time for school when he snaps, “Aw elevator!” and he’s up and off.

Jill doesn’t seem surprised when we come back through the front door. “Kind of makes you want to die,” she says. Should we scream and yell? Seek help? Who can help Alex understand a connection only

Alex can see?

Moreover, what happens if he does this again tomorrow? The next day? For the rest of his life? It’s a peek at living with an autistic adult who doesn’t, when you get right down to it, have to do a thing he doesn’t want to. Nobody can live like this. “We’re very unhappy with you, Alex,” we say. “Very unhappy.”

He stares. “Tiger? iPad?”

I haven’t lost that much sense as a parent. “There won’t be any iPad, Alex. If you stay home today you will clean your room, do the laundry, wash the floor. We’re very unhappy with you, Alex.”

“Very unhappy with you,” he says.

Jill stays home with him. At my desk at work, I keep thinking how he’s home but if I call to see how he is, no illness is the enemy this time. I don’t call. Instead I rehearse what I’ll say to him tonight: *And you’re going to school tomorrow, aren’t you? ... And tomorrow, school ... The bus is coming in the morning and you’re getting on it.*

What will he reply? Repeat it back, which for some stupid reason I still take to mean agreement? Say, “I’m sorry, I’m sorry?” and pat my arm? Or just more “Tiger”?

No easing of my mind will come until Thursday morning at 7:25 am when he

climbs into that bus. Even then, how will I avoid thinking, *What about the next day?* All I can do is hope he just gets better.

(On Thursday morning Alex goes to school as if nothing happened. On Friday morning, he again refuses to go anywhere near our front door without a plastic animal. He says it’s a chicken but it’s really a rooster.)

Jeff Stimpson’s two books are Alex: The Fathering of a Preemie and Alex the Boy: Episodes From a Family’s Life With Autism. His blog is <http://jeffslife.tripod.com/alextheboy>. Reach him at jeff_stimpson@yahoo.com and on Twitter @jeffslife.

PEERS from page 12

adulthood and across the lifespan and may, in fact, represent a more chronic feature of ASD (Orsmond, Krauss & Seltzer, 2004), it is key that intervention aims to improve social functioning during these formative years prior to adulthood.

Commencing this fall, NYU Child Study Center intends to address these issues by offering the Program for the Education and Enrichment of Relational Skills (PEERS; Laugeson et al., 2009; Laugeson & Frankel, 2010). UCLA developed PEERS over the last few years as an evidence-based social skills group intervention for adolescents presenting with higher functioning ASD. An adaptation of Frankel and Myatt’s (2003) elementary school-aged evidence based Children’s Friendship Training Program (CFT), UCLA’s program has produced promising treatment results and longer-term gains post treatment. The program is unique, not only in light of its strong evidence base and maintenance of gains over time (Mandelberg et al., 2014), but mostly, perhaps, because it incorporates structured parent involvement concurrently alongside the participation of adolescents. As research shows, parents significantly impact their child’s relationships, yet few programs have actively included them in the child’s process (Schohl et al., 2014). Research, including PEERS, indicates that parents’ engaged and consistent involvement in treatment assists adolescents in making longer lasting and meaningful gains. By equipping parents with greater knowledge concerning the trials their child faces, they can learn to socially coach their child by helping him/her locate appropriate friendship networks and employ the skills he/she develops in groups in the outside world; parents can also model and supervise appropriate so-

cial behavior long after the program has ended (Frankel & Myatt, 2003; Schohl et al., 2014). Research has also revealed that PEERS participants demonstrated significant improvements in their knowledge of social skills, including, for example, an overall growth in their frequency of hosting get-togethers with friends (Laugeson et al., 2009). A recent replication study of PEERS has shown that PEERS further improves co-morbid conditions, such as social anxiety (Schohl et al., 2014).

PEERS lasts 14 weeks with weekly sessions that run 90 minutes each. The PEERS curriculum is taught in a small group format using a variety of evidence based methods, including didactic instruction, modeling of appropriate social skills, coaching and feedback regarding the use of newly learned social skills and weekly homework assignments completed by participations with the support and guidance of their parents (Laugeson & Frankel, 2010). A variety of pertinent topics are reviewed as part of the program, such as teaching adolescents how they can choose appropriate friends and discover common interests by exchanging information and using appropriate conversation skills, and how they can more effectively manage conflict with friends as well as experiences of rejection, teasing and bullying (Laugeson & Frankel, 2010). Later modifications to the program include training in: the appropriate use of social media and online safety, and engaging others through suitable humor and learning-strategies for handling rumors and gossip (Laugeson, Frankel, Gantman, Dillion & Mogil, 2011). PEERS has also been expanded to provide social skills intervention to young adults and teachers have directly incorporated it in their classrooms (Laugeson, Ellingsen, Sanderson, Tucci & Bates, 2014).

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If you are interested in learning more about Autism Spectrum Disorder Clinical and Research Program, including PEERS, and other our programs, please contact our Intake Department at (646) 754-5000 or by email at: csc.intake@nyumc.org. You can also contact Dr. Karina G. Campos, directly at (646) 754-4876 or at karina.campos@nyumc.org.

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Technology from page 21**Technology is the Key to Collaboration and Better Results**

I don't think anyone doubts that technology will play a growing role in treatment as we learn to harness our clients' natural attraction to screen-based technology. But we should not overlook the power of technology to dramatically improve the ease and efficiency of providing treatment to children nor its use as a collaborative tool.

Collaboration with tele-therapy - I work in the Pacific Northwest. In many rural areas, there are literally no specialists available to parents. I also get calls from parents in other countries who cannot find well-trained therapists in their home countries. I have found tele-therapy to be the most effective way to address these issues. It is an efficient, cost-effective way to share information and "observe" individuals more often than only with in-vivo sessions. Tele-therapy addresses the access issues many families contend with today, especially with the rising number of diagnoses and the lack of access in many regions to high quality

therapy or to any therapy services at all.

Tele-therapy allows me to check data real-time, see skill acquisition through video clips and Skype sessions, and communicate with all team members essentially at one time. Again, this does not at all replace in-vivo therapy, it just enhances that time between the individual with exceptionalities and his or her therapist.

Tele-therapy is not as hard as it sounds. I use a combination of several online products: Skype (a video conferencing tool), Dropbox (a file sharing tool), and GemIni (an online library of video modeling tools). It may sound complicated, but the power of tools such as those three used together have benefitted all of my clients, regardless of their access to services in the area. With these types of technological tools, we can overcome the geographic barriers to care so many families currently face.

To start, I conduct a full video-conference with the parents to get a full picture of the current therapy program, the home environment and the child's current skill set. I then spend time speaking with the child (when possible) to get a clinical determination of the issues we will be addressing. I speak with whatever other educators or

specialists are working with the child. I also include a heavy dosage of parent education. Finally, I ask the parents to video the child in various situations and share those files via Dropbox.

Once I have determined the best course of action, I use technology to provide a blend of interventions and often work directly with the child or watch her doing various activities with her parents. In the past, I have often wished I could be a "fly on the wall," and with Skype I can be just that—the child often forgets that I am there. I get to observe much more natural interactions than I have been privileged to see in the past.

Finally, after a tele-therapy session, for many of my clients I go online to create a customized video modeling homework session for the child from GemIni's online library of videos. This provides hours of clinically appropriate therapy for the parents and is a great primer for my next session.

Collaboration of community through technology - While working so heavily with online tools, I have come to see how technology has become such a powerful tool for collaboration and data collection. Everyone

who works with one of my tele-therapy clients knows, for example, that she learned the word "cat" through GemIni's videos. This is crucial for generalization. We want to make sure that the client not only says "cat" when she sees the picture of a cat on the computer screen, but that she says "cat" when she sees a real cat in her environment. When we all use the same tool - parents, babysitters, teachers, therapists - we are all on the same page and we all provide multiple learning opportunities throughout the day for her to work on her new skills.

Conclusion

If we are to continue to strive for success in the future, it will be by working as a team and becoming as efficient as possible in the way we use our time and resources. The key to doing that will be collaboration and the effective use of technology. The more I embrace each, the better results I see. In that spirit, I am happy to share my experiences with any of you who have questions, and I am eager to hear what new technologies have helped you provide more focused and efficient care for your clients. You can reach me at maria@wynnesolutions.com.

Grant Recipients from page 4*Autism and Phelan McDermid Syndrome*

Goal: Characterize the clinical features of Phelan McDermid Syndrome compared to idiopathic autism; provide autism-intensive training to medical school students to build a pipeline of knowledgeable, autism-friendly physicians

**Donghui Wei/Dr. Daniele Piomelli:
University of California, Irvine***Endocannabinoid Enhancement of Sociability in Autism-related Mouse Models*

Goal: Develop and test novel therapies for ASD

Undergraduate Summer Research Grants

Nine undergraduate research grants will be awarded to highly-accomplished undergraduate student/mentor teams conducting research in autism genetics, animal mod-

els, language development, vocational training evaluation, imaging, and treatment disparity. "It's critically important to develop the next generation of autism scientists and to provide early training to highly promising young scientists" said ASF president Alison Singer. "This was an extremely impressive group of applicants and we are proud to be able to support so many outstanding young researchers."

"We developed this new funding mechanism so that ASF could help encourage the brightest young scientists to pursue a career in autism research" said ASF co-founder Karen London. "These students are paired with well-established mentors and will work on promising projects that will give them exceptional 'hands-on' experience and pave the way to their own autism research careers."

In its five years of operations, the Autism Science Foundation has funded over \$1.6 million in grants including pre and postdoctoral fellowships, medical school gap year research fellowships, 3-year

The following students were selected for summer 2014 funding:

Student:	University:	Mentor:
Andrea Chu	Boston University	Dr. Helen Tager-Flusberg
Jordan Doman	University of Pittsburgh	Dr. Carla Mazefsky
Molly Johnson	University of Pennsylvania	Dr. David Mandell
Veronica Kang	University of Washington, Seattle	Dr. Sara Jane Webb
Cynthia Peng	Rutgers University	Dr. Emanuel DiCicco-Bloom
Jonathan Raduazzo	Harvard University	Dr. Christopher Cowan
Nicholas Ray	San Diego State University	Dr. Inna Fishman
Sam Tomlinson	Yale University	Dr. James McPartland
Michelle Won	University of Notre Dame	Dr. Joshua Diehl

early career awards, treatment grants, undergraduate summer research funding, research enhancement mini-grants and travel scholarships to enable stakeholders to attend the annual International Meeting for Autism Research (IMFAR).

The Autism Science Foundation (ASF) is a 501(c) (3) public charity. Its mission is to sup-

port autism research by providing funding to scientists and organizations conducting autism research. ASF also provides information about autism to the general public and serves to increase awareness of autism spectrum disorders and the needs of individuals and families affected by autism. To learn more about the Autism Science Foundation or to make a donation visit www.autismsciencefoundation.org.

Insurance from page 22

communicated with the Colorado Division of Insurance that these numbers would represent a 50%-70% reduction in services for children with autism. After many months of deliberation and several public hearings, the Colorado Division of Insurance announced that they were halting the rule making process until a new study could be ordered.

While nothing in HB 13-1266 allowed "a carrier to reduce benefits provided for autism spectrum disorders if a health benefit plan already provides coverage," the Colorado Division of Insurance issued bulletin B 4.71 to provide further clarification. Specifically, B 4.71 stated, "Nothing in this bulletin or in Colorado Insurance Regulation 4-2-47 prohibits a policyholder from requesting or receiving additional ABA therapy above the \$34,000/550 visit minimum from a carrier. This bulletin and Colorado Insurance Regulation 4-2-47 should not be construed as the Division taking a position regarding whether federal law requires carriers to cover medically necessary ABA therapy in excess

Age	Old Limit	Actuarial Equivalent from Wakely Consulting
0-8 years old	\$34,000 per year	550 visits per year*
9-19 years old	\$12,000 per year	185 visits per year* (* each visit lasting 25 minutes)

of the \$34,000/550 visit minimum required by Regulation 4-2-47."

"Dollar Value" Limits

It's being argued by many that any actuarial equivalent is still in violation of the ACA. In an article soon to be published in the George Washington Law Review, author Matthew Thrasher states, "The text of the [ACA] clearly says that limitations on the 'dollar value of benefits' are prohibited. [The ACA] does not say 'dollar amount' or simply 'dollar limit' of benefits. The word 'value' means: 'the amount of money something is worth' or the 'usefulness or importance' of a thing. This concept of determining the 'dollar value of a benefit' is key in

health insurance design and regulation."

Thrasher elaborated further by saying, "The text of the law excludes the possibility of converting dollar amount caps into non-dollar frequency caps because both limit the 'dollar value of benefit.' In fact, frequency limits are designed precisely to restrict the 'dollar value of benefit' as a cost saving measure. Additionally, allowing these limits defeats the purpose of the provision as it does not protect patients or improve the quality of the insurance purchased."

Of course while the Colorado Division of Insurance has been careful to explain that any actuarial equivalent will be a minimum level of treatment required, it is known by families that insurers will treat these as maximums. From there, families will have to appeal, file

complaints through state's regulatory authority, take their cases through litigation, or simply do without the necessary therapy.

Cari Brown's son was diagnosed with Autism just after his second birthday. In order to prevent lost services during the ACA conversion, Cari started a grassroots movement in Colorado. For more information, she can be reached at cari.b.brown@gmail.com or www.celebratesmallstuff.blogspot.com.

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www.centerforautism.com/data/sites/1/press/Affordable_Care_Act_by_state.pdf

Diagnosis from page 17

making a significant amount of subtle noise to create upset within the group. He also repeatedly disobeyed established group guidelines by attempting to discuss off-limits subjects, which he knew would insight other members. Additionally, in each group he attended, he left early, prompting a facilitator to address his escalating behavior. Knowing this behavior was occurring, his parents chose not to remain onsite and were unreachable by phone. "John" is an example of an incorrect diagnosis. Although he had awkward social interactions and intellectual learning disabilities, his Schizo-Affective Disorder, his living situation, and his family dynamics were creating the appearance of ASD without properly meeting the criteria.

"Jane," age 22, attends our groups regularly. She has had both auditory and visual challenges since birth. Because of these specific challenges, she had difficulty academically, in maintaining relationships, and in activities of daily living. Due to her physical disabilities, she required an IEP and needed services from her school district. However, in order to receive these services, she needed to obtain an additional diagnosis justifying the expenditure. A school psychologist gave her an Asperger's Syndrome diagnosis to provide her with necessary academic and residential assistance. Although "Jane" had challenges in particular areas that individuals with ASD share, she did not ultimately meet the current criteria for the diagnosis.

"Bill," age 48, has attended our groups for over eight years. He currently has a co-occurring diagnosis of Schizo-Affective Disorder and Asperger's Syndrome. His parents were WWII survivors; having endured an extremely traumatic experience. After the war, the family moved to the United States to begin a new life. For many years, the family was isolated culturally, linguistically, and socially. His mother comforted herself and "Bill" with

food. Because of his childhood, he became an adult with social issues and weight concerns. This led to his psychological evaluation determining his diagnoses. Although "Bill" showed no signs of developmental delay, rigid interests, self-stimulating behavior or other criteria, he was given an Asperger's Syndrome diagnosis due to the effects of his family system and overlapping symptomology.

Lastly, "Bob," age 31, attended our groups and programs for approximately one year. He had an Asperger's Syndrome diagnosis and presented with several significant physiological ties, speech impediments, and social issues. However, he repeatedly lied to the Facilitators and members and had inconsistent physical issues, meaning the issues varied occurring only part of the time. After several behavioral issues, and considerable, lengthy discussions on our part, we confronted "Bob" with our observations. The story emerged that although he had a speech impediment as a child, he no longer did. Due to his speech issues, he was mocked incessantly by his classmates and, therefore, had difficulty with social interactions. His father was also extremely abusive toward him; his mother seemed to act as if nothing had occurred. His behavior as a teen became erratic, involving property destruction and alcohol abuse, and was consequently diagnosed with Conduct Disorder. He learned that the more disabilities and issues he had, the less he was ultimately responsible for. As a result, he attempted and succeeded in lying to psychological evaluators to gain an Asperger's Syndrome diagnosis. He lived with the ASD diagnosis for over a decade until discovery. He has since been reevaluated and given an ASPD (Anti-Social Personality Disorder) diagnosis. Although he presented with past speech issues, body ties, and social difficulties, his erratic behavior, lying, manipulating, lack of remorse, and lack of repetitive behaviors was not consistent with ASD diagnostic criteria.

Video Games from page 13

diagnosis in the United States as it is in other countries such as China and South Korea; it has only recently been listed as a provisional diagnosis in the DSM-V entitled "Internet Gaming Disorder." However, a great deal of research evidence confirms that 8-12% of young people develop an impairing behavioral addiction to video games. These youth become psychologically dependent on video games to give them an immediate sense of competence, independence, and relatedness (through interaction with video game characters) and to relieve negative moods. However, over time addicted youth feel diminishing competence, independence and relatedness in the real world often leading to decline in mood and depression. Excessive video game play negatively impacts the lives of children in a number of ways, including deteriorating sleep and academics habits as noted above. Overuse of video games often results in decreased face-to-face social contact with peers, which can degrade existing social relationships and skills and ultimately lead to social anxiety. Caring parents often respond by attempting to control the child's video game habit, which is very threatening to a child who has become dependent on the video game habit to meet their psychological needs, resulting in severe

conflict which can impair the parent-child relationship as well.

How can we parents protect our children from the insidious effects of excessive video game play? Although it is important for us to teach our children that too much time playing video games is unhealthy, most children need parents to set firm limits to guide their screen habits. The American Academy of Pediatrics recommends a total screen time (including television, computer, and video game play) of no more than one or two hours per day. This is a healthy but ambitious goal, as it is significantly less than the average amount of screen time the average American youth engages in. Whatever limit parents decide upon, it is vital that they maintain the rules in their household, using rewards or punishments to ensure the child's compliance as needed. In order for parents to adequately supervise their children's media habits, all screens should be left in public areas of the home, not allowed into a child's bedroom. Parental controls can be set on video game consoles (such as the Xbox or PlayStation) which will limit what types of video games will play and can set time limits for game play by the day or week. Details on how to set these controls (which can be locked with a password) can be found with a YouTube search or by calling the console manu-

facturer. If parents significantly restrict the amount of time their child spends on video games, it may create a void in their child's free time. It will be important to help the child to fill that void by encouraging healthier activities, such as reading for enjoyment, social contact with peers, sports or family activities. In order to protect our children from inappropriate content, parents should understand how to use video game ratings system (such as the ESRB) and encourage video games with positive and educational content. Playing video games with our children can be an enjoyable way to understand the game's content and what it means to our children. Finally, it's important for parents to act as a positive role model by monitoring and limiting their own electronic media habits as appropriate.

Although youth who are addicted to video games are in particular need of such limits, those whose access to video games has been abruptly restricted will sometimes threaten their parents or themselves in a desperate attempt to coerce their parents to relent or simply out of despair. In such situations, a parent must act immediately to ensure the safety of their child and themselves. If a parent feels that they cannot effectively enforce limits on their child's excessive video game habits, or if they feel that attempting to do so may

As the DSM-5 states, the descriptions are "essential to improve understanding, reduce stigma, and advance the treatment and eventual cures for these conditions" (American Psychological Association, 2013). But, as the previous examples illustrate, due to overlapping symptomology of diagnoses, an increasing number of individuals are not receiving the proper treatment to assist them in leading more productive lives (Herbert, 2014). Where do we go from here?

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cause their child to act out in an unsafe manner, consultation with a qualified mental health professional is indicated.

For most American youth, video games are an enjoyed in healthy moderation. However, a number of youth, particularly those on the Autism Spectrum, suffer from the effects of excessive play. It is the duty of all parents to protect our children from the dangers of excessive video game play and guide them towards healthy media habits which will last a lifetime.

Paul Weigle, MD, is a Child and Adolescent Psychiatrist and the president of the medical staff at Natchaug Hospital. Dr. Weigle has served on the American Academy of Child and Adolescent Psychiatry's Media Committee since 2002. Since that time he has studied the mental health effects of electronic media habits, and has taught on the topic at numerous national psychiatric meetings, as well as on radio and television. Correspondence for this article can be sent to paul.weigle@hhchealth.org.

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Problem Solving from page 19

appropriately, demonstrating self-control, controlling emotions, solving social problems, managing anger, and generalizing learned social skills across settings. Elliott and Gresham (1991) indicated that social skills are primarily acquired through learning (observation, modeling, rehearsal, & feedback); comprise specific, discrete verbal and nonverbal behaviors; entail both effective and appropriate initiations and responses; maximize social reinforcement; are influenced by characteristics of environment; and that deficits/excesses in social performance can be specified and targeted for intervention. Social skills can be conceptualized as a narrow, discrete response (i.e., initiating a greeting) or as a broader set of skills associated with social problem solving. The former approach results in the generation of an endless list of discrete skills that are assessed for their presence/absence and are then targeted for instruction. Although this approach has an intuitive appeal and is easily understood, the child can easily become dependent on the teacher/parent in order to learn each skill.

An alternative approach focuses on teaching a problem solving model that the child is able to apply independently. Rather than focusing on teaching a specific behavioral skill, the focus is on teaching a social problem solving model that the learner would be able to use as a "tool box." The well-used saying "give a person a fish and she eats for a day but teach her to fish and she eats for a lifetime" is particularly relevant. The social problem solving approach offers the promise of helping the child with ASD to become a better problem solver, thereby promoting greater independence in social situations and throughout life.

After many years of conducting social skills training using the specific skill ap-

proach, the authors have developed a model of social problem solving that uses the easily learned acronym of POWER. The steps of POWER-Solving® include:

- Put problem into words
- Observe feelings
- Work out your goal
- Explore solutions
- Review plan

Each of the five steps of POWER-Solving® has been previously identified as reliably distinguishing between children with emotional/behavioral disorders and psychologically well-adjusted individuals. The ability to "Put problem into words" is critical in order to start the problem solving process. Children with ASD often have difficulties finding the words to identify a problem. Thus, the first step in this approach involves direct training in the use of the rubric "I was... and then..." Upon entering the classroom and finding a peer in his seat Joey immediately pushed the peer in an attempt to get him out of his seat. Through the use of POWER-Solving® Joey was taught to articulate "I was walking into the classroom and then I saw that Billy was in my seat."

The second step of "Observe feelings" was addressed by helping Joey develop a feelings vocabulary (e.g., angry, frustrated, scared, sad) as well as measuring the intensity of these emotions using a scale from one to ten, with a one being "very weak" and a ten being "very strong." Photographs and drawings were used extensively to capitalize on his strong visual skills.

The third step of POWER-Solving®, "Work out your goal?" involves identifying the goal and the motivation to reach the chosen goal. This critical step sets the stage for what follows. The goal must be specific and measurable, consistent with Applied Behavior Analysis (ABA) principles. Joey was

able to identify that his goal consisted of two parts. First, he wanted to get Billy out of his seat and second he wanted him to still be his friend. He reported that his desire to reach this goal was a nine on the ten-point scale.

The fourth step of POWER-Solving® involves "Explore solutions." Socially skilled individuals are able to generate a range of effective solutions but those with impairments are more limited and often apply the same rigid solution over and over again in spite of repeated ineffectiveness. Joey was taught to "brainstorm," which involves generating as many solutions as possible that might reach the stated goal, provided the solution is safe, fair, and effective. Joey was able to identify that approaching Billy and saying "Excuse me but I need to sit in my seat now" would help him to accomplish his goal(s). Behavioral rehearsal, combined with coaching and feedback, helped Joey to become fluent in applying this solution.

The final step of POWER-Solving®, "Review plan," involved Joey reviewing his plan to use this skill the next time the situation presented and to reward himself by saying "I am proud of myself for figuring this out."

POWER-Solving® has been applied successfully in multiple settings such as the classroom, a summer treatment program, clinical settings and home environments. The curriculum is systematic and relies heavily on visual cues and supports. Children are taught *how* to problem-solve first using their "toolbox" (i.e., the five steps of POWER-Solving®). The children are presented with specific unit lessons on each of the five steps of POWER-Solving®. All children have an opportunity to practice each step of POWER-Solving®. After learning each step of POWER, the children have acquired a "toolbox" which they can begin to apply to social situations.

When teaching social skills, it is important to coach the children through behavioral

rehearsal activities to promote skill acquisition, performance, generalization and fluency. Additionally, daily activities reinforce these skills, some of which include designing their own feelings thermometer, developing novel products via group collaboration, and developing a skit to teach a specific skill.

To increase students' performance of the desired skills, use of a token economy may be helpful, whereby points are earned during the day for displaying appropriate behavior, demonstrating a predetermined individualized social behavioral objective and for using the POWER-Solving® steps. At the end of every day, points could be exchanged for a reward. In addition to the direct instructional format, incidental teaching should be used in anticipation of a challenging situation as well as a consequence for failure to use the steps when confronted with a specific problem. An experienced social skills coach, generalization strategies, and a systematic plan to teach and reinforce skills are critical for success.

Please feel free to contact us at Behavior Therapy Associates for more information about best practices for social skills training, as well as information regarding the POWER-Solving curriculum. We can be reached at 732-873-1212, via email msebst@behaviortherapyassociates.com or on website at www.BehaviorTherapyAssociates.com.

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TED-Style Talks from page 6

During the question and answer session at the end of his talk, Mr. Morris shared that his greatest dream is for people with and without autism to become friends, and for all people to have a greater understanding of ASDs.

Rounding out the day's talks was Dr. Paul Offit, Chief of the Division of Infectious Diseases and the Director of the Vaccine Education Center at the Children's Hospital of Philadelphia. Dr. Offit's talk asked, *Is Alternative Medicine Really an Alternative?* He explained that because there is no clear cure for autism right now, people often look to alternative, untested

medicine for answers. Dr. Offit warned the audience to be careful when considering alternative medicine because it is an unregulated industry.

Other topics of ASF's TED-Style Talks included the new "1 in 68" autism prevalence numbers from Dr. Cathy Rice of the CDC, a look at why autism interventions often fail in schools from Dr. David Mandell of the University of Pennsylvania, and a talk on finding autism biomarkers in young babies by Dr. Ami Klin of the Marcus Autism Center at Emory University.

Many of the Day of Learning's attendees were parents who embraced the unique opportunity to hear first-hand from numerous scientists presenting the field's

latest research in understandable manner. Lauren Rimland, a parent of a child with autism, stated, "The speakers were well aware that they were addressing families who might not have the same background or experience as scientists, and they prepared accordingly, using humor and family-friendly language in many instances."

Dr. Connie Anderson, Director of Autism Studies at Towson University, also attended the event. One of Dr. Anderson's favorite parts of the TED-Style Talks was the fact that they were all recorded and uploaded to the Autism Science Foundation's website. She commented, "I have never attended an event where the latest research was shared in such a succinct, understandable and fo-

cused fashion. There's not a single talk that I won't be sharing with my students. And the fact that all of these can be shared with so many makes them much more valuable."

If you were unable to attend this year's Day of Learning, take heart in knowing that the Autism Science Foundation is already planning next year's TED-Style Talks. In the meantime, all of this year's talks can be found at www.autismsciencefoundation.org/TEDstyletalks.

For more information about the Autism Science Foundation or about the TED-Style Talks, please visit www.autismsciencefoundation.org or contact Meredith Gilmer at mgilmer@autismsciencefoundation.org

Collaboration from page 20

IEP team leaders; and any other providers working with the family. The purpose of the meetings is to help ensure that the child's care is not fragmented, and to clarify the goals that the youth and family agree are most important to them.

Families and professionals who have been involved in the ABC Program have reported great satisfaction with it. One guardian said, "From our first meeting, it was clear I now had a team working with me and I was so relieved. I've felt like I've been on my own all of these years and it was like a breath of fresh air to learn about all the resources that are available to our family, and to know that professionals

were going to work together to truly make a difference in my child's life."

A parent whose child was in the program stated, "We have a complex family dynamic, and the ABC team has been able to take the time to troubleshoot difficulties and come up with new approaches for us to try. One of the most impressive parts of the program is that the doctors gave our son the encouragement and a safe place to express angry feelings, which has opened up a whole new level of communication with him."

An in-home therapist said of the program: "Our meetings with the ABC team have enabled us to work together to offer a more comprehensive level of care to our client. I believe that through this innovative collaboration, we have helped the fam-

ily balance the educational, medical, and mental health needs of their child."

With the initial success of the Tufts ABC Program, it was expanded from a monthly clinic to three times a month during the first year. So that a rigorous evaluation of the positive results of the program could be conducted, the ABC team applied for and was awarded a highly competitive two-year grant of \$250,000 in May 2014 from the Office of the Massachusetts Attorney General (AGO). The purpose of the AGO grant is to increase "access to, and measure the benefits of, providing behavioral health services in Massachusetts" and the ABC Program will do so by striving toward three objectives: 1.) to increase health and well-being of patients with

ASD; 2.) to improve quality of care; and 3.) to reduce costs.

The Tufts ABC Program will be expanding further this fall to a twice-weekly clinic to better meet the needs of families. Referrals must come from a youth's current medical provider (pediatrician, psychiatrist, psychologist, etc.) who will be responsible for care coordination after the program is finished. For an ABC intake form or more information, please contact bbentley@tuftsmedicalcenter.org.

Bernadette Murphy Bentley, MPA, is the Autism Resource Specialist/Family Support Coordinator at the Center for Children with Special Needs at Floating Hospital for Children at Tufts Medical Center in Boston.

Treatment from page 14

included under the ASD diagnosis, autism treatment techniques are oftentimes beneficial for children diagnosed with social pragmatic communication disorder.

The impact of DSM-5 on the diagnosis of autism remains closely monitored, particularly in relation to how it might influence autism's rising prevalence.

ABA Treatment

As we continue to strive for a better understanding of autism and how to address it, we know that early and sustained intervention programs currently offer the best hope of improving outcomes for individuals experiencing the disorder.

Over the past several decades, applied behavior analysis (ABA) has steadily gained acceptance for its substantial clinical research and documented effectiveness in improving the developmental challenges often present with autism, and has been endorsed by several state and federal agencies, including the American Psychological Association, the National Institute of Mental Health, and by the U.S. Surgeon General.

ABA treatment methods are designed to modify behaviors by observing and addressing the environment in which a particular behavior takes place, and by using positive reinforcement to strengthen various social and developmental skills. Under the direct supervision of a trained ABA professional, clients typically receive anywhere between 10-25 hours of treatment per week or 26-40 hours if more intensive treatment is required. Treatment hours are increased or decreased according to the client's progress.

Treatment plans address behavioral and

developmental goals specific to the unique needs and abilities of the client, and may include targets such as hygiene, compliance with medical and dental procedures, positive participation in family and community events, or reducing the occurrence of inappropriate speech and physical aggression. Additionally, caregivers are trained on how to promote their child's optimal functioning and behavior outside of a therapy setting.

Studies have shown that ABA therapy techniques produce significant developmental improvements for persons with autism regardless of age, cognitive level or co-occurring conditions, and that children who participate in a meaningful ABA program exhibit greater adaptability, engagement and aptitude—both in the classroom and in the world at large.

Though many children benefit from ABA treatment, obtaining coverage for it still remains a challenge for many families. Presently, 37 states have enacted autism insurance reform laws mandating coverage of autism treatment services for state-regulated insurance plans. However, some state mandates define ASD and ABA as behavioral health benefits, and impose age limits on treatment and monetary caps on autism therapies. The impact of the mental health parity law on these caps is uncertain, and the interpretation by state regulators may vary state by state.

Even the autism community is divided on the approach to legislation. As of this writing, a debate is stirring on Capitol Hill over the renewal of the Combating Autism Act, which is set to expire in September. Advocates of the legislation's renewal argue that since its enactment in 2006, the act has provided more than a billion dollars of funding for programs and research,

and has increased both awareness and treatment options for autism. Meanwhile, opponents of the renewal believe that current legislation has been largely ineffective, and are calling for a total overhaul of the program rather than allocating millions in additional funding.

As the push continues for effective legislation and expanded coverage options, we continue to promote the benefits of ABA treatment, particularly as delays in receiving vital developmental services positions children with autism to become reliant on more comprehensive therapy options as they mature into adulthood.

Opening the Door to Treatment

In my work with ValueOptions, a managed behavioral health care company, I frequently present the business case for making autism coverage a standard part of any company health plan. Autism coverage, I explain, should not be viewed as a "perk," but as a business necessity: with autism rates rising, more employees will require access to treatment options, and businesses that meet this need are positioned to achieve a number of gains.

For one, children who achieve higher levels of functioning have lower overall health care costs (of course, that same argument can be applied to caregivers, who will be less likely to incur the mental and physical health issues as a result of providing non-stop support). Children that are higher functioning also produce better outcomes in school, and require less assistance from their families. This allows employees more time and energy to focus on their work, not to mention a reduction in personal stress, which tends to bleed over into our work relationships. And as vital staff members

won't feel the need to leave for a job that does offer autism coverage, companies can expect to maximize employee retention.

Though the number of children and families facing autism has grown, so has our understanding of the disorder and its challenges. As growing demand delivers improved assessments and better access to high-quality treatment services—and we are working to make sure it will—more children will benefit, and families can spend their time together enjoying life rather than fighting to ensure the quality of it.

Christopher Dennis, MD, MBA, FAPA is Chief Medical Officer of ValueOptions' Commercial Division, a Fellow of the American Psychiatric Association and an assistant professor at St. George's University AIM.

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Kayak from page 25

and do! He stims and grunts and zooms around, yelling out weird phrases he picks up from the lovely and educational Cartoon Network, like, "This is so *disturbing!*"

Trust me when I say that we are not embarrassed by him. If anything, his stimming is part of my background noise, the tympani of my day. But I am mindful that other people *may* or *may not* want their wedding vows punctuated by a ten-year old boy shouting something he heard Sponge Bob Square Pants say.

We got through the ceremony okay. Henry's pants stayed up and our eight-year-old son Charlie dropped the frog he caught just before the music started. Jack rocked a few times but otherwise remained quiet, and tween Joey didn't roll his eyes once. Our six-year old daughter, Rose, stood in awe, as the bride walked down the aisle in her long white gown.

Afterwards, we filed into the reception area to admire the decorations and décor; the bride and groom's initials in bright yellow, flowers tied with ribbons and candles in glass bowls. The personal touches! The details! Weddings like this make mine look as though we got married in a big box store under fluorescent lighting.

There was a little basket full of coasters made from wood, and guests were asked to leave pieces of advice for the newlyweds. I caught a glimpse of what other people wrote, sweet things like *never go to bed angry* and *the couple who prays together stays together*. In his big loopy handwriting, Jack

wrote, "I met your sister Donna today."

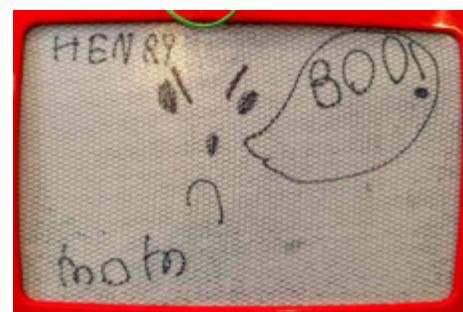
This wouldn't have been so bad, given the circumstances, except her sister's name is Dawn.

And the cake! Please, the cake. The cake was set in the middle of the dance floor during lunch, all three yummy tiers of it. For the rest of the meal we yelled at Jack to get away from it, because nothing says "Congratulations! You're married!" quite like a boy with autism stimming into the wedding cake and knocking it to the floor.

Then there was a wooden bench that the groom made by hand. It was beautiful. It was symbolic of family, strength, and everlasting love, and after lunch the bride's brother announced that everyone should write a special message and sign their name.

On the bench.

Armed with black Sharpies, all five of my kids raced over to the aforementioned bench. But I have no idea what they wrote because I was too scared to look. I just prayed they spelled their own names right and no one drew anything that looked like this:



Henry drew this because he was mad I

wouldn't let him have more Cheez-Its.

When the dances were finished, everyone headed outside to enjoy the beautiful weather. The men took off their ties and loaded kids into paddle boards and canoes for a quick trip around the lake. I sat on the boathouse with Rose in my lap, soaking in the sun and talking about what kind of wedding she'd like to have.

I looked towards shore and saw Jack pulling a kayak off of the sand. "Jack? No buddy, we aren't going to take that out. Those tip really easily." He looked up and nodded, and satisfied that he'd understood my answer, I turned back to Rose.

"So, I don't have a sister but maybe *Daddy* could be my maid of honor?"

"Well, um, usually—"

Mid-sentence, I was interrupted by a high-pitched shriek I'd recognize anywhere. I looked back to the shore to see Jack standing—drenched—in two feet of water, screaming in front of fifty-plus people with the kayak tipped over by his side.

And I was, excuse my language, pissed. *Seeing red* pissed. As in I'd-better-sit-here-for-a-moment-and-collect-myself kind of pissed. I took a deep breath, stood up, and made my way over to him. With one hand on his shoulder, I propelled him onto the sand. "Jack," I whispered-screamed. "You disobeyed me. I am very angry."

(Note: "Whisper-scream" is a tactic I use to appear as though I'm calm (whisper) but I'm really, really mad (scream). It involves screwing your face up like an alien.)

At the end of the reception, after the top of the cake had been preserved for the first

anniversary and the last picture taken, the bride and groom climbed into a rowboat and paddled off into the sunset.

(Watching their silhouettes on the water, I paused for a moment to reflect once more on my own wedding, and how my mother's date at the time, a man named Al, ate the top of my cake on the car ride home. Apparently, Al was hungry.)

The next morning I caught Jack trying to plug the waffle iron in after I told him to wait for my help. I curled my lips around my teeth and hissed, "Remember the KAYAK!" and he jumped back, startled by the memory. "I tipped it over," he remembered sadly.

Huh, I thought to myself. *Maybe he learned something*. Maybe the memory of the kayak sliding out from underneath him and the cold rush of water and wet pants will help keep his impulses at bay. For now, anyway.

That night Joe and I watched the video he took of the bride and groom sailing off on the lake. And we almost fell off the couch laughing. Because standing on the boathouse in the background is none other than Jack himself, white towel clutched around his waist, black dress socks pulled to his bony knees, waving his little heart out to his favorite person in the world.

It was as special as special can be.

"*What Color Is Monday?*" is available on Amazon.com and BarnesandNoble.com. You can also follow Carrie on her weekly blog: www.WhatColorIsMonday.com and Facebook.com/WhatColorIsMonday.

Autism Paradox from page 22

for him to know it. That's because autism impacts the regions of the brain (housed in the front) that produces speech and fine-motor skills.

My favorite math problem he solves: A horizontal line with a second line forming an angle, asking which angle to measure, acute or obtuse. The next normal step to is to take a compass and measure the angle. Not Fridrik. He looks at it and knows instantly to the exact degree the size of the angle: 40, 94, 61, 137, 12, or 154. He has been right every single time. Amazing.

Not knowing how intelligent Fridrik really is or the hidden talent he possesses has hampered his ability to grow within the U.S. education system. It's not a knock on it or New York City's public schools, or even their teachers. Special education simply hasn't adopted for the new strange, counter-intuitive world of children on the spectrum.

Communication Deficit of the School System

With the explosion of autism rates soaring the past two decades from 1-in-2,000 born with ASD to 1-in-68 in a recent CDC study, U.S. schools will continue to be overwhelmed by the epidemic, which has an environmental component (www.cdc.gov/media/releases/2014/p0327-autism-spectrum-disorder.html). "Better diagnosis" cannot explain away the sharp rise of autism incidence rates. That math doesn't add up.

After treating the environmental impact of Fridrik's diagnosis - Pervasive Developmental Disorder (PDD) - with glutathione injections, an assortment of nutrients and vitamins, a year of chelation therapy, and other alternative medicine regimens, in 2009 a research study at Columbia University that uses transcranial Direct Current (tCDC) treatment to bridge signaling impairment accepted Fridrik as one of the patients in the study.

After undergoing a functional magnetic resonance, a 3-hour neuroimaging procedure under sedation, Dr. Harry Schneider (www.harryschneidermd.com/html/autism.html) mapped Fridrik's brain activity as it reacted to external stimuli: music with lyrics, favorite songs, the voice of his mother and father, their voices played backwards. The renderings of 40 MRI slides captured his brain's reactions to each stimulus.

Compiled, the slides showed Fridrik's

reaction to words and music. They told Dr. Schneider that the boy not only comprehended receptive language, but that he had a very active brain. On the slides that showed him deciphering his parents' voices played backwards, the colors of his brain lit up like a Christmas tree. Not all ASD children in the study showed Fridrik's remarkable ability.

For the next five years, "Dr. Harry," as he is called by children and parents, used tCDC treatment on Fridrik to help him read. When he wore the headband with the two sponges that delivered extremely low amperage from a 9-volt battery, Fridrik could read out loud full sentences, albeit speaking slow. When he wasn't being treated during the week, his speech would regress. No doubt, tCDC improved his comprehension. Today he responds to people's questions with one or two words. He also understands the nuances of grammar, such as the subtle difference in pronouns. And although the therapy hasn't spurred Fridrik to speak fully - yet - it did set him on a journey of self-discovery.

For a child who at the age of five years old in 2005, who was totally mute for three years, too many of his early special education staff thought of him as kind of dumb; they continued to test him with the same boring stuff time and again, as special educators have not been able to reach him. What they learned the following year, silent Fridrik put full sentences together with words on a table, arrange them into a sentence to match an image or picture. He constructed the sentences backward; from the objects he saw coming first.

Unfortunately, that information got lost in files when he aged out and transitioned from one public school program to another. So the next special ed class started from scratch.

Music's Autism Paradox

Dr. Harry, who is a linguist, neuroscientist, and speaks several languages, has taken tCDC stimulation therapy on the road to Indiana, North Carolina, Puerto Rico, Brazil, Israel, and parts of Europe. His research discovered something unique in all spectrum children: The region of the brain that receives music is not impacted by autism.

In a peer-reviewed paper *Neural Systems for Speech and Song in Autism*, co-written with Grace Lai, Spiro P. Pantazatos, and Dr. Joy Hirsh ([www.readcube.com/articles/10.1093/](http://www.readcube.com/articles/10.1093/brain/awr335)

[brain/awr335](http://www.readcube.com/articles/10.1093/brain/awr335)), Dr. Schneider stated:

"To investigate this paradox between impaired language and preserved music functions in autism, we combined functional MRI, functional connectivity and diffusion tensor imaging (DTI) to evaluate functional and structural systems sensitive to language and music in low-functioning autistic patients and typically developing age - matched controls."

What does that mean? One day, a mobile app could be developed that would allow a parent or teacher to speak into a smartphone, and on the other side their command would be sung in a lullaby. Instead of the autistic child ignoring the command, as it happens today everywhere, the child would get dressed, sit down for a meal, or go play. More research is needed, but the future looks bright for a new way to communicate with non-verbal children on the spectrum like my son.

Today, Dr. Joy Hirsch, Ph.D., Professor of Psychiatry and Neurobiology, Yale School of Medicine, as head of Yale University's new Brain Functioning Laboratory (<http://fmri.org/team-2/>) has taken Dr. Harry Schneider with her to Yale as a visiting professor, since "His research focuses on autism and the neural circuitry that underlies language disorders."

Brain Signals and Communication Barrier

In the fall of 2012, I attended the annual *Advances in Autism Conference* at Mt. Sinai Hospital's Seaver Autism Center. During the morning presentation, Dr. Timothy Roberts of the Children's Hospital at the University of Pennsylvania, said something that caught my attention: His 15 years of research analyzing the brain waves of children, he told the rapt audience that the signal processing in autistic children was "delayed by 50 milliseconds," or a twentieth of a second.

That was the same 20th of a second delay that Infochimps' CEO Jim Kaskade told me what's called "near real time" in big data databases (http://www.huffingtonpost.com/james-grundvig/big-data_b_2068814.html). For autistic children that delay prevents them from spitting out words. Time and again, I have seen the frustration in Fridrik's eyes as he tried hard to talk, but without a single word coming out.

The words of Timothy P.L. Roberts, PhD, (the Oberkircher Family Chairman in Pedi-

atric Radiology, Vice-chairman, Research Dept. of Radiology at Children's Hospital of Philadelphia, Professor of Radiology at the Perelman School of Medicine, and Adjunct Professor of Linguistics at the University of Pennsylvania) compelled me to learn more about signaling delays.

The following January, I drove Fridrik down to Philadelphia to me with Dr. Roberts in his lab at Children's Hospital. He showed Fridrik and I the radiology lab where he uses the Magnetoencephalography (MEG) imaging machine to measure brain waves and signal processing of autistic children.

In a paper he co-wrote as the lead researcher, *Auditor Magnetic Mismatch Field Latency: A Biomarker for Language Impairment in Autism* (<http://www.ncbi.nlm.nih.gov/pubmed/21392733>), it reads:

"Mounting electrophysiological evidence suggests that deficits in discriminating rapid changes in sound may be associated with impaired speech processing in children suffering from developmental disorders."

From Dr. Harry's transcranial direct current to Dr. Roberts' research on brain wave processing, I see my son's speech deficits in a new light with his super fast ability to compute the most complex math problems.

With one part of Fridrik's brain delayed by 50 milliseconds at a very early age, other parts of his brain developed with incredible results. Like a blind person, whose other senses are heightened due to the lost sight, Fridrik has a gift that Pythagoras of Pythagorean theorem fame might have appreciated.

If Fridrik is the Michael Jordan of math, then he will have to overcome his OCD as much as the broken U.S. education system will have to change. When that happens, I suspect many other bright children, with their inability to talk, will be discovered and set on a course for a brighter future.

It's time for normal people to remove their biases and misunderstandings of autism and learn to listen and communicate in new ways.

James O. Grundvig is the father of an autistic son and is a freelance journalist with Huffington Post, Financial Times Foreign Direct Investor Magazine and Epoch Times, covering subjects from energy to technology. James also has 25 years in the engineering-construction industry and lives and works in New York City. You may contact him at james.4base@gmail.com.

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

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

For more information, visit our website www.FAAHFA.com or contact the facilitators:

Bonnie Kaplan - Parenttalk@gmail.com | Judith Omidvaran - Judyomid@aol.com

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For further information contact the facilitators:

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

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Criminal Acts from page 18

others, via possible criminal means, to try to resolve these developmental tasks.

The relevance of the resolution of these Eriksonian stage deficits was already exemplified in the case of Mr. "M" who presented with an ASD, psychopathology and psychosocial developmental deficits and terroristic threats (Faccini, 2014); these three factors were presented as contributing to criminal behavior, as opposed to earlier research indicating autism-based deficits or psychopathology. Mr. "M" presented with problems with theory of mind (that others could have thoughts and a feelings different from oneself), high systematization (organizing and counting of newspaper articles, etc.), and an average amount of empathy. In addition, he also evidenced compulsive cleanliness rituals and an unresolved trauma with underlying exaggerated fears of the world being dangerous. Also, he had a substantial number of significantly negatively resolved Eriksonian developmental stages. The negative resolution of these stages left him regarding himself as worthless, with a constant fear that others would see him as inadequate and powerless to control his life and make important decisions for himself. Pri-

marily, the only area of his life where he felt "alive," important and equal to others was when he engaged in uttering terroristic threats. Basically, after about three years in reconstructive therapy, Mr. "M" was able to develop a sense that he was as good as others and had self-value, a sense of initiative with tasks that were important to him, a sense of pride in his capabilities, and developed a sense of positive identity in helping others and advocating for himself and other. A certain degree of autonomy was addressed, but he was taught to rely more on his social support circle than to just stand on his own, especially when making important life decisions. In addition, when skill building was needed in therapy it could be easily incorporated into the reconstructive therapy framework. In fact, this may be an important concept that is either a coherent identity or these psychosocial stages need to be positively resolved before skill building approaches can be effective. This may especially be the case with individuals with a high functioning ASD who have also committed lifelong criminal acts.

In conclusion, the positive resolution of Eriksonian psychosocial stages towards self-value, autonomy, initiative, pride, identity and intimacy are as relevant to per-

sons with autism as they are to everyone. This is especially relevant when an adult with autism evidences the negative resolution of these stages and/or when they start engaging in inappropriate or even criminal acts, via manipulation and control strategies as a means of trying to reconcile these same stages. In this way, reconstructive therapy can develop an essential personal base so that more cognitive-behavioral interventions and skills can be "embedded" into a coherent identity for the person with autism and criminal acts. To date, reconstructive therapy has been applied to a handful of cases with positive outcomes.

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Hospitalization from page 10

patient's participation in the transition planning process

- Creating a collaborative team approach with all treatment providers and family members during and following the hospitalization

Individuals with ASD/DD often require additional supports that inpatient units frequently do not provide. These supports include:

- Visual Supports (pictures, words, symbols)
- Use of concrete, short chunks of language
- Clearly established rules and expectations
- Communication of treatment goals in clear, discrete descriptions

During hospitalization family/caregiver involvement is important. Many hospitals have family therapy and family groups, and attendance in these offerings is recommended. Family and caregiver participation includes the following:

- Teleconferencing into sessions when unable to attend in person
- Obtaining a visit summary following visits
- Periodically checking in with mental health providers
- Write questions down prior to appointments
- Taking notes at appointments
- Request informational handouts

Even with the best psychiatric care, patients can easily become upset with their providers; it is essential that family/caregivers remain objective about the providers being involved in the treatment will allow

them to assess the providers themselves. The more informed the family/ caregivers are, the better able they are to participate in the discharge process.

Preparing for Discharge

Early on in the process family/caregivers should start thinking about their role after discharge. It is important to realize that the inpatient treatment team represents a "fresh set of eyes" that can make recommendations to be implemented during admission and continued after discharge. Make sure that discharge instructions are explained thoroughly and ask questions if there is any uncertainty. The patient (or legal guardian) should sign legal releases so inpatient discharge summaries can be forwarded to the outpatient provider(s).

Understandably hospitalization is a stressful process and the discharge can be equally as stressful. Family/caregivers should be aware that there is a choice in who provides outpatient psychiatric care to a patient after discharge. Sometimes it is best to continue with provider(s) that were in place prior to admission, but sometimes it is best to seek more specialized provider(s). Also evaluate the needs of the patient including:

- What level of care does the patient need?
- Are additional resources needed to meet the patient's needs?
- Will the patient benefit from working with a provider who specializes in specific diagnoses of symptoms (i.e., ASDs, OCD, etc.)?

Viable recommendations for additional supports should be investigated. Appropriate referrals should be sought from the inpatient team and other reliable professional sources. All services should be in place prior to discharge. Contact information for the outpatient treatment team should be established to enable the inpatient team to communicate the discharge plan and facilitate a successful transition. Also, if possi-

ble, family/caregivers should accompany the patient to the first appointment as part of the reintegration process. It is important that all be aware that on discharge, patients are usually not "fixed" and are frequently highly vulnerable, making the need for patience, support and involvement in their treatment even more essential.

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Senior Staff Psychologist and Natalia Appenzeller, PhD, is Clinical Director at the Fay J. Lindner Center for Autism and Developmental Disabilities. Contributions to this article were also made from Carole Kalvar, Faith Kappenberg, PhD, and Bernice Polinsky.

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Caregiver Tips for Easing the Way After Hospitalization

Work with the individual to create a structured daily routine. Structure is essential to encourage focus and avoid the damaging impact of boredom and isolation. Work with them to start a diary to create structure and routine, with specific times for waking, personal hygiene and grooming rituals, meals, chores, exercise, recreation, and bedtime. Try to keep the time intervals as short as possible. Structured activity keeps the mind focused, preventing brooding and repetitive thinking, encouraging good "mental hygiene," and preventing a spiral down into inappropriate acting out or depression.

Help the individual put an exercise routine in place. Any exercise program should be approved by their physician but, if possible, some form of vigorous activity should be incorporated into their schedule. This can be as simple as brisk walking and is extremely important for overall health and well-being.

Everyone needs a purpose to feel useful. Work with the individual to better access their strengths and interests. They could develop a better sense of self by assisting an elderly neighbor with chores or taking care of their animal.

Defuse conflicts by learning more effective communication skills. Use short and simple declarative statements to convey expectations. Often, less talk is more effective. Don't try to "talk down" an agitated person. Don't tell them to "just calm down" or to "take it easy." Instead, simply state what is expected and walk away. It takes at least two for a fight and if you make yourself scarce the individual is more likely to regain self-control. Make sure that what you are asking the individual to do is reasonable and within their ability, and then be steadfast in requiring them to meet the expectation. Be clear, firm, and, above all, consistent.

- Contributed by Maureen Holohan, Carole Kalvar, and Eric Schissel

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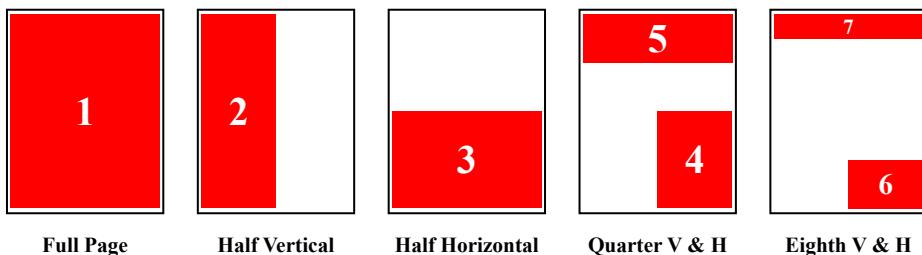
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Ad Sizes - In Inches

	<u>Width</u>	<u>Height</u>
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Half Vertical (2)	5.1	12.8
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